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Assessing preventive gynecological decisions in individuals with Lynch syndrome

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Assessing Preventive Gynecological Decisions in Individuals with Lynch Syndrome

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Ryan Patrick Mahoney

Thesis Committee:
Associate Professor Jason Zell, Chair
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ABSTRACT OF THE THESIS

Assessing Preventive Gynecological Decisions in Individuals with Lynch Syndrome

by

Ryan Patrick Mahoney

Master of Science in Genetic Counseling

University of California, Irvine, 2023

Associate Professor Jason Zell, Chair

Lynch syndrome causes increased risks of developing colorectal, endometrial, ovarian, and other cancers. Current screening guidelines for gynecological cancers are vague and often left to a clinician's discretion whether to recommend them. Individuals at risk of developing gynecological cancers often view screening as important whereas some providers believe it is more important to stress prophylactic hysterectomy and oophorectomy for their patients with Lynch syndrome. This study aimed to identify factors associated with decisions to undergo prophylactic surgery or pursue regular gynecological screening.

A survey to collect information about individuals with Lynch syndrome was distributed to online and social media based support groups. Participants included 115 individuals without a history of gynecological cancer who had an intact uterus and/or ovaries when they received their genetic testing results identifying Lynch syndrome. Participants' demographics, genetic testing and Lynch syndrome history, gynecological healthcare decisions, and Lynch syndrome education were collected. It was found that age, having less than a college degree, having children, not desiring future pregnancies, and having a previous non-gynecological cancer are significantly associated with choosing to undergo both prophylactic hysterectomy and oophorectomy.

Menopausal status at the time of genetic test results was also associated with the decision to undergo one or both surgeries. Characteristics that are associated with level of risk, including individual gene mutation or family history of gynecological cancer, were not associated with surgical decisions.

Receiving information about symptoms of gynecological cancer was significantly associated with pursuing regular gynecological cancer screening while receiving information about Lynch syndrome related gynecological cancer risks and gynecological cancer screening were approaching a significant association. Participant comments also provided insight into emotional factors experienced while navigating decisions to undergo gynecological cancer screening and/or prophylactic hysterectomy and oophorectomy.

These results serve as a reminder that decision-making is not straightforward. Each person will be influenced by their personal experiences and healthcare encounters when making medical management decisions. Approaching encounters with patient centered care and information gained by listening to members of the Lynch syndrome community may help facilitate trusting relationships and ultimately empower patients to be aware of their personal risks and make confident, informed decisions about their gynecological health and wellness.

I. Introduction

1.1 Background and Significance of Research

1.1.1 Overview of Lynch Syndrome

Lynch syndrome was first officially described by Henry T. Lynch, M.D, in the mid 1960's after expanding the research initially done by Aldred Scott Warthin, MD in the early 20th century. Dr. Warthin worked closely with a family that appeared to have an increased amount of colon, uterine, and stomach cancer. He observed that the family members with cancer diagnosed went on to have children that were affected by similar cancers while family members who did not develop cancer in their lifetimes had children who also did not develop the same types of cancer found in their other affected family members. In 2005 with the help of 929 descendants of "Family G" that Warthin initially discovered in 1895, it was found that the descendants of this original family were more likely to develop colon, uterine, or stomach cancer if they were found to have a mutation in the gene *MSH2*. Other studies occurring in the mid 1990's in Sweden found that families with similar histories of colon, uterine, and stomach cancer also appeared to have mutations in the genes *MLH1*, *MSH6*, or *PMS2*. Once the genetic basis of the disease became established and technology for genetic analysis became more widely available, it was found that mutations in the stop codon of *EPCAM*, the gene immediately upstream of *MSH2*, could also have an epigenetic silencing effect on *MSH2* resulting in a similar phenotype to individuals with mutations in *MSH2* (Boland and Lynch 2013).

As previously described, individuals with Lynch syndrome have an increased risk for colorectal, endometrial, ovarian, and gastric cancer in addition to cancers of the renal pelvis, ureter, bladder, small bowel, pancreas, biliary tract, prostate, and brain when compared to the general population. Lynch syndrome is now believed to be the most common hereditary cancer syndrome with approximately 1 in 279 individuals having one pathogenic mutation in either *MLH1*, *MSH2*, *MSH6*, *PMS2*, or *EPCAM* (Win et al. 2017). Due to the prevalence of Lynch syndrome around the world, there are currently many options for individuals to prevent, detect, and/or reduce their risk of developing certain cancer associated with Lynch syndrome.

1.1.2 Historical and Contemporary Lynch Syndrome Management

The National Comprehensive Cancer Network (NCCN) guidelines are an essential tool for practicing clinicians in the United States to be aware of up to date and evidence based surveillance and surgical guidelines for a variety of cancers and hereditary cancer syndromes. Within the Genetic/Familial High-Risk Assessment: Colorectal guidelines under the Detection, Prevention, and Risk Reduction portion of the NCCN lie a multitude of screening and surgical recommendations for those found to have a mutation in one of the mismatch repair genes causing Lynch syndrome. Pathogenic mutations in each of these genes pose different risks of developing certain types of cancers; because of this, each of the genes that can cause Lynch it has its own specific screening recommendations.

As of February 2022, Version 2.2022 of the Genetic/Familial High-Risk Assessment: Colorectal guidelines state that individuals with pathogenic *MLH1*, *MSH2*, or *EPCAM* mutations are advised to begin annual colonoscopies starting between 20 and 25 years of age or 1 to 2 years prior to the earliest diagnosis of colorectal cancer if younger than 25. Conversely, individuals with pathogenic *MSH6* or *PMS2* mutations are recommended to begin colonoscopies starting between 30 and 35 years of age or 2 to 5 years prior to the earliest diagnosis of colorectal cancer if younger than 35, repeat every 1 to 3 years. However, some screening recommendations for other Lynch related cancers are the same despite which Lynch Syndrome gene is mutated in an individual, such as the recommendation that anyone diagnosed with Lynch syndrome should consider receiving an upper endoscopy to monitor for gastric and small bowel cancer starting between 30 and 40 years old and repeating every 2 to 4 years. While some cancer types are more explicit with their recommended screening techniques and frequencies, screening guidelines for gynecological cancers are not as readily agreed upon by medical practitioners.

1.1.3 Current Gynecological Cancer Prevention and Screening Practices

As of February 2022, Version 2.2022 of the Genetic/Familial High-Risk Assessment: Colorectal guidelines state that the best way to prevent the development of endometrial and ovarian cancer is to undergo prophylactic surgery and receive a total abdominal hysterectomy with bilateral salpingo-oophorectomy (TAH-BSO). There is also emerging evidence that taking oral contraceptives may decrease the risk of developing endometrial and ovarian cancer.

In the context of Lynch syndrome, a total abdominal hysterectomy with bilateral salpingo-oophorectomy (TAH-BSO) is a surgical procedure involving the removal of the uterus, cervix, fallopian tubes, and both ovaries in order to prevent the development of gynecological cancers or stop the growth of a gynecological cancer that is already present. This procedure can also be performed to treat a variety of other gynecological conditions, such as endometriosis, uterine fibroids, and/or ovarian cysts. Because of this removal of the uterus and ovaries, people will no longer be able to become pregnant or have menstrual periods after the surgery is completed. In addition, removal of the ovaries can cause a sudden and severe surgically induced menopause due to the body's main sources of estrogen and progesterone production being removed. This can cause a variety of physical and emotional changes for the person including, but not limited to, hot flashes, irregular changes in mood, and decreased libido. Since estrogen and progesterone are also involved in the maintenance of the body's bone density and cardiovascular health, surgically induced menopause can lead to an increased risk of osteopenia, osteoporosis, bone fractures, heart disease, and stroke. To combat these symptoms, people are often prescribed exogenous hormone replacement therapy, which can increase the risk of developing breast cancer. Because of the many physical and psychological effects of undergoing a TAH-BSO, the NCCN guidelines recommend that this decision be individualized to each patient. Factors such as which Lynch mutation the individual has, the age of the patient, their desire to have biological children, as well as their current menopause status should be considered when a medical practitioner discusses the importance of prophylactic gynecological surgery in people with Lynch syndrome. Other individualized personal, societal, and socioeconomic factors must be considered as well such as the patient's fear of undergoing surgery or experiencing surgical complications, the fear of making permanent changes to their body, lack of familial support needed when recovering from the surgery, the costs involved with surgery, or even the fact that their insurance may not cover the costs of the surgery. Current guidelines include three gynecological cancer screening methods as an alternative to a TAH-BSO if patients decline surgical intervention: endometrial biopsy, transvaginal ultrasound, and CA-125 blood testing. These endometrial and ovarian cancer screening methods are discussed only briefly and nestles amongst language indicating that there is no proven benefit of these screening methods and that the decision to offer them to patients with Lynch syndrome should be up to the clinician's discretion.

An endometrial biopsy is a medical procedure in which a small sample of tissue is taken from the endometrium, the lining of the uterus, and examined for abnormalities. A thin, flexible instrument is inserted through the cervix and into the uterus to obtain the tissue sample. Although local anesthesia may be used to reduce discomfort during the procedure, endometrial biopsies can still be extremely painful. Aside from endometrial cancer screening, endometrial biopsies may be performed in someone experiencing abnormal uterine bleeding, infertility, or other symptoms or risk factors that may indicate a problem with the endometrium.

A transvaginal ultrasound is an imaging procedure that uses high-frequency sound waves to create multiple images of the reproductive organs within the pelvis including the uterus, ovaries, cervix, and fallopian tubes. During a transvaginal ultrasound, a transducer is inserted into the vagina which allows for a closer and more detailed view of the pelvic organs than an ultrasound performed the traditional way through the outside of the abdomen. The procedure is generally painless but some women can experience discomfort and pressure during the exam. Similarly to an endometrial biopsy, transvaginal ultrasounds may be used to diagnose and monitor a variety of gynecological conditions, such as ovarian cysts, uterine fibroids, and endometriosis.

CA-125 testing is a gynecological screening test which is considerably less invasive than both endometrial biopsy and transvaginal ultrasounds. This blood test measures the level of a protein called Cancer Antigen 125 in the bloodstream. CA-125 is a tumor marker that is used to monitor the presence and progression of ovarian cancer and other gynecologic cancers, such as endometrial or fallopian tube cancer.

Oral contraceptives have been shown to reduce the risks of both endometrial and ovarian cancer (Iversen et al. 2017). A study performed in women with *BRCA1* and *BRCA2* variants also identified a significantly decreased risk of developing ovarian cancer with a 36% reduction of risk for every 10 years of taking oral contraceptives without an observed increase in the risk of developing breast cancer (Iodice et al., 2010). Although these studies have not been performed in a population of individuals with Lynch syndrome, ovarian cancer risk reduction was observed in *BRCA1/2* carriers making it reasonable to assume that ovarian cancer risk reduction is applicable for the general population as well as high risk individuals.

Some women have expressed that undergoing regular gynecological cancer screening allows them to feel an increased sense of control over their increased risk of developing endometrial and/or ovarian cancers. Although gynecological cancer screening avoids the need to remove the uterus and ovaries and may give individuals the perception that they are being more proactive about their increased risk of gynecological cancer, it has been shown that they may not be effective in actually preventing cancer.

1.1.4 Efficacy of Gynecological Cancer Screening in Lynch Syndrome

The efficacy of each of these screening measures is heavily debated and therefore a comprehensive recommendation for gynecological cancer screening has not yet been agreed upon. The lack of reliable data supporting the efficacy of the aforementioned gynecological cancer screening methods has resulted in the Manchester International Consensus Group releasing a statement explaining that they do not recommend invasive gynecological cancer screening services for those with Lynch syndrome (Crosbie et al. 2019). Members of the Consensus Group have since stated that offering gynecological screening services may do more harm than good as it could give the patient a false sense of security and cause them to delay their

TAH-BSO and thus eliminate the risk of developing endometrial and ovarian cancer (Ryan et al. 2021).

Although it is a reliable tool to identify endometrial cancer in those presenting with symptoms related to endometrial cancer, the use of endometrial biopsy may not be an effective method of early detection of endometrial cancer. In a study of 236 women with Lynch syndrome participating in screening via endometrial biopsy, 13 of them developed endometrial cancer, but 6 of those individuals who came back with an abnormal endometrial biopsy were already experiencing other symptoms of endometrial malignancy (Ketabi et al. 2014). Others argue that it is better to avoid an invasive procedure and instead make patients aware of these “red flag” symptoms of endometrial cancer which include postmenopausal bleeding, heavy or irregular menstrual bleeding in premenopausal patients, vaginal discharge, hematuria, anemia, thrombocytosis, raised blood glucose, and abdominal pain (Walker et al. 2013)

The changing thickness of the endometrial lining throughout the menstrual cycle may obstruct the transponder's ability to identify an abnormal growth in the uterus during a transvaginal ultrasound, making it an unreliable screening method to detect endometrial cancer in premenopausal women. In the event that it does detect endometrial cancer and premalignant pathological abnormalities, there is no evidence that this leads to a stage shift or improved survival in women with Lynch syndrome associated endometrial cancer (Crosbie et al. 2019). Transvaginal ultrasonography does seem to be an effective way of identifying endometrial cancer in postmenopausal women (Jacobs et al. 2011), but considering that the average age of onset for endometrial cancer for people with Lynch syndrome ranges between 47 and 55 years of age, it is likely that they would have developed endometrial cancer before going through menopause and thus having the potential to receive a more accurate screening result from a transvaginal ultrasound.

CA-125 testing has been critiqued for its propensity towards both false positive and false negative results. Although CA-125 is primarily considered as a tumor marker for ovarian cancer, it is important to note that a high level of CA-125 does not always mean a person has cancer. There are other common conditions such as endometriosis, pelvic inflammatory disease, and even pregnancy that can elevate CA-125 levels (Buamah, 2000). Due to the wide variety of conditions that could increase CA-125 levels aside from the presence of ovarian cancer, CA-125 is not a highly sensitive or specific way to detect early stage ovarian cancer. However, when combined with other cancer biomarkers, the sensitivity of this surveillance increases and has the potential to detect ovarian cancer in a less developed state than previously possible (Yang et al., 2019).

1.1.5 Conflicting Attitudes Toward Gynecological Screening Amongst Patients and Providers

Leaving the decision of whether to perform or even offer gynecological cancer screening up to the clinician managing the patient is concerning for a variety of reasons. A survey completed by 41 gynecological oncologists practicing in the United Kingdom found that 37% of the respondents were unfamiliar with any clinical guidelines for the management of Lynch syndrome and only 43% were aware of a where women with Lynch syndrome could receive local gynecological surveillance service if they desired (Ryan et al. 2021). Although this study did not survey gynecological oncologists in the United States, the reported lack of awareness on the healthcare providers part to be able to address the wants of needs of their patients with Lynch syndrome is concerning. Another concern arises when considering that Lynch syndrome is generally known as a colorectal cancer risk syndrome with less attention paid to the increased risks of endometrial cancer. A study of 342 first, second, third, and fourth year medical students in the United States identified that 93% of them were able to correctly state the colorectal cancer is the most commonly seen cancer in Lynch syndrome, but only 37% of them selected endometrial cancer as the second most common malignancy seen in Lynch syndrome (Brodsky et al. 2022). Healthcare providers who lack the knowledge to be aware of the commonly increased gynecological cancer risks may also be unaware of the types of screening practices that people with Lynch syndrome should be made aware of. This lack of provider knowledge would logically lead to a population of people with Lynch syndrome who may not be fully aware of all of their increased cancer risks or the variety of options for screening methods.

The same study that identified gynecological oncologists lack of awareness about gynecological management in Lynch syndrome also surveyed 298 women with Lynch syndrome in the United Kingdom about their attitudes and experiences with gynecological surveillance. Of all of the women surveyed, 77% reported that gynecological surveillance in Lynch syndrome was very important, with 10% saying it was important. Of the women surveyed who had not already undergone a TAH-BSO, 62% said that they wished to receive more frequent gynecological surveillance. A Finnish study concerning the attitudes towards gynecological surveillance in a cohort of women with Lynch syndrome found that 84.2% of respondents reported having positive experiences with gynecological surveillance visits, and overall the study found that the respondents perception of the quality of the information and advice obtained played an important role in their decision-making concerning prophylactic surgery (Kalamo et al., 2020). Another study examining the provider documented recommended care and care adherence following a diagnosis of Lynch syndrome found that 70% of patients were completely adherent to recommendations for colonoscopy while only 31% (n=9) of patients at risk of developing endometrial cancer ever received information about endometrial biopsy (Mittendorf et al., 2019). Of these patients that did receive provider documented recommendations, 1 was reported to have 0% adherence and never received an endometrial biopsy, 5 had adherence between >0% and 50% to the recommendations provided, 3 had between >50% and <100% adherence to recommendations, but none of the patients demonstrated 100% adherence to endometrial biopsy recommendations by their provider. Although these studies have a small sample size, the similarities in the attitudes of women towards gynecological screening and uptake of said screening when provided information on the subject is something that should emphasize the importance of healthcare providers delivering this information so that their patients can make the most informed and appropriate decision they feel they are ready for at that time.

1.2 Significance of Research

The discordance between the beliefs of some healthcare practitioners and the wants and needs of people with Lynch syndrome at risk of developing gynecological cancers is evident. Although there may not be large bodies of evidence supporting the implementation of gynecological screening practices for all women with Lynch syndrome, it is important to consider the factors that may influence someone to choose to proceed with screening rather than to undergo a TAH-BSO. The purpose of this study is to examine which of these factors may influence the gynecological screening habits of women with Lynch syndrome. Factors such as an individual's age, desire for more children, family history of cancer, education about their cancer risks and screening options may play a role in their uptake of endometrial biopsies, transvaginal ultrasounds, CA-125 blood testing, and prophylactic gynecological surgery. This research has the potential to reveal which of these factors are most influential in ones decision to pursue screening versus prophylactic surgery which could in turn provide more insight for medical practitioners on how to work with each patient with Lynch syndrome on an individualized basis in order to have them achieve their goal of preserving their gynecological and overall health and wellbeing.

II. Methods

2.1 IRB Approval

This study was reviewed by the University of California, Irvine (UCI) Institutional Review Board (IRB). The procedures of this research were classified as exempt category 2 research, and self-determination of exempt research was approved by the UCI IRB under study HS#1878.

2.2 Study Population

The intended population consisted of adults who have been diagnosed with Lynch syndrome who were at risk of developing endometrial and/or ovarian cancer at the time they received their genetic testing results. To meet these criteria, each respondent was required to be living in the United States at the time of taking the survey, to have received genetic testing in the United States of America which identified a mutation in a gene causative of Lynch syndrome, to not have undergone a TAH-BSO before receiving their Lynch syndrome diagnosis, and to not have been diagnosed with endometrial and/or ovarian cancer before being diagnosed with Lynch syndrome.

2.3 Lynch Syndrome Support Groups Contacted

2.3.1 Online Support Groups

The survey was distributed by support groups whose goal it is to educate and provide a sense of community for individuals who themselves may have hereditary cancer syndromes including Lynch syndrome. Facing Hereditary Cancer Empowered, more commonly referred to as FORCE, is a nonprofit organization whose stated mission is to improve the lives of individuals and families facing hereditary cancer. They provide information and resources to individuals who may be interested in community and emotional support, education concerning hereditary cancer syndromes, details about current research to participate in, and information about legal advocacy and public policy. Kintalk is a nonprofit organization similar to FORCE in that their stated goal is to empower families with hereditary cancers through communication and education. AliveAndKickn is another nonprofit organization with a similar mission to FORCE and Kintalk, however the information and resources provided are aimed specifically towards individuals diagnosed with Lynch syndrome. The web link to access the survey was distributed to members of each group's mailing lists on a regular basis to allow for individuals to have the opportunity to complete the survey over the course of approximately four months. In addition to sending out the survey by email to members of the groups mailing list, the Colorectal Cancer Alliance for Research and Education for Lynch Syndrome and FORCE also posted information about the research and a link to the survey on their websites.

2.3.2 Social Media Based Support Groups

In addition to the formally established hereditary cancer support groups, the survey link was also posted in a variety of social media based support groups with a focus specifically on Lynch syndrome. The web link to the survey was posted on Reddit under the subreddit r/lynchsyndrome (605 members) and in the following private Facebook groups: Lynch Syndrome Support Group/LSI (7,075 members), Lynch syndrome (1,816 members), *MSH6* Lynch Syndrome Knowledge and Support (1,427 members), *PMS2* Lynch Syndrome (1,141 members), *MSH2* Lynch Syndrome Support Group (1,015 members), Lynch Syndrome / HNPCC Support Group (989 members), Lynch Syndrome Previvors (687 members). HNPCC/Lynch Syndrome - Education and Support (568 members), and LYNCH SYNDROME (284 members). The number of members who have joined each of the aforementioned groups were recorded on March 6th, 2023.

2.4 Survey Construction

The survey distributed was comprised of six main sections: Study Information and Consent, Inclusion Criteria, Demographic Information, Genetic Testing and Lynch Syndrome History, Gynecological Care Decision Making, and Lynch Syndrome Education.

After reading through the study information sheet, confirming their interest in participating in the study, and confirming that they meet each of the predetermined inclusion criterion, participants then answered questions concerning where they heard about the study and general demographic information. These questions were then followed by others concerning the participants' history of genetic testing and genetic counseling in addition to their personal and family histories of cancer diagnoses. Participants were also asked for details about their histories of gynecological surgery as well as their current and future plans for gynecological cancer screening. Finally, participants were asked questions to assess their current knowledge of the most common Lynch syndrome associated malignancies, their current perceived risk of developing endometrial and ovarian cancer, and their education about symptoms of gynecological cancers, gynecological cancer risks in people with Lynch syndrome, and gynecological cancer screening options.

Branching logic was implemented to ensure that patients only answered the most appropriate and pertinent questions for them (e.g. an individual who indicated they had not previously received an endometrial biopsy would not be asked about their perceived pain level during their endometrial biopsies). A complete view of the survey questions asked during this study can be seen in Appendix A.

2.5 Data Collection

Respondents who agreed to participate in this survey had their responses recorded in an online database through REDCap, a secure web platform for building and managing online databases and surveys. Survey distribution began on November 19th, 2022 and concluded on March 10th, 2023. All survey response data was downloaded into Microsoft Excel and SPSS files to begin analysis of the recorded responses once the survey had closed.

2.6 Data Analysis

Data were analyzed using the IBM Statistical Package for the Social Sciences (SPSS) Statistics version 28.0.1.0. Incomplete and partial survey responses were removed from the data set before analysis began. Continuous variables were summarized using means and standard deviations and counts and percentages were used for categorical variables. Pearson's and Fisher's exact chi-square values were calculated using SPSS. P-values of less than 0.05 were considered statistically significant.

III. Results

3.1 Sample Characteristics and Demographic Information

A total of 174 study respondents clicked the survey link and began the survey. Of these 174 respondents, 115 met the inclusion criteria and completed the entire survey. The mean and median age of respondents were 45.7 and 44.0 respectively (SD=10.4), and all respondents were female with 98.3% identifying as women and 1.7% identifying as non-binary. The majority of respondents (93.0%) reported that they were of non-Hispanic White or European ancestry. Other self-reported ancestries and ethnicities included Hispanic (1.7%), Asian (1.7%), Native American or Alaska Native (0.9%), and Multiracial (0.9%) with two respondents preferring not to answer (1.7%).

Most respondents reported that their highest level of education results in either a college degree (36.5%) or postgraduate degree (43.5%) with fewer respondents reporting that their highest level of education was completing high school (2.6%), some college or technical school (13.0%), and completing technical school (4.3%).

Respondents were asked which support group or Lynch syndrome focused social media page they first received the link to complete the survey from. Facebook (29.6%) and Lynch Syndrome International (27.8%) were the most commons responses followed by FORCE (14.8%), Reddit (9.6%), AliveAndKickn (1.7%), and CCARE (0.9%). A portion of respondents (15.7%) also indicated that they were unsure of which specific group they received the link from.

Current relationship status was assessed and 76.5% respondents reported that they are married, followed by single (7.0%), living together (7.0%), widowed (3.5%), divorced (3.5%), separated (0.9%), and self-described relationships (1.7%).

	Frequency (N)	Percent (%)
Age Group (years)		
20 - 29	6	5.2
30 - 39	27	23.5
40 - 49	44	38.3
50 - 59	25	21.7
60 - 69	11	9.6
70 - 79	2	1.7
Gender		
Woman	113	98.3
Nonbinary	2	1.7
Ancestral Background		
White or European	107	93.0
Hispanic	2	1.7
Asian	2	1.7
Native American/Alaska Native	1	0.9
Multiracial (White or European and Native American/Alaska Native)	1	0.9
Prefer not to answer	2	1.7
Highest Level of Education		
High school graduate	3	2.6
Some college or technical school	15	13.0
Technical school graduate	5	4.3
College graduate	42	36.5
Postgraduate degree	50	43.5
Group		
Facebook	34	29.6
Lynch Syndrome International	32	27.8
FORCE	17	14.8
Reddit	11	9.6
AliveAndKickn	2	1.7
CCARE	1	0.9
Unsure	18	15.7
Relationship Status		
Married	88	76.5
Single	8	7.0
Living together	8	7.0

Widowed	4	3.5
Divorced	4	3.5
Separated	1	0.9
Other	2	1.7

Table 1. Demographic information: This table summarizes the general demographic information reported by the 115 respondents.

Of the 115 respondents, 73.9% reported that they have at least one biological child. Of respondents who already have at least one biological child, 92.9% reported that they are not planning to have more biological children, 4.7% reported that they are planning to have more biological children, and 2.4% reported that they are not unsure whether they want more biological children. Respondents who indicated they do not currently have any biological children, 63.3% reported that they are not planning to have more biological children, 26.7% reported that they are planning to have more biological children, and 10.0% reported that they are not unsure whether they want more biological children.

Respondents were asked about whether they currently take or have taken oral birth control pills with 73.0% reporting that they have. Respondents were also asked about their menopause status, and 69.6% reported that they were no longer having periods at the time of taking the survey, however 30.4% reported that they were no longer having periods at the time of their genetic testing.

	Frequency (N)	Percent (%)
Have children		
Yes	85	73.9
No	30	26.1
Planning to have more children		
Yes	4	4.7
No	79	92.9

Unsure	2	2.4
Planning to have any children in the future		
Yes	8	26.7
No	19	63.3
Unsure	3	10.0
Have taken oral contraceptive pills		
Yes	84	73.0
No	31	27.0
Current menopause status		
Menopausal	80	69.6
Premenopausal	35	30.4
Menopause status at time of genetic testing		
Menopausal	35	30.4
Premenopausal	80	69.6

Table 2. Family planning and fertility information: This table summarizes information the respondent reported pertaining to their children, family planning, and menopause status.

Participants self-reported which of their MMR genes were found to have a mutation in them through genetic testing with 29.6% reporting mutations in *PMS2*, 28.7%% reporting mutations in *MSH6*, 27% reporting mutations in *MSH2*, and 14.8% reporting mutations in *MLH1*. Most respondents did not have a personal history of non-gynecological cancer (67.9%) with 32.1% of respondents indicating they had been diagnosed with a non-gynecological cancer at least once. Of the individuals who had been diagnosed, 72.2% were diagnosed with cancer one time, 25.0% were diagnosed with cancer two times, and 2.8% were diagnosed with cancer three times. Of the types of cancer reported, colorectal cancer was the most common (32.7%) followed by breast (22.5%), non-melanoma skin cancer (20.4%), thyroid (6.1%), melanoma (6.1%), breast ductal carcinoma in situ (6.1%), small intestine (2.0%), bladder (2.0%), and adrenal cancers (2.0%). Respondents also noted whether they had a family history of endometrial or ovarian cancer with 47.0% indicating they had at least one family member who had been diagnosed with endometrial or ovarian cancer and 53.0% indicating they did not have any family members who had been diagnosed.

	Frequency (N)	Percent (%)
Mutation		
MLH1	17	14.8
MSH2	31	27.0
MSH6	33	28.7
PMS2	34	29.6
Personal history of non-gynecological cancer		
Yes	36	67.9
No	76	32.1
Number of cancer diagnoses for those with a personal history of non-gynecological cancer		
One	26	72.2
Two	9	25
Three	1	2.8
Cancers reported		
Colorectal	16	32.7
Breast	11	22.5
Non melanoma skin cancer	10	20.4
Thyroid	3	6.1
Melanoma	3	6.1
DCIS	3	6.1
Small intestine	1	2.0
Bladder	1	2.0
Adrenal	1	2.0
Family member diagnosed with endometrial and/or ovarian cancer		
Yes	54	47.0
No	61	53.0

Table 3. Lynch syndrome, personal cancer, and family cancer history: This table summarizes information related to the respondent’s Lynch syndrome diagnosis, personal cancer history, and family history of cancer. Individuals who were diagnosed with gynecological cancer before receiving their diagnosis of Lynch syndrome did not meet

requirements to be included in this study. The number of cancers reported is not representative of the number of individuals who have been diagnosed with cancer as individuals who were diagnosed with more than one type of cancer have been recorded once for each of their cancer diagnoses. Respondents were able to choose from a general drop down list of Mother, Father, Aunt, Uncle, Grandmother, Grandfather, Cousin, Sister, Brother, Daughter, Son, Niece, Nephew, Granddaughter, and Grandson when indicating which of their family members had previously been diagnosed with endometrial and/or ovarian cancer.

Each respondent's prophylactic surgery history was collected. In particular, each individual was asked whether they have received both prophylactic hysterectomy and oophorectomy, prophylactic hysterectomy only, prophylactic oophorectomy only, or no prophylactic surgery after receiving their diagnosis of Lynch syndrome. Among the study population, 45.2% reported they had undergone both prophylactic surgeries, 9.6% reported they had only a prophylactic hysterectomy, 7.0% reported they had only a prophylactic oophorectomy, and 38.3% reported they have not undergone any prophylactic surgery. Of 44 respondents who had not undergone any prophylactic surgery, 31 are currently planning surgery and 13 indicated that they are not currently planning on undergoing a prophylactic hysterectomy and oophorectomy; however only 1 of these 13 individuals reported that they will not be having either prophylactic surgery in the future.

	Frequency (N)	Percent (%)
Surgical Status		
Received prophylactic hysterectomy and oophorectomy	52	45.2
Received prophylactic hysterectomy only	11	9.6
Received prophylactic oophorectomy only	8	7.0
Have not received prophylactic surgery	44	38.3
Planning on receiving regular gynecological cancer screening		
Yes	16	29.1
No	39	70.9
Currently planning to undergo prophylactic surgery		
Yes	31	70.5
No	13	29.5

Planning to undergo prophylactic surgery in the future		
Yes	12	92.3
No	1	7.7

Table 4. Surgical status of respondents: This table summarizes the surgeries that respondents reported that they have undergone. Regular gynecological cancer screening refers to having an endometrial biopsy, transvaginal ultrasound, and/or a CA-125 blood test to screen for endometrial and/or ovarian cancer on a regular basis. Respondents were able to choose from a drop down list of More than once every 6 months, Every 6 months, Once a year, Every 2 years, Every 3 years, Every 4 years, Every 5 years, Less than every 5 years, and I do not plan on receiving regular screening for each of the specific types of gynecological cancer screening assessed in this study.

After determining the respondents current surgical history, respondents were then asked to select all of the reasons that impacted their choice to undergo or not undergo prophylactic surgeries and to then determine which of those reasons was most impactful on their decision. For those who underwent both prophylactic hysterectomy and oophorectomy, (N=52) , all participants indicated that their desire to avoid cancer influenced their decision. Others also indicated that they had received a recommendation from a medical practitioner (75.0)%, they viewed surgery as the responsible decision to make (71.2%), they were not planning on having children in the future (57.7%), their family member was affected by uterine and/or ovarian cancer (38.5%) or a non-gynecological cancer (36.5%), they desired to avoid gynecological cancer screening in the future (23.1%), they experienced excessive bleeding or abdominal pain during periods (21.2%), or that they were postmenopausal already (11.5%). No participants indicated that they underwent prophylactic surgery due to pressure from an individual outside of their medical care team. Regarding the main reason for undergoing prophylactic surgeries, nearly all indicated that a desire to avoid cancer was their main reason for undergoing these surgeries, however some participants noted that it was a family member's history of endometrial or ovarian cancer, excessive bleeding or pain during periods, or a recommendation from a medical practitioner as their main reason.

The most common reason selected for not undergoing prophylactic surgery was that the participant was not ready to go into menopause (59.1%), however the most common main reason was the desire for a future pregnancy or more children (25.6%). Unlike the reasoning participants gave for undergoing prophylactic surgery, the variety of reasons individuals reported for not undergoing prophylactic surgery was much more variable.

	Frequency (N)	Percent (%)
Reasons selected for undergoing prophylactic hysterectomy and oophorectomy (N=52)		
Desire to avoid cancer	52	100.0
Recommendation from a medical practitioner to undergo surgery	39	75
Viewed surgery as the responsible decision to make	37	71.2
I am not planning on having any more children	30	57.7
Family member affected by uterine and/or ovarian cancer	20	38.5
Family member affected by other cancer	19	36.5
Desired to avoid gynecological screening in the future	12	23.1
Experienced excessive bleeding and/or abdominal pain during period	11	21.2
I am postmenopausal	6	11.5
Felt pressure from an individual outside of my medical care team to undergo surgery	0	0.0
Other	3	5.8
Main reason for undergoing prophylactic hysterectomy and oophorectomy		
Desire to avoid cancer	47	90.4
Family member affected by uterine and/or ovarian cancer	1	1.9
Experienced excessive bleeding and/or abdominal pain during period	1	1.9
Recommendation from a medical practitioner to undergo surgery	1	1.9
Other	2	3.8
Reasons selected for not undergoing prophylactic surgeries		
Not ready to go into menopause	26	59.1
Desire for future pregnancy or more children	16	36.4
Fear of undergoing surgery and/or surgical complications	16	36.4
Too young to undergo surgeries	15	34.1

Fear of making permanent changes to my body	15	34.1
Comfortable with current gynecological screening	10	22.7
Costs involved with surgery	10	22.7
Surgery is not necessary since I don't have cancer	3	6.8
Lack of family support to recover from surgery	3	6.8
Was not made aware of surgical options to reduce risk of cancer	2	4.5
Insurance did not cover surgery	1	2.3
Other	8	18.2
Main reason for not undergoing prophylactic surgeries		
Desire for future pregnancy or more children	11	25.6
Not ready to go into menopause	9	20.9
Comfortable with current gynecological screening	4	9.3
Fear of undergoing surgery and/or surgical complications	3	7.0
Too young to undergo surgeries	3	7.0
Costs involved with surgery	2	4.7
Fear of making permanent changes to my body	2	4.7
Lack of family support to recover from surgery	2	4.7
Was not made aware of surgical options to reduce risk of cancer	1	2.3
Other	6	14.0

Table 5. Reasoning for surgery versus screening: This table summarizes the reasons that respondents reported that influenced their decision to undergo prophylactic hysterectomy and oophorectomy or regular gynecological cancer screening.

Participants were asked whether they had received genetic counseling as part of their genetic testing process and, if they had genetic counseling, whether they received that counseling before undergoing genetic testing, after undergoing genetic testing, or both before and after. 88.7% of participants indicated that they had received genetic counseling with 13.7% of them receiving it only before, 38.2% receiving it only after, and 48.0% of them receiving genetic counseling both before and after undergoing genetic testing. Participants were also asked whether they had received information about Lynch related gynecological cancer risks, screening options, and associated symptoms with 92.2%, 88.7%, and 78.3% saying they received information about these topics, respectively. They were also asked to identify which two types of cancer are most commonly seen in individuals with Lynch syndrome. 96.4% of respondents correctly chose colorectal cancer and 73.2% of respondents chose endometrial cancer. The other sites chosen by respondents included ovarian cancer (21.4%), small intestine (6.3%), and gastric (2.7%).

	Frequency (N)	Percent (%)
Received genetic counseling		
Yes	102	88.7
No	13	11.3
When was genetic counseling received		
Before	14	13.7
After	39	38.2
Both before and after	49	48.0
Received information about Lynch related gynecological cancer risks		
Yes	106	92.2
No	9	7.8
Received information about gynecological cancer screening options		
Yes	102	88.7
No	13	11.3
Received information about symptoms of gynecological cancer		
Yes	90	78.3
No	25	21.7
Responses to which are the two most common Lynch related malignancies		
Colorectal	108	96.4
Endometrial	82	73.2
Ovarian	24	21.4
Stomach	7	6.3
Small intestine	3	2.7

Table 6. Education related information: This table summarizes factors related to patient education and information pertaining to Lynch syndrome and gynecological health and wellness that they may received during their care.

Respondents who were still at risk of developing endometrial and/or ovarian cancer at the time of taking the survey were asked to report what they felt was their current risk of developing endometrial and ovarian cancer. Of those at risk for endometrial cancer (N=44), 7 were reported to have *MLH1* mutations, 10 with *MSH2*, 14 with *MSH6*, and 13 with *PMS2*. For those at risk of developing ovarian cancer (N=55), 8 were reported to have *MLH1* mutations, 13 with *MSH2*, 16 with *MSH6*, and 18 with *PMS2*. Statistically significant differences between their reported gene causing Lynch Syndrome and their perception of risk were not analyzed due to small sample size (Figures 1a and 1b).

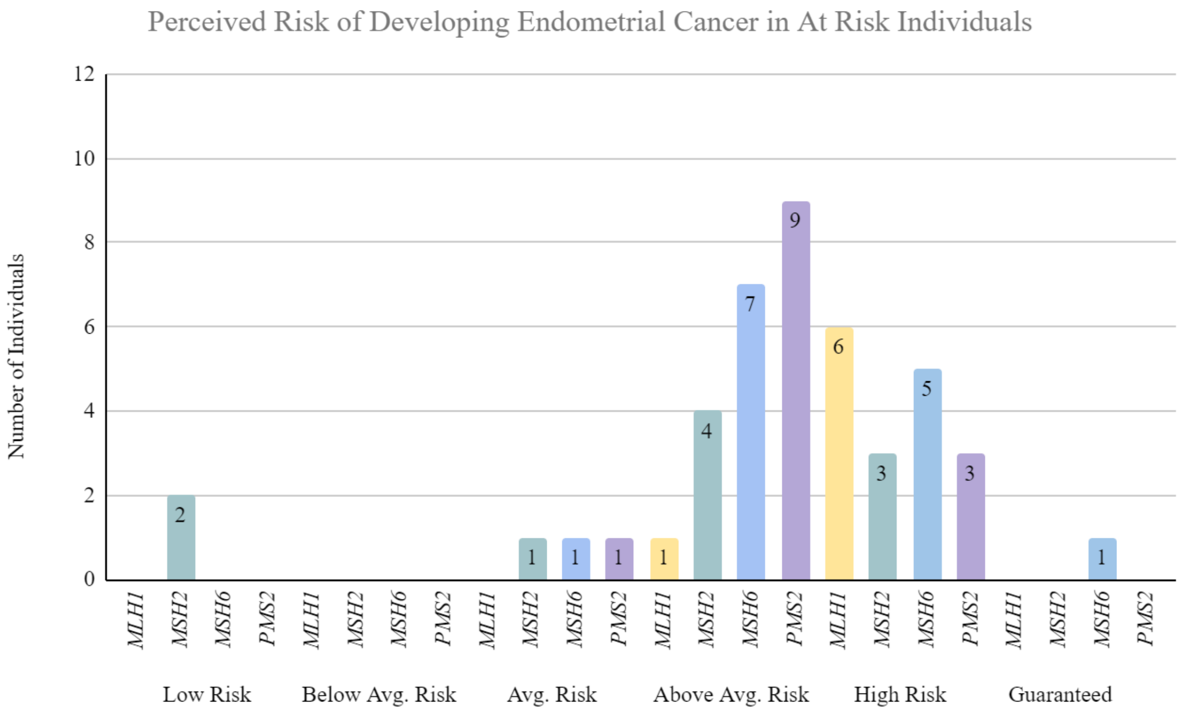

Figure 1a. Perceived risk of developing endometrial cancer in at risk individuals: Respondents who indicated they had not had their uterus removed were asked to describe what they felt their current risk of developing endometrial cancer is. Answer choices included no risk, low risk, below average risk, average risk, above average risk, high risk, and guaranteed to develop endometrial cancer. Responses have been divided by which gene mutation the respondent reported they have.

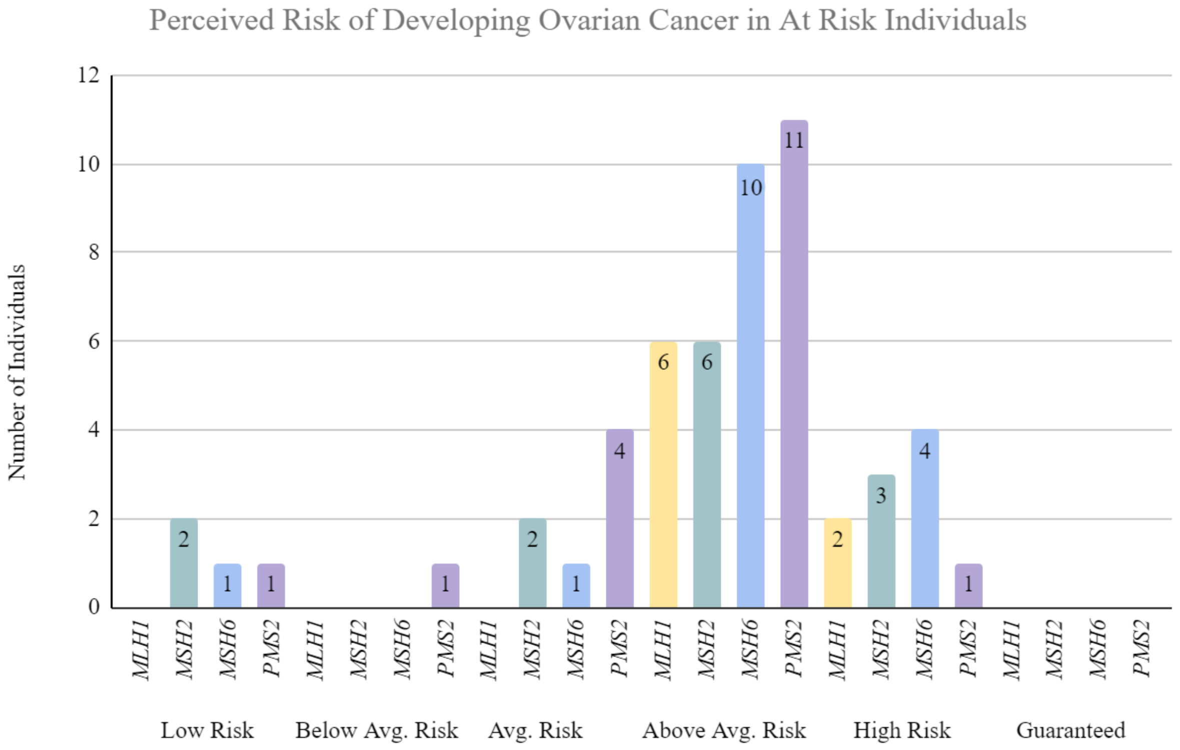

Figure 1b. Perceived risk of developing ovarian cancer in at risk individuals: Respondents who indicated they had not had their ovaries removed were asked to describe what they felt their current risk of developing ovarian cancer is. Answer choices included no risk, low risk, below average risk, average risk, above average risk, high risk, and guaranteed to develop ovarian cancer. Responses have been divided by which gene mutation the respondent reported they have.

3.2 Factors Associated with Undergoing Prophylactic Surgery

A chi-square test was performed to determine if there were any significant associations between undergoing both prophylactic hysterectomy and oophorectomy and other factors assessed within the survey. The factors studied included age, education level, having children, number of current children, desire for future pregnancies, gene mutation, receiving genetic counseling as part of the genetic testing process, when genetic counseling was received, menopause status at the time of undergoing genetic testing, whether first to undergo genetic testing in the family, personal history of non-gynecological cancer, diagnosis with a non-gynecological Lynch related cancer, family history of endometrial/ovarian cancer, receiving gynecological cancer screening for endometrial and/or ovarian cancer, receiving abnormal results from gynecological cancer screening, receiving information about symptoms of gynecological cancers, gynecological cancer risks for Lynch syndrome, and gynecological cancer screening options.

Five of the factors assessed through the survey demonstrated statistically significant associations with undergoing both prophylactic hysterectomy and oophorectomy: age (χ2=24.538, p=<0.001), having less than a college degree (χ2=4.642, p=0.031), having biological children (χ2=7.847, p=0.005), not desiring more children in the future (χ2=7.263, p=0.009), and having a previous diagnosis of a non-gynecological cancer (χ2=6.503, p=0.011).

Participants with less than a college degree were more likely to undergo prophylactic hysterectomy and oophorectomy (65.2%) when compared to those with a college degree or higher (40.2%).

Those who indicated that they do not currently have biological children were less likely to have undergone prophylactic surgeries (23.3%) when compared to those who already have children of their own (52.9%). The individuals who indicated that they already have children were further analyzed and were asked whether they were planning on having more children in the future. Unsurprisingly, none of the respondents who indicated that they were planning for more children or were unsure of having more children in the future had not undergone prophylactic surgeries. Of those who reported that they are not planning on having any more biological children, 57.0% already had their uterus and ovaries removed.

Individuals who reported that they had previously been diagnosed with a non-gynecological type of cancer were more likely to undergo prophylactic surgery (63.9%) when compared to those who had not been diagnosed with any cancer (38.2%). A fear of experiencing the negative side effects of cancer treatment or the experience of prior cancer screening may be an explanation as to why those with prior cancer diagnoses chose to surgically reduce their risk of endometrial and ovarian cancer, however these emotional factors were not able to be analyzed in this study.

Although it was not found to be statistically significant, whether an individual received information about symptoms of gynecological cancers had an association with undergoing prophylactic surgery that was approaching significance ($\chi2=3.823$, $p=0.051$). This study did not delve into what types of specific information participants were given pertaining to symptoms of gynecological cancer so it is difficult to determine if the information these individuals received was truly associated with their decision to undergo prophylactic surgery.

Although not observed when assessing factors associated with undergoing both prophylactic hysterectomy and oophorectomy, another significant association was observed when assessing factors associated with receiving any prophylactic surgery. Respondents who were still having periods at the time of undergoing genetic testing were less likely to undergo any prophylactic surgery when compared to those who were menopausal at the time of testing ($p=0.025$).

In addition to the associations described above, there were many other factors that were not found to have significant associations. Some factors which may have been thought to influence one's decision to undergo surgery but were not supported by this analysis include which MMR gene was found to be mutated, whether an individual had a family history of endometrial or ovarian cancer, whether they were still having periods at the time of their genetic testing, and whether they received genetic counseling as part of their genetic testing process.

Table 7. Factors Associated with Undergoing both Prophylactic Hysterectomy and Oophorectomy

		N	**Have not undergone prophylactic hysterectomy and oophorectomy N=63**	**Have undergone prophylactic hysterectomy and oophorectomy N=52**	**p-value**
Age Group	20 to 29 years old	6	6 (100.0%)	0 (0.0%)	**<0.001**
	30 to 39 years old	27	21 (77.8%)	6 (22.2%)	
	40 to 49 years old	44	26 (59.1%)	18 (40.9%)	
	50 to 59 years old	25	6 (24.0%)	19 (76.0%)	
	60 to 69 years old	11	4 (36.4%)	7 (63.6%)	
	70 to 79 years old	2	0 (0.0%)	2 (100.0%)	
Education level	Less than a college degree	23	8 (34.8%)	15 (65.2%)	**0.031**
	College degree or higher	92	55 (59.8%)	37 (40.2%)	
Have biological children	No	30	23 (76.7%)	7 (23.3%)	**0.005**
	Yes	85	40 (47.1%)	45 (52.9%)	
Number of biological children	One	14	8 (57.1%)	6 (42.9%)	0.174
	Two	44	19 (43.2%)	25 (56.8%)	
	Three	23	13 (56.5%)	10 (43.5%)	
	Four	4	0 (0.0%)	4 (100.0%)	
Planning to have more biological children	Yes	4	4 (100.0%)	0 (0.0%)	**0.009***
	Unsure	2	2 (100.0%)	0 (0.0%)	
	No	79	34 (43.0%)	45 (57.0%)	
Planning on having **any** biological children	Yes	8	8 (100.0%)	0 (0.0%)	0.091*
	Unsure	3	3 (100.0%)	0 (0.0%)	
	No	19	12 (63.2%)	7 (36.8%)	
Gene mutation	*MLH1*	17	10 (58.8%)	7 (41.2%)	0.501
	MSH2	31	14 (45.2%)	17 (54.8%)	
	MSH6	33	21 (63.6%)	12 (36.4%)	
	PMS2	34	18 (52.9%)	16 (47.1%)	
Received genetic counseling as part of	Yes	102	53 (52.0%)	49 (48.0%)	0.089

the genetic testing process					
	No	13	10 (76.9%)	3 (23.1%)	
When genetic counseling was received	Before genetic testing	14	8 (57.1%)	6 (42.9%)	0.186
	After genetic testing	39	23 (59.0%)	16 (41.0%)	
	Both before and after genetic testing	49	22 (44.9%)	27 (55.1%)	
Period status at time of genetic testing	Having periods	80	47 (58.8%)	33 (41.3%)	0.196
	Menopausal	35	16 (45.7%)	19 (54.3%)	
First person to undergo genetic testing in the family	Yes	61	37 (60.7%)	24 (39.3%)	0.179
	No	54	26 (48.1%)	28 (51.9%)	
Previously diagnosed with a non gynecological cancer	No	76	47 (61.8%)	29 (38.2%)	**0.011**
	Yes	36	13 (36.1%)	23 (63.9%)	
Family history of endometrial or ovarian cancer?	Yes	54	29 (53.7%)	25 (46.3%)	0.827
	No	61	34 (55.7%)	27 (44.3%)	
Received gynecological cancer screening for endometrial and/or ovarian cancer	Yes	110	61 (55.5%)	49 (44.5%)	0.409
	No	5	2 (40.0%)	3 (60.0%)	
Received abnormal results of endometrial and/or ovarian cancer screening	Yes	25	13 (52.0%)	12 (48.0%)	0.463
	No	90	50 (55.6)	40 (44.4%)	
Received information about symptoms related to gynecological cancers	No	25	18 (72.0%)	7 (28.0%)	0.051
	Yes	90	45 (50.0%)	49 (50.0%)	
Received information	Yes	106	56 (52.8%)	50 (47.2%)	0.136

about gynecological cancer risks for Lynch syndrome					
	No	9	7 (77.8%)	2 (22.2%)	

Table 7. Factors associated with undergoing both prophylactic hysterectomy and oophorectomy: Chi square tests were performed on the factors included in this table. p-values of less than 0.05 are deemed significant and their values are in bold. * indicate a p-value obtained using the Fisher's exact test. Gynecological cancer screening refers to having an endometrial biopsy, transvaginal ultrasound, and/or a CA-125 blood test to screen for endometrial and/or ovarian cancer.

3.3 Factors Associated with Planning to Pursue Regular Gynecological Cancer Screening

A chi-square test was performed to determine if there were any significant associations between planning to pursue regular gynecological cancer screening and other factors assessed within the survey. One factor assessed through the survey demonstrated statistically significant associations with planning to receive regular gynecological cancer screening while two other factors were approaching significance: receiving information about symptoms of gynecological cancers ($\chi 2=6.785$, $p=0.022$), receiving information about risks of Lynch related gynecological cancers ($\chi 2=4.610$, $p=0.053$), and receiving information about gynecological cancer screening options ($\chi 2=4.610$, $p=0.053$).

Individuals who reported that they had received information about symptoms of gynecological cancers were more likely to pursue regular gynecological cancer screening (81.6%) when compared to those who did not receive any information (47.1%). As mentioned previously, this study did not assess what specific information about symptoms of gynecological cancers was provided to the respondents so it is unclear how the information may or may not have facilitated their decision to pursue gynecological cancer screening. Similarly, those who received information about risks of Lynch related gynecological cancers and gynecological cancer screening options were more likely to pursue screening although this association was not found to be significant and we cannot be sure of how the information they received affected their decision to pursue screening.

As previously stated for factors associated with undergoing prophylactic surgery, there were many other factors that were not found to have significant associations with pursuing gynecological cancer screening. Some factors which may have been thought to influence one's decision to undergo surgery but were not supported by this analysis include whether they had been previously diagnosed with a non-gynecological cancer, whether an individual had previously received abnormal gynecological cancer screening results, whether they have a family history of endometrial or ovarian cancer, and whether they received genetic counseling as part of their genetic testing process.

Table 8. Factors Associated with Planning to Receive Regular Gynecological Cancer Screening

		N	**Not planning on receiving regular gynecological cancer screening N=16**	**Planning on receiving regular gynecological cancer screening N=39**	**p-value**
Education level	Less than a college degree	7	3 (42.9%)	4 (57.1%)	0.402*
	College degree or higher	48	13 (27.1%)	35 (72.9%)	
Have biological children	No	21	6 (28.6%)	15 (71.4%)	0.947
	Yes	34	10 (29.4%)	24 (70.6%)	
Planning on having more biological children	Yes	4	1 (25.0%)	3 (75.0%)	0.789*
	Unsure	2	1 (50.0%)	1 (50.0%)	
	No	28	8 (28.6%)	20 (71.4%)	
Planning on having any biological children	Yes	8	2 (25.0%)	6 (75.0%)	1.000*
	Unsure	3	1 (33.3%)	2 (66.7%)	

	No	10	3 (30.0%)	7 (70.0%)	
When you had genetic testing, which of the following of your genes was found to be causative of Lynch syndrome?	*MLH1*	9	1 (11.1%)	8 (88.9%)	0.666*
	MSH2	13	4 (30.8%)	9 (69.2%)	
	MSH6	16	5 (31.3%)	11 (68.8%)	
	PMS2	17	6 (35.3%)	11 (64.7%)	
Received genetic counseling as part of the genetic testing process	Yes	45	13 (28.9%)	32 (71.1%)	1.000*
	No	10	3 (30.0%)	7 (70.0%)	
Period status at the time of genetic testing	Having periods	45	12 (26.7%)	33 (73.3%)	0.453*
	Menopausal	10	4 (40.0%)	6 (60.0%)	
Previously diagnosed with a non gynecological cancer	No	45	13 (28.9%)	32 (71.1%)	1.000*
	Yes	10	3 (30.0%)	7 (70.0%)	
Family history of endometrial and/or ovarian cancer	Yes	25	6 (24.0%)	19 (76.0%)	0.448
	No	30	10 (33.3%)	20 (66.7%)	
Received abnormal results of your endometrial and/or ovarian cancer screening	Yes	8	0 (0.0%)	8 (100.0%)	0.089*
	No	47	16 (34.0%)	31 (66.0%)	
Received information about symptoms related to gynecological cancers	No	17	9 (52.9%)	8 (47.1%)	**0.022***
	Yes	38	7 (18.4%)	31 (81.6%)	
Received information about gynecological cancer risks for Lynch syndrome	Yes	49	12 (24.5%)	37 (75.5%)	**0.053***

	No	6	4 (66.7%)	2 (33.3%)	
Received information about gynecological cancer screening options for Lynch syndrome	Yes	49	12 (24.5%)	37 (75.5%)	**0.053***
	No	6	4 (66.7%)	2 (33.3%)	

Table 8. Factors associated with planning to receive regular gynecological cancer screening: Chi square tests were performed on the factors included in this table. p-values of less than 0.05 are deemed significant and their values are in bold. * indicate a p-value obtained using the Fisher's exact test.

3.4 Participant Comments

An optional comments box was available for respondents to fill out with any information they felt they were not able to provide by answering the rest of the survey questions. Of the 115 complete responses, 53 (46.1%) left an optional comment. A spectrum of comments provided further insight into some of the emotional factors that respondents experienced while navigating their own decisions to undergo gynecological cancer screening and/or prophylactic hysterectomy and oophorectomy. Most comments described negative experiences pertaining to their diagnosis, surgical outcomes, and screening procedures while others used the comments box to express gratitude towards their care team for making them feel more secure in their personal gynecological health decisions. Common themes of frustration with the lack of knowledge about Lynch syndrome amongst medical practitioners were common, as was the confusion that many patients encounter when multiple providers suggest different and even contradictory screening practices to be followed.

3.4.1 Fear, Anxiety, and Frustration

Of the 54 comments left by respondents, approximately half discussed topics such as fears and anxieties related to Lynch syndrome management, prophylactic surgery regrets, and frustration with current gynecological cancer screening practices. It was not uncommon for respondents to express inherently elevated levels of anxiety due to their Lynch syndrome; one respondent remarked that, "The fear is always there, we feel like the proverbial ticking time bomb… Anything that helps us feel like [cancer has] not yet started helps us get through the next day/month/year."

Others expressed anxiety about not about increased cancer risks, but rather how their providers may treat them differently if they expressed concerns about gynecological cancer screening versus prophylactic surgery. One individual stated that after being a self advocate and attempting to pursue gynecological cancer screening, their gynecologist claimed the screening was "overkill." Another remarked that despite her father and grandfather passing away from colorectal cancer at young ages, she "couldn't get anybody to take my gyn symptoms seriously."The importance of a strong patient-provider relationship with high levels of trust is extremely relevant for individuals in these uncertain situations.

Discordance among providers regarding gynecological cancer screening were also commonly reported amongst the comments: "Gynecologist wants endo biopsy but pcp… doesn't feel it's necessary. Who do you listen to? Seems like not everyone is on the same page for Lynch related gynecological cancers/screenings."

Others expressed a lack of autonomy and education about prophylactic surgery using terminology like, "I wasn't really given options other than surgical removal of my uterus", "My gynecologist oncologist was pretty forceful about me getting a hysterectomy", and "I regret having both ovaries removed…I feel gynecologists are reacting [too] quickly with these surgeries.” In addition, other respondents expressed frustration with the lack of education they received about the lasting impacts a TAH-BSO may have on their bodies: “I was told by both [Northwestern] and Boston to have the surgeries so I did... but I do not feel enough education is provided before or after the surgeries,” and, “In general I have felt that the impact of surgical menopause has been poorly communicated or downplayed.”

Many comments expressed frustration with their providers lack of knowledge about Lynch syndrome: “I wish there were more doctors informed of Lynch syndrome,” “Most doctors are unaware of Lynch Syndrome,” and “I'm really angry at the lack of research and general concern the medical community has about gynecological cancers.”

3.4.2 Surgical Decision Making

Respondents also used the comments box to describe their surgical decision making process as well as factors that they personally reported influenced them. Some individuals reported having an easy time making their decision and are comfortable with the choice they have made: “I knew that if I tested positive for Lynch syndrome that I would have prophylactic surgery so there was never any emphasis on screening”, and “I may decide to get more aggressive with screening as I get closer to my 40's or if the recommendations for *PMS2* get stronger, but at the moment I'm pretty comfortable with the wait and see approach.”

Others described their difficulties of coming to a solution but expressed confidence when they arrived at their decision at their own pace: “I chose to do my hysterectomy after several years of research and wrestling emotionally with the decision…In the end I chose to remove uterus, both Fallopian tubes, and one ovary, and to keep my other ovary to retain my natural hormones to maintain overall health. I am confident in my decision.”

3.4.3 Gratitude toward Decision Facilitators

The recurring theme with the smallest number of comments concerned expressions of gratitude for care team members and comfort with decisions regarding gynecological cancer risk management: “I'm forever thankful to [my doctor] and the genetic counseling team for staying on top of my screening needs so I can be here for my babies,” “I have built a team of doctors behind me that I feel work within my wants and needs and the recommendations available for Lynch patients and their families,” and “I have been grateful to have a GI provider who specializes in patients diagnosed with Lynch.”

Of the comments expressing gratitude, a majority of them focused on the specific Lynch syndrome specialists, doctors, or genetic counselors that helped to facilitate the decisions each participant felt were best for them at the time, however one comment also expressed gratitude for a family member: “These were tricky decisions [to] make. My sister and I made them together which was comforting to have a buddy.”

Lynch syndrome is a very scary thing to have. However, I regret having both ovaries removed. This has impacted my quality of life. I feel gynecologist are reacting to quickly with these surgeries.
My gynecologist oncologist was pretty forceful about me getting a hysterectomy in the year after I got diagnosed, even though the research wasn't nearly as strong for risks of pms2. She also recommends the 6 month screening with biopsy, ultrasounds, and ca125, even though they are not proven to decrease cancer deaths. It's interesting that they do not seem to follow the science, but are trying to find anything proactive they can do to prevent or catch cancer. I hope we find better options soon.
The fear is always there, we feel like the proverbial ticking time bomb when we're told we have, say, an 85% chance of developing some form of cancer. Anything that helps us feel like it's not yet started helps us get through the next day/month/year.
The nature of ovarian cancer symptoms makes it so difficult to detect (i.e. indigestion, pain, spotting, etc.). Coupled with the lack of definitive and reliable screening tests, I don't feel that it's good enough. It feels hopeless and almost futile sometimes. I've literally been told "it's better than nothing". So the best bet is for me to get a hysterectomy and go into menopause in my 30s, or wait every 6 months in fear of my invasive test results that don't really tell me anything definitively? Last year I was diagnosed with medical PTSD regards to my Lynch diagnosis (specifically around GYN) as a result, and am undergoing treatment for it. I'm really angry at the lack of research and general concern the medical community has about gynecological cancers (and GYN health overall), especially considering the subtlety of the symptoms. Even though I'm highly monitored, I feel so let down by this area of medicine, especially when you juxtapose it next to the definitive nature of a colonoscopy. We

need to do better, and I often feel like no one is paying enough attention because it's women's reproductive health, and that's historically the case...
I was done having kids and I knew that having both my uterus and ovaries removed would get rid of those cancer risks. It was an easy decision for me to make. I'd much rather deal with hot flashes than go through chemo again.
Since I have 4 children I wasn't really given options other than surgical removal of my uterus.
Uterine biopsy was done with NO deadening or pain medicine. Was excruciating. They should put women under for it. Totally barbaric. Genetic test results should be gone over once received with a genetic counselor and gynecologist present so that everyone understands/is on the same page. This is life-altering news.
Because I was entering menopause and was finished having children my choice to have surgery was easier to make. I feel many young women are being pressured to have surgery too early. I may decide to get more aggressive with screening as I get closer to my 40's or if the recommendations for PMS2 get stronger, but at the moment I'm pretty comfortable with the wait and see approach. I have decided to wait to undergo a hysterectomy due to my age and not being 100% sure whether I want kids or not. I had only been married for a year when I received my diagnosis and my husband and I have not made a decision over whether to have kids. Right now we are not in a position to have kids financially.
Gynecologist wants endo biopsy but pcp says normal pap, normal transvaginal ultrasound and normal CA125 level, she doesn't feel it's necessary. Who do you listen to? Naturally I would like to Listen to PCP because I've been told the biopsy is painful. Seems like not everyone is on the same page for lynch related gynecological cancers/screenings.
I almost always have to educate my medical professionals regarding Lynch Syndrome, and I have to self-advocate for my screenings, some of which my gynecologist felt were "overkill". My main medical support regarding Lynch Syndrome comes from my genetic counselors.
Since I have already had a hard time finding providers knowledgable about Lynch, I worry that my gynecologist (appointment scheduled for tomorrow) will not take the mutation seriously OR will recommend that I get a hysterectomy immediately, which I am not ready for.
I chose to do my hysterectomy after several years of research and wrestling emotionally with the decision. I spoke to top Lynch expert docs at several cancer centers before making my decision. And in the end I chose to remove uterus, both Fallopian tubes, and one ovary, and to keep my other ovary to retain my natural hormones to maintain overall health. I am confident in my decision. I am willing to take the (hopefully now somewhat reduced risks) of ovarian cancer in order to main the benefits of my natural hormones to my overall health. I will continue to get annual transvaginal ultrasounds until I remove my last ovary at the time of natural menopause. I made this decision with my gynecologic oncologist's support at Cleveland Clinic.
I had everything removed with the exception of my ovaries… Once I had my hysterectomy it became clear that the screenings are not where they need to be. Part of me wishes I had my ovaries removed.
I knew that if I tested positive for lynch syndrome that I would have prophylactic surgery so there was never any emphasis on screening for uterine or ovarian cancer.
I was diagnosed with PMS2 in October. My gyn/onc advised immediate surgery for complete hysterectomy. I went to Dana Farber Lunch Center and was advised I can keep my ovaries until the age of 50. I have surgery scheduled for March and will most likely keep one ovary. .
I was sure from the beginning of diagnosis that I wanted hysterectomy. oopherectomy but it took 8 months to go through steps to get surgery
I was told by both Northwesters and Boston to have the surgeries so I did... but I do not feel enough education is provided before or after the surgeries. I also don't feel that they know what to do with the symptoms after the surgery... hot flashes, night sweats... and do not provide help with this if you can't take hormone replacement.
In general I have felt that the impact of surgical menopause has been poorly communicated or downplayed by the genetic counselors and gyn-oncologists who I've consulted.

Table 9. Examples of comments left by respondents : Respondents were invited to share any additional information they felt they were unable to share by answering the other survey questions.

A complete list of the respondents’ comments pertaining to their own experiences with gynecological health and wellness and other related topics is available for viewing in Appendix B.

IV. Discussion

The aims of this study were to assess what factors may influence the gynecological healthcare decisions of individuals with Lynch syndrome. Factors such as age, preserving fertility, family history of cancer, and education about cancer risks and available screening options were analyzed to determine whether they are associated with an individual’s uptake of endometrial biopsies, transvaginal ultrasounds, CA-125 blood testing, and prophylactic gynecological surgery. General demographic information, Lynch related history, gynecological healthcare management, and knowledge of Lynch syndrome related material was also obtained and was used to assess for any significant associations between an individual's decision to pursue prophylactic surgeries or regular gynecological cancer screening. Respondents also provided information about the Lynch syndrome and gynecological cancer education they received. Additionally, respondents had the ability to express themselves through an optional comments box to provide any relevant information about their experiences with gynecological health and wellness in the context of Lynch syndrome that they were unable to provide by answering the remaining questions in the survey.

Overall, significant associations were found between undergoing both prophylactic hysterectomy and oophorectomy and the respondents’ current age, highest level of education, parity, desire for more children, and personal history of non-gynecological cancer. Additionally, a significant association was observed between undergoing any prophylactic surgery and the respondents’ menopausal status at the time they underwent genetic testing. A significant association was observed between planning to undergo regular gynecological cancer surveillance and whether the respondent received information regarding symptoms of gynecological cancers. Two other associations were also found to be approaching significance concerning whether the respondent received information about gynecological cancer risks for Lynch syndrome and gynecological cancer screening options. The participant comments left at the end of the survey revealed common themes amongst their responses including fear, anxiety, frustration, additional surgical decision making information, and gratitude towards decision facilitators.

4.1 Factors Associated with Prophylactic Surgical Decisions

Out of all of the associations tested to assess for significance with undergoing both prophylactic hysterectomy and oophorectomy, the respondents' age was the most significant association with a p-value of <0.001. There are likely many other factors correlated to age which could influence the strength of this relationship. Since the average age of onset for endometrial cancer and ovarian cancer in Lynch syndrome is approximately 48 and 42-49 years of age (Lu et. al 2007, Nakamura et. al 2014), respectively, younger respondents may be less likely to undergo prophylactic surgery as they are not as close to the average age of onset for these cancers. Conversely, respondents who are 40 years of age and older would be closer to the expected average age of onset and may take more measures to drastically reduce their risk of developing endometrial and ovarian cancer, a general trend supported by the data the respondents provided.

Another factor that is likely linked to age is the respondents parity and desire for future pregnancies; whether the participant has biological children (p=0.005) and whether they are planning to have more in the future (p=0.009) were also significantly associated with one's decision to pursue prophylactic hysterectomy and oophorectomy. Those without any biological children and those who indicated they already have children but are either planning on or unsure about having more children were all less likely to pursue prophylactic surgery than those who do already have children, likely to preserve their fertility until they have the number of children desired.

There are other factors that were associated with surgical decisions: the respondents' highest level of education and their personal cancer history. Individuals whose highest level of education was less than a college degree were more likely to undergo prophylactic hysterectomy and oophorectomy than those with a college degree or higher. Previous studies have shown a relationship between lower socioeconomic status and receiving hysterectomy (Erekson et. al, 2009). Although this study did not collect information about each respondents household income and employment status, it is possible that those with less than a college degree may belong to a different socioeconomic status than those with a college degree or higher, potentially resulting in reduced access to long term medical care which may lead to them undergoing surgery once versus potentially multiple years of gynecological cancer screening. It is possible that these individuals may also have an insurance plan that does not cover gynecological cancer screening, ultimately making a one time surgery a more cost effective approach to managing their gynecological health and wellness.

Respondents who reported that they had been diagnosed with a non-gynecological cancer were also more likely to undergo prophylactic hysterectomy and oophorectomy than those who have not previously been diagnosed with cancer. Information was not collected about how the respondents' initial cancer diagnosis was treated, a prior negative experience with cancer therapy may be influencing the individual to undergo risk-reducing surgery in order to avoid a second experience with cancer therapies. Similarly, a previous cancer diagnosis may cause increased fear and anxiety about a second cancer diagnosis ultimately resulting in the individual reducing their risk of developing other cancers as much as possible.

The fact that certain genetic mutations cause differing increased risks for endometrial and ovarian cancer was not found to be significant as the respondents' gene mutation was not found to be significantly associated with their decision to pursue prophylactic hysterectomy and oophorectomy (p=0.501). Similarly, having a family member with endometrial and ovarian cancer was not found to be significantly associated with one's decision to pursue prophylactic surgery (p=0.827). Because all of the data collected in this study were self reported, we cannot be sure that each respondent correctly reported their Lynch syndrome gene mutation. Since endometrial and ovarian cancer risks vary within and between genes, we also cannot be sure of the risk estimate that was provided to each respondent and how this in combination with their own personal risk tolerance contributed to their decision to undergo or not undergo prophylactic surgery.

4.2 Factors Associated with Gynecological Cancer Screening

There were fewer significant associations found between factors assessed and whether an individual was planning to pursue regular gynecological screening. Respondents who reported that they received information about symptoms of gynecological cancer were more likely to pursue regular gynecological cancer screening than those who did not receive information (p=0.022). Although the information given to respondents about symptoms of gynecological cancers was not collected as part of this survey, a general awareness of red flag symptoms may cause them to be increasingly aware of their gynecological health. Postmenopausal bleeding, heavy or irregular menstrual bleeding in premenopausal individuals, vaginal discharge, hematuria, anemia, thrombocytosis, raised blood glucose, and abdominal pain may cause them to come in more frequently for screening tests if they feel that they may be experiencing any of these red flag symptoms. Respondents who received information about symptoms of gynecological cancers may also have been the same respondents who received information about Lynch related gynecological cancers and gynecological cancer screening options. Although the combined effects of these three factors related to patient education were not analyzed, this may be another possible explanation for this significant association.

Two other factors that were both approaching a significant association with regular gynecological cancer screening were whether the respondent received information about Lynch syndrome related gynecological cancer risks (p=0.053) and whether they received information about gynecological cancer screening options (p=0.053). Receiving information about increased risk of developing endometrial and ovarian cancer may be sufficient for respondents to pursue cancer screening, however in the context of what information the individual receives about gynecological cancer screening options, we cannot be sure if the information they received was given in a neutral fashion about the availability of gynecological cancer surveillance methods, or a negative one which focused on the poor efficacy and unreliability of screening methods such as endometrial biopsy, transvaginal ultrasound, and CA-125 testing.

4.3 Common Themes Present among Participant Comments

Approximately half of respondents who completed the survey provided further information in the optional comments box at the end of the survey. Much like the other data submitted by each participant, these comments provided valuable insight into the unique experiences that individuals in the Lynch syndrome community have encountered. Although each of the comments were provided by individuals with differing backgrounds, common themes within their responses were able to be observed. A complete list of participant comments can be viewed in Appendix B.

4.3.1 Fear, Anxiety, and Frustration

It is likely that a more robust set of gynecological cancer screening guidelines for patients with Lynch syndrome could alleviate these anxiety levels amongst the Lynch community as well as provide guidance for providers who may not be comfortable discussing screening options due to the vagueness of current guidelines. Although there is debate about whether gynecological cancer screening methods are reliable methods of reducing the incidence of endometrial and ovarian cancer, individuals with Lynch syndrome are known to view gynecological cancer screening as an important aspect of their gynecological health care management (Ryan et al. 2021).

Respsondents also expressed their frustration with their providers that they deemed as not being knowledgeable of Lynch syndrome. Since this data is self reported we cannot be sure of the level of knowledge each of their providers had regarding Lynch syndrome, but a recent study of medical school students in the United States also identified a lack of education regarding the gynecological cancer risks associated with Lynch syndrome (Brodsky et al. 2022). As the most common hereditary cancer syndrome, it is extremely relevant for medical practitioners to be knowledgeable of basic Lynch syndrome information such as increased cancer risks and available screening options. Provider knowledge has also been shown to be particularly relevant to those with Lynch syndrome in order to reduce patient anxieties and maximize the benefit of having discussions regarding cancer risk management (Torbit et al. 2016).

4.3.2 Surgical Decision Making

Although the decision to undergo prophylactic surgery is a complex one with many factors influencing it, all but one of the survey respondents have either had gynecological cancer risk reducing surgery, are currently planning on undergoing surgery, or are planning on undergoing the surgery in the future. In addition to the remarks from the optional comments, it is clear that even if an individual has not undergone prophylactic surgery the importance of this decision is not lost on them. Although Ryan et. al 2019 claimed that, "Offering gynaecological surveillance despite a lack of robust evidence for its clinical effectiveness may falsely reassure women and delay risk-reducing hysterectomy," it appears that the respondents to this survey are knowledgeable of these risks and are willing to undergo prophylactic surgery when the time is right for them despite their uptake of gynecological cancer screening.

4.3.3 Gratitude toward Decision Facilitators

It has been previously observed that medical providers can be both barriers and facilitators regarding decisions about disease management; the ability to be knowledgeable of Lynch syndrome and foster a facilitative relationship with their patients has the potential to increase adherence to the protocols discussed (Watkins et al 2011). In addition to provider support, familial support in families with hereditary cancer syndromes has been shown to be associated with decreased levels of hereditary cancer distress and cancer worry (Van Oostrom et al 2006).

Fostering communication of patient fears and anxieties with both providers and family members with similar cancer risks seems to be associated with an overall positive outcomes in terms of decision making and adherence to recommended followup. Although the time spent with each patient is limited, it is reasonable to conclude that normalizing patients’ fear and anxiety and presenting the option of discussing these feelings may have long lasting effects on the patient's mental and physical health.

4.4 Limitations

This study had several limitations which should be acknowledged. All of the data collected through this study were self-reported which could increase the chance for erroneously entered information due to recall bias. When asking respondents about whether they received information about a particular topic, we cannot be sure of what type of information was given to them and whether it was positive, such as informing patients of the availability of gynecological cancer screening, or negative, such as informing patients of the efficacy of certain screening measures and their utility in detecting and preventing gynecological cancers. The small sample size and subsequently smaller subgroups which were analyzed greatly limited the power of the analyses performed and could possibly be obscuring the true significance of associations observed in this study. The demographic information of the respondents who completed the survey were also unrepresentative of the general population making it difficult to generalize the results of this study and apply them to the rest of the population.

4.5 Future Studies

Socioeconomic factors play a large role in one's ability to access quality and consistent healthcare. This survey did not account for socioeconomic factors such as household income, employment status, or medical insurance plan which may all impact a respondents ability to obtain regular gynecological cancer screening or other relevant medical interventions. Collecting this information may allow for further insight into what factors may be influencing an individual to choose to undergo prophylactic hysterectomy and oophorectomy or gynecological cancer screening.

Performing this study in a clinical setting may help to prevent any sampling bias that could have occurred by having the survey distributed online through hereditary cancer support groups and Lynch syndrome focused social media groups. Administering this survey shortly after an individual was given information about Lynch syndrome and any pertinent medical management could also inform clinicians about the patient’s immediate thoughts and feelings regarding the information they were just given and how that might impact their plan to move forward with gynecological cancer screening and/or prophylactic hysterectomy and oophorectomy.

4.6 Conclusions

This study provided insight into various factors associated with an individual's decision to pursue gynecological cancer risk reducing surgeries and/or regular gynecological cancer screening. Participant comments were also compiled and served as anecdotal information regarding their unique but overlapping experiences with managing their gynecological health and wellness.

Overall, the information collected as part of this study has the potential to make clinicians more aware of the many factors that influence a patient’s personal decision making strategies. Although the results produced from these analyses are not generalizable to the population at large, the information provided by the survey respondents serves as a reminder that each person will be influenced by their own experiences when making their medical management decisions.

Approaching these encounters with patient centered care as well as information gained by listening the members of the Lynch syndrome community may help to facilitate trusting relationships and ultimately empower patients to be aware of their personal risks and make confident and informed decisions about their gynecological health and wellness.

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APPENDIX A: Thesis Survey

Assessing preventive gynecological decisions of individuals with Lynch syndrome

Please read the information below and ask any questions about anything that you do not understand. A researcher listed above will be available to answer your questions.

Purpose: To examine how individuals with Lynch syndrome make decisions regarding their gynecological health and what factors may impact the decisions that they make, explore what resources are utilized when making gynecological care decisions, and assess if certain factors are correlated with an increased frequency of gynecological screening or prophylactic surgery.

Participation in this survey is voluntary. You may refuse to participate or terminate your involvement at any time without any penalty.

Estimated time to complete the survey is approximately 30 minutes.

Eligibility: Anyone 18 years old and above residing in the United States of America without a diagnosis of uterine or ovarian cancer at the time they were diagnosed with Lynch syndrome through genetic testing and had not had their uterus and ovaries removed yet at the time of their Lynch syndrome diagnosis is eligible to participate in this study. Individuals must also have received their genetic testing in the United States of America, be able to read and write in English to participate as the survey is not offered in other languages.

Possible Risks and Discomforts: This survey could be stressful for some participants as it will discuss topics such as medical procedures and cancer diagnoses.

Potential Benefits: There are no direct benefits from participation in this study, however this study may reveal factors influential in one's life when making important and personal decisions about their future medical management which may help medical providers more mindfully counsel patients in the future regarding screening and surgical options.

Participants who consent to completing the survey will have the option to enter a drawing to win one of 10 available $20 Amazon electronic gift cards. You may submit an email address at the end of the survey for the gift card code to be sent to in the case that you are chosen as a gift card recipient. Email addresses will be assigned a number and a random number generator will select the 10 winners. Electronic gift cards will be emailed to winners by June 2023 and all email addresses collected will be destroyed once compensation is distributed.

This research may also educate participants on gynecological cancer risk management options the participant may not have been informed of before which may prompt further discussions about these care options between the participant and their medical providers.

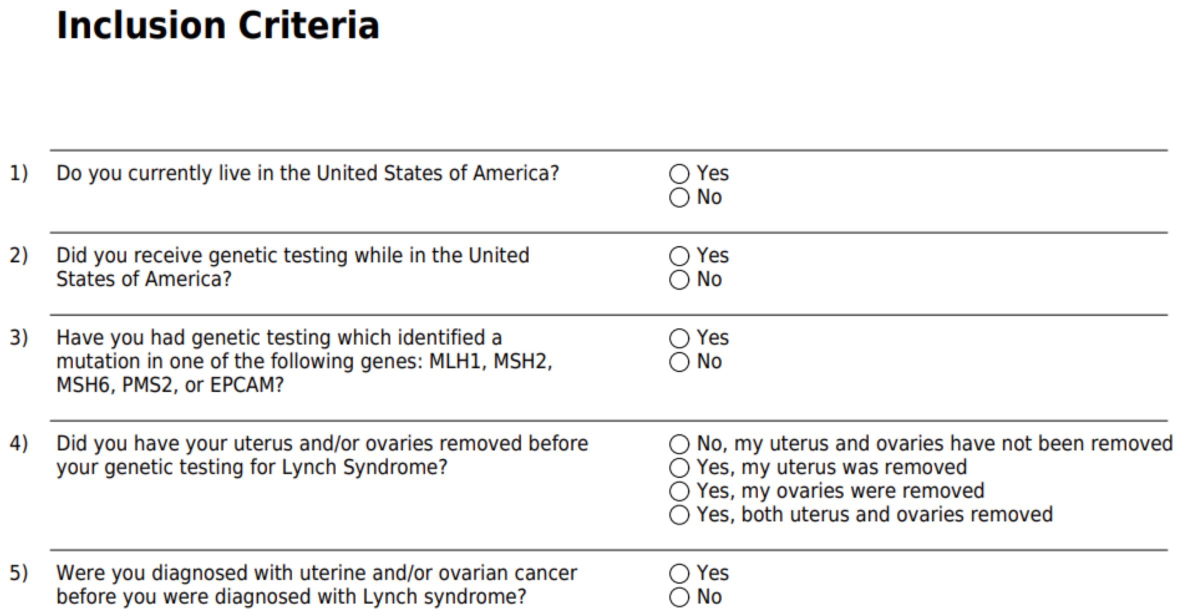
Information Storage: All responses to survey questions will be stored securely and confidentially. Information will be password protected and maintained in an encrypted format on the UCI REDCap server.

Questions? If you have any comments, concerts, or questions regarding this study please contact the researchers listed at the top of this form (Ryan Mahoney: rpmahone@hs.uci.edu or Jason Zell DO, MPH: jzell@hs.uci.edu)

Please contact the UCI Institutional Review Board by phone (949) 824-6662, by email at IRB@research.uci.edu or at 160 Aldrich Hall, Irvine, CA 92692-7600 if you are unable to reach the researchers listed above and have general questions, have concerns or complaints about the research, have questions about your rights as a research subject, or have general comments or suggestions.

What is an IRB? An Institutional Review Board (IRB) is a committee made up of scientists and non-scientists. The IRB's role is to protect the rights and welfare of human subjects involved in research. The IRB also assures that the research complies with applicable regulation, laws, and institutional policies. If you would like to participate in this study, are 18 years old or older, have received a diagnosis of Lynch syndrome through genetic testing, and currently have or have had in the past a risk of developing cancer of the uterus or ovaries, please complete the verification below to start the survey.

1)	Do you consent to participating in this study?	○ Yes, I would like to participate in this study and take the survey. ○ No, I would not like to participate in this study.



Inclusion Criteria

1)	Do you currently live in the United States of America?	○ Yes ○ No
2)	Did you receive genetic testing while in the United States of America?	○ Yes ○ No
3)	Have you had genetic testing which identified a mutation in one of the following genes: MLH1, MSH2, MSH6, PMS2, or EPCAM?	○ Yes ○ No
4)	Did you have your uterus and/or ovaries removed before your genetic testing for Lynch Syndrome?	○ No, my uterus and ovaries have not been removed ○ Yes, my uterus was removed ○ Yes, my ovaries were removed ○ Yes, both uterus and ovaries removed
5)	Were you diagnosed with uterine and/or ovarian cancer before you were diagnosed with Lynch syndrome?	○ Yes ○ No

Part 1 of 4: Demographic Information

From which support group did you receive the link to participate in this study?	○ FORCE ○ AliveAndKickn ○ Lynch Syndrome International ○ Kintalk ○ Unsure ○ Other
Please specify what group you received the link to participate in this survey from:	________________________________
What is your current age?	________________________________
What sex were you assigned at birth?	○ Male ○ Female ○ Intersex ○ Prefer not to answer ○ Other
Please specify your sex:	________________________________
What is your gender?	○ Man ○ Woman ○ Nonbinary ○ Prefer not to answer ○ Other
Please specify your gender:	________________________________
What is your ethnicity?	○ Hispanic or Latino ○ Not Hispanic or Latino ○ Unknown ○ Prefer not to answer
What is your race?	○ Native America/Alaska Native ○ Asian ○ Native Hawaiian or Pacific Islander ○ White or European ○ Black or African American ○ More than one race ○ Unknown ○ Prefer not to answer
Please select all races that apply.	☐ Native America/Alaska Native ☐ Asian ☐ Native Hawaiian or Pacific Islander ☐ White or European ☐ Black or African American

What is your relationship status?	○ Married ○ Living together ○ Single ○ Divorced ○ Separated ○ Widowed ○ Prefer not to answer ○ Other
Please specify your relationship status:	________________________________
What is the highest grade or year of school you completed?	○ Never attended school or only kindergarten ○ Grades 1-8 (Elementary) ○ Some high school (Grades 9-11) ○ High school graduate (or GED) ○ Some college or technical school ○ Technical school graduate ○ College graduate ○ Postgraduate degree ○ Prefer not to answer
Do you have biological children?	○ Yes ○ No
How many biological children do you have?	________________________________
Are you considering having more biological children in the future?	○ Yes ○ No ○ Unsure
Are you considering having biological children in the future?	○ Yes ○ No ○ Unsure
Do you still have menstrual periods?	○ Yes ○ No
My periods stopped at age:	________________________________
My periods stopped because of:	○ Natural menopause ○ Both uterus and ovaries removed ○ Hysterectomy (uterus removed) ○ Ovaries removed ○ Chemotherapy ○ Other
Please specify why your periods stopped:	________________________________

Part 2 of 4: Genetic Testing and Lynch Syndrome History

When you had genetic testing, which of the following of your genes was found to be causative of Lynch syndrome?	○ MLH1 ○ MSH2 ○ MSH6 ○ PMS2 ○ EPCAM
How old were you when you received your genetic testing results?	________________________
Did you receive genetic counseling as part of your genetic testing process?	○ Yes ○ No
When did you receive genetic counseling?	○ Before genetic testing ○ After genetic testing ○ Both before and after genetic testing
Did you still have menstrual periods when you received your genetic testing results?	○ Yes ○ No ○ Unsure
Were you the first person in your family to undergo genetic testing?	○ Yes ○ No ○ Unsure
Which of your family member(s) were tested before you? Choose all that apply:	☐ Child(ren) ☐ Parent(s) ☐ Grandparent(s) ☐ Sibling(s) (brother or sister) ☐ Half sibling(s) ☐ Aunt(s) or Uncle(s) ☐ Niece(s) or Nephew(s) ☐ Cousin(s) ☐ Unsure ☐ Other
Please specify which family members tested before you:	________________________
Have you been diagnosed with cancer?	○ Yes ○ No

What type of cancer have you been diagnosed with?	○ Bladder ○ Bone ○ Brain ○ Breast ○ Breast DCIS ○ Cervix ○ Colorectal ○ Esophagus ○ Kidney ○ Leukemia ○ Liver ○ Lung ○ Lymphoma ○ Melanoma ○ Multiple myeloma ○ Ovary ○ Pancreas ○ Prostate ○ Sarcoma ○ Skin ○ Stomach ○ Testicle ○ Thyroid ○ Uterus ○ Other ○ Unknown
Please specify the type of cancer you were diagnosed with:	______________________________
How old were you when you were diagnosed with this cancer?	______________________________
Have you been diagnosed with any other types of cancer?	○ Yes ○ No
Have any of your family members been diagnosed with uterine or ovarian cancer?	○ Yes ○ No
Which family member has been diagnosed with uterine or ovarian cancer?	○ Mother ○ Father ○ Aunt ○ Uncle ○ Grandmother ○ Grandfather ○ Cousin ○ Sister ○ Brother ○ Daughter ○ Son ○ Niece ○ Nephew ○ Granddaughter ○ Grandson
What side of your family is this relative related to you through?	○ Mother's side ○ Father's side ○ Both (use for full siblings, children, full nieces/nephews, and grandchildren)
Were they diagnosed with uterine or ovarian cancer?	○ Ovarian ○ Uterine
How old were they when they were diagnosed with this cancer?	______________________________
Have any other family members been diagnosed with uterine or ovarian cancer?	○ Yes ○ No

Part 3 of 4: Gynecological Care Decision Making

Have you had both a hysterectomy and an oophorectomy, the surgical removal of your uterus and ovaries, after you were diagnosed with Lynch syndrome?	○ Yes ○ No
How old were you when you had your hysterectomy?	______________________________
What was the reason for your hysterectomy? Select all that apply:	☐ Prevention ☐ Cancer (Diagnosed before genetic testing) ☐ Cancer (Diagnosed after genetic testing) ☐ Suspected Cancer ☐ Symptoms ☐ Removed during an oophorectomy (removal of ovarie ☐ Uterine Fibroids ☐ Other
Please specify the reason for your hysterectomy:	______________________________
How old were you when you had your oophorectomy?	______________________________
What was the reason for removing your ovaries? Select all that apply:	☐ Prevention ☐ Cancer (Diagnosed before genetic testing) ☐ Cancer (Diagnosed after genetic testing) ☐ Cysts ☐ Suspected Cancer ☐ Symptoms ☐ Removed during a hysterectomy (removal of uterus) ☐ Other
Please specify the reason for your oophorectomy:	______________________________
Which of the following options best describes your reason(s) for undergoing both a hysterectomy and oophorectomy before uterine or ovarian cancer developed? Select all that apply:	☐ Desire to avoid cancer ☐ Family member affected by uterine and/or ovarian cancer ☐ Family member affected by other cancer ☐ Recommendation from a medical practitioner to undergo surgery ☐ Felt pressure from an individual outside of my medical care team to undergo surgery ☐ Viewed surgery as the responsible decision to make ☐ Experienced excessive bleeding and/or abdominal pain during period ☐ Desired to avoid gynecological screening in the future ☐ I am not planning on having any more children ☐ I am postmenopausal (i.e. no more menstruation) ☐ Other
Please specify your reason for undergoing both a hysterectomy and oophorectomy before uterine or ovarian cancer developed:	______________________________

Of the options you selected above, what would you say is the main reason for undergoing these surgeries? Select only one:	○ Desire to avoid cancer ○ Family member affected by uterine and/or ovarian cancer ○ Family member affected by other cancer ○ Recommendation from a medical practitioner to undergo surgery ○ Felt pressure from an individual outside of my medical care team to undergo surgery ○ Viewed surgery as the responsible decision to make ○ Experienced excessive bleeding and/or abdominal pain during period ○ Desired to avoid gynecological screening in the future ○ I am not planning on having any more children ○ I am postmenopausal (i.e. no more menstruation) ○ Other
Please specify your main reason for undergoing both a hysterectomy and oophorectomy before uterine or ovarian cancer developed:	______________________________
Have you had a hysterectomy, the surgical removal of your uterus, after you were diagnosed with Lynch syndrome?	○ Yes ○ No
How old were you when you had your hysterectomy?	______________________________
What was the reason for your hysterectomy? Select all that apply:	☐ Prevention ☐ Cancer (Diagnosed before genetic testing) ☐ Cancer (Diagnosed after genetic testing) ☐ Suspected Cancer ☐ Symptoms ☐ Removed during an oophorectomy (removal of ovaries) ☐ Uterine Fibroids ☐ Other
Please specify the reason for your hysterectomy:	______________________________
Which of the following options best describes your reason(s) for undergoing a hysterectomy before uterine cancer developed? Select all that apply:	☐ Desire to avoid cancer ☐ Family member affected by uterine and/or ovarian cancer ☐ Family member affected by other cancer ☐ Recommendation from a medical practitioner to undergo surgery ☐ Felt pressure from an individual outside of my medical care team to undergo surgery ☐ Viewed surgery as the responsible decision to make ☐ Experienced excessive bleeding and/or abdominal pain during period ☐ Desired to avoid gynecological screening in the future ☐ I am not planning on having any more children ☐ I am postmenopausal (i.e. no more menstruation) ☐ Other
Please specify your reason for undergoing a hysterectomy before uterine cancer developed:	______________________________

Of the options you selected above, what would you say is the main reason for undergoing this surgery? Select only one:	○ Desire to avoid cancer ○ Family member affected by uterine and/or ovarian cancer ○ Family member affected by other cancer ○ Recommendation from a medical practitioner to undergo surgery ○ Felt pressure from an individual outside of my medical care team to undergo surgery ○ Viewed surgery as the responsible decision to make ○ Experienced excessive bleeding and/or abdominal pain during period ○ Desired to avoid gynecological screening in the future ○ I am not planning on having any more children ○ I am postmenopausal (i.e. no more menstruation) ○ Other
Please specify your main reason for undergoing a hysterectomy before uterine cancer developed:	__________________________
Have you had an oophorectomy, the surgical removal of one or both of your ovaries, after you were diagnosed with Lynch syndrome?	○ Yes ○ No
How old were you when you had your oophorectomy?	__________________________
Did you have one or both of your ovaries removed?	○ One ○ Both ○ Unsure
Did they also remove your fallopian tubes?	○ Yes ○ No ○ Unsure
What was the reason for removing your ovaries? Select all that apply:	☐ Prevention ☐ Cancer (Diagnosed before genetic testing) ☐ Cancer (Diagnosed after genetic testing) ☐ Cysts ☐ Suspected Cancer ☐ Symptoms ☐ Removed during a hysterectomy (removal of uterus) ☐ Other
Please specify the reason for your oophorectomy:	__________________________

Which of the following options best describes your reason(s) for undergoing an oophorectomy before ovarian cancer developed? Select all that apply:	☐ Desire to avoid cancer ☐ Family member affected by uterine and/or ovarian cancer ☐ Family member affected by other cancer ☐ Recommendation from a medical practitioner to undergo surgery ☐ Felt pressure from an individual outside of my medical care team to undergo surgery ☐ Viewed surgery as the responsible decision to make ☐ Desired to avoid gynecological screening in the future ☐ I am not planning on having any more children ☐ I am postmenopausal (i.e. no more menstruation) ☐ Other
Please specify your reason for undergoing an oophorectomy before ovarian cancer developed:	______________________________
Of the options you selected above, what would you say is the main reason for undergoing this surgery? Select only one:	○ Desire to avoid cancer ○ Family member affected by uterine and/or ovarian cancer ○ Family member affected by other cancer ○ Recommendation from a medical practitioner to undergo surgery ○ Felt pressure from an individual outside of my medical care team to undergo surgery ○ Viewed surgery as the responsible decision to make ○ Desired to avoid gynecological screening in the future ○ I am not planning on having any more children ○ I am postmenopausal (i.e. no more menstruation) ○ Other
Please specify your main reason for undergoing an oophorectomy before ovarian cancer developed:	______________________________
Which of the following options best describes your reason(s) for not undergoing a hysterectomy and/or oophorectomy? Select all that apply:	☐ Too young to undergo these surgeries ☐ Desire for pregnancy or more children ☐ Fear of undergoing surgery and/or surgical complications ☐ Surgery is not necessary since I don't have cancer ☐ Was not made aware of surgical options to reduce risk of cancer ☐ Comfortable with current gynecological screening ☐ Fear of making permanent changes to my body ☐ Not ready to go into menopause ☐ Costs involved with surgery ☐ Lack of family support to recover from surgery ☐ Insurance did not cover surgery ☐ Other
Please specify your reason for not undergoing a hysterectomy and/or oophorectomy:	______________________________

Of the options you selected above, what would you say is the main reason for not undergoing these surgeries? Select only one:	○ Too young to undergo these surgeries ○ Desire for pregnancy or more children ○ Fear of undergoing surgery and/or surgical complications ○ Surgery is not necessary since I don't have cancer ○ Was not made aware of surgical options to reduce risk of cancer ○ Comfortable with current gynecological screening ○ Fear of making permanent changes to my body ○ Not ready to go into menopause ○ Costs involved with surgery ○ Lack of family support to recover from surgery ○ Insurance did not cover surgery ○ Other
Please specify your main reason for not undergoing a hysterectomy and/or oophorectomy:	__________________________________
Are you currently planning on undergoing either or both of these surgeries?	○ Yes ○ No
When are you planning on undergoing one or both of these surgeries?	○ After menopause ○ After childbearing ○ Other
Please specify when you are planning on undergoing a hysterectomy and/or oophorectomy:	__________________________________
Are you still considering whether or not to undergo these surgeries in the future?	○ Yes, I am still in the process of deciding if I will have these surgeries in the future. ○ No, I am not considering whether or not I will have these surgeries and am sure I will not have them.

The following questions will be discussing several types of uterine and ovarian cancer screening methods. There is no right or wrong answer to these questions about whether you have undergone the screening methods discussed. It is important to answer the questions honestly so that we can get an accurate view of what kinds of gynecological screening practices people are receiving within the Lynch community. After completing this survey, you will be sent information adapted from the National Comprehensive Cancer Network and their stance on the following gynecological screening methods for people with Lynch syndrome.

Have you ever had an endometrial biopsy performed? An endometrial biopsy is a procedure in which a tissue sample is obtained from the inside lining of the uterus and is then examined under a microscope for any cell abnormalities or cancer.	○ Yes ○ No
How many endometrial biopsies have you received?	__________________________________
How old were you when you had your first endometrial biopsy?	__________________________________
In what year was your last endometrial biopsy?	__________________________________

How often do you plan on receiving endometrial biopsies? Please select "I have already had my uterus removed" if you have already had a hysterectomy.	○ More than once every 6 months ○ Every 6 months ○ Once a year ○ Every 2 years ○ Every 3 years ○ Every 4 years ○ Every 5 years ○ Less than every 5 years ○ I do not plan on receiving regular endometrial biopsies ○ I have already had my uterus removed
Have you ever had an abnormal endometrial biopsy?	○ Yes ○ No ○ Unsure
On a scale of 0 to 10 with 0 being no pain and 10 being the worst pain imaginable, what is the average level of pain you have experienced?	0 (No Pain) 5 10 (Worst Pain Imaginable) *(Place a mark on the scale above)*
Have you ever received a transvaginal ultrasound? A transvaginal ultrasound is a procedure used to examine the vagina, uterus, fallopian tubes, ovaries, and bladder by inserting an ultrasound probe into the vagina that causes sound waves to bounce off organs inside the pelvis to create an image that can be analyzed for any abnormal structures or growth indicative of cancer.	○ Yes ○ No
How old were you when you had your first transvaginal ultrasound?	________________________________
How many transvaginal ultrasounds have you received?	________________________________
In what year was your last transvaginal ultrasound?	________________________________
How often do you plan on receiving transvaginal ultrasounds? Please select "I have already had my uterus and ovaries removed" if you have already had a hysterectomy and oophorectomy.	○ More than once every 6 months ○ Every 6 months ○ Once a year ○ Every 2 years ○ Every 3 years ○ Every 4 years ○ Every 5 years ○ Less than every 5 years ○ I do not plan on receiving regular transvaginal ultrasounds ○ I have already had my uterus and ovaries removed
Have you ever had an abnormal transvaginal ultrasound?	○ Yes ○ No ○ Unsure

Have you ever received a CA-125 blood test? A CA-125 blood test measures the amount of the Cancer Antigen 125 protein in the blood which can be used to monitor the presence of certain cancers, such as ovarian cancer, in the body.	○ Yes ○ No
In what year was your last CA-125 blood test?	______________________________
How old were you when you had your first CA-125 blood test?	______________________________
How many CA-125 blood tests have you received?	______________________________
How often do you plan on receiving CA-125 blood testing? Please select "I have already had my ovaries removed" if you have already had both ovaries removed.	○ More than once every 6 months ○ Every 6 months ○ Once a year ○ Every 2 years ○ Every 3 years ○ Every 4 years ○ Every 5 years ○ Less than every 5 years ○ I do not plan on receiving regular CA-125 testing ○ I have already had my ovaries removed
Have you ever had an abnormal CA-125 blood test?	○ Yes ○ No ○ Unsure
Oral contraceptives (oral birth control pills) have been shown to reduce the incidence of certain gynecological cancers. Do you currently use or have you ever used oral contraceptive pills?	○ Yes ○ No
For how many years did you take or have you been taking oral birth control pills?	______________________________
What is your reason for taking oral birth control pills? Select all that apply:	☐ Birth control ☐ Reduce risk of gynecological cancers ☐ Regulate period symptoms ☐ Help reduce acne ☐ Other
Please specify your reason for taking oral birth control pills:	______________________________
What is your main reason for taking oral birth control pills?	○ Birth control ○ Reduce risk of gynecological cancers ○ Regulate period symptoms ○ Help reduce acne ○ Other
Please specify your main reason for taking oral birth control pills:	______________________________

Part 4 of 4: Lynch Syndrome Education

Information about Lynch syndrome, symptoms of gynecological cancers, Lynch related gynecological cancer risks, and gynecological cancer screening options will be provided at the end of this survey.

Which two places in the body are most likely to develop cancer in people who have Lynch syndrome? Choose only two of the following:	☐ Bladder ☐ Brain ☐ Breast ☐ Colorectal ☐ Kidney ☐ Ovarian ☐ Pancreatic ☐ Prostate ☐ Stomach ☐ Small intestine ☐ Uterus
How would you estimate your current risk of developing uterine cancer?	○ No Risk ○ Low Risk ○ Below Average Risk ○ Average Risk ○ Above Average Risk ○ High Risk ○ Guaranteed to Develop Uterine Cancer
How would you estimate your current risk of developing ovarian cancer?	○ No Risk ○ Low Risk ○ Below Average Risk ○ Average Risk ○ Above Average Risk ○ High Risk ○ Guaranteed to Develop Ovarian Cancer

Gynecological Cancer Symptoms

Have you received information about symptoms of gynecological cancer to be aware of?	○ Yes ○ No
Which of the following resources have you used to receive information about symptoms of gynecological cancers? Select all that apply:	☐ Primary care provider ☐ Gynecologist ☐ Gynecologic oncologist ☐ Genetic counselor ☐ Lynch syndrome support groups ☐ Family members ☐ Friends ☐ Online information seeking (not including support group webpages) ☐ Other
Please specify what other resource you used to receive information about symptoms of gynecological cancers:	________________________________

Where did you first receive information regarding these symptoms? Choose only one option:	○ Primary care provider ○ Gynecologist ○ Gynecologic oncologist ○ Genetic counselor ○ Lynch syndrome support groups ○ Family members ○ Friends ○ Online information seeking (not including support group webpages) ○ Other
Please specify the first resource you used to receive information about symptoms of gynecological cancers:	__________________________________
In what format was this information about gynecological cancer symptoms given to you the first time you received it? Select all that apply:	☐ Verbally ☐ Written ☐ Informational pamphlet ☐ Other
Please specify the format the information about gynecological cancer symptoms was in the first time you received it:	__________________________________
Do you feel like you received enough information from your healthcare providers about the symptoms of gynecological cancers?	○ Yes ○ No
Did you hope that you would receive information about the symptoms of gynecological cancer when attending medical appointments where your diagnosis of Lynch syndrome was discussed?	○ Yes ○ No

Gynecological Cancer Risks

Have you received information about gynecological cancer risks for Lynch syndrome?	○ Yes ○ No
Which of the following resources have you used to receive information about gynecological cancer risks for Lynch syndrome? Select all that apply:	☐ Primary care provider ☐ Gynecologist ☐ Gynecologic oncologist ☐ Genetic counselor ☐ Lynch syndrome support groups ☐ Family members ☐ Friends ☐ Online information seeking (not including support group webpages) ☐ Other
Please specify what other resource you used to receive information about symptoms of gynecological cancers:	__________________________________

Where did you first receive information regarding these cancer risks? Choose only one option:	○ Primary care provider ○ Gynecologist ○ Gynecologic oncologist ○ Genetic counselor ○ Lynch syndrome support groups ○ Family members ○ Friends ○ Online information seeking (not including support group webpages) ○ Other
Please specify the first resource you used to receive information about gynecological cancer risks:	________________________________
In what format was this information about gynecological cancer risks given to you the first time you received it? Select all that apply:	☐ Verbally ☐ Written ☐ Informational pamphlet ☐ Other
Please specify the format the information about gynecological cancer risks was in the first time you received it:	________________________________
Do you feel like you received enough information from your healthcare providers about the risks of developing gynecological cancers?	○ Yes ○ No
Did you hope that you would receive information about the risks of developing gynecological cancer when attending medical appointments where your diagnosis of Lynch syndrome was discussed?	○ Yes ○ No

Gynecological Cancer Screening

Have you received information about gynecological cancer screening options for Lynch syndrome?	○ Yes ○ No
Which of the following resources have you used to receive information about gynecological cancer screening options for Lynch syndrome? Select all that apply:	☐ Primary care provider ☐ Gynecologist ☐ Gynecologic oncologist ☐ Genetic counselor ☐ Lynch syndrome support groups ☐ Family members ☐ Friends ☐ Online information seeking (not including support group webpages) ☐ Other
Please specify what other resource you used to receive information about gynecological cancer screening options:	________________________________

Where did you first receive information regarding these screening options? Choose only one option:	○ Primary care provider ○ Gynecologist ○ Gynecologic oncologist ○ Genetic counselor ○ Lynch syndrome support groups ○ Family members ○ Friends ○ Online information seeking (not including support group webpages) ○ Other
Please specify the first resource you used to receive information about gynecological cancer screening options:	________________________________
In what format was this information about gynecological cancer screening options given to you the first time you received it? Select all that apply:	☐ Verbally ☐ Written ☐ Informational pamphlet ☐ Other
Please specify the format the information about gynecological cancer screening options was in the first time you received it:	________________________________
Do you feel like you received enough information from your healthcare providers about gynecological cancer screening options?	○ Yes ○ No
Did you hope that you would receive information about gynecological cancer screening options for Lynch syndrome when attending medical appointments where your diagnosis of Lynch syndrome was discussed?	○ Yes ○ No
(Optional) Please feel free to share any other thoughts you have not shared yet about your Lynch syndrome diagnosis and your decision-making process with regards to gynecological cancer.	____
(Optional) Please enter your email for a chance to receive one of ten $20 Amazon electronic gift cards. The gift card code will be sent to the address provided in the event that you win. Electronic gift cards will be emailed to winners no later than June 2023 and all email addresses collected will be destroyed once compensation is distributed.	________________________________

Thank you for participating!

Provided below is a PDF file of information about Lynch syndrome, symptoms of gynecological cancers, Lynch related gynecological cancer risks, and gynecological cancer screening options. Please feel free to download or print a copy of this information to keep with your other Lynch syndrome health care information.

Please make sure to press the "Submit" button below once you have opened the PDF to make sure that your responses are recorded properly.

[Attachment: "Lynch Syndrome Information.pdf"]

Lynch Syndrome Cancer Screening and Management Information

Lynch syndrome is the most common inherited cancer disorder, affecting around 1 in 300 people. The genes responsible for causing Lynch syndrome are involved in repairing the DNA in our body when it gets damaged. When one of these genes is mutated and can't work properly, our body has a harder time defending itself from certain types of cancer. It can increase the risk of developing many types of cancers, but the greatest increased risks are for colorectal, uterine, ovarian, and stomach cancer. Each of the 5 genes that can cause Lynch syndrome when mutated hold different increased risks for these three most common cancers. The table below shows the chance of a person with Lynch syndrome to develop colorectal, uterine, ovarian and stomach cancer over their lifetime based on which of their genes is mutated.

Cancer Type	MLH1	MSH2 and EPCAM	MSH6	PMS2	General population
Colorectal	46%-61%	33%-52%	10%-44%	8.7%-20%	4.2%
Uterine (Endometrial)	34%-54%	21%-57%	16%-49%	13%-26%	3.1%
Ovarian	4%-20%	8%-38%	≤1%-13%	1.3%-3%	1.3%
Stomach (Gastric)	2% – 7%	0.2 – 9.0%	1% - 7.9%	Inadequate Data	0.9%

These percentages have been adapted from data reported in the National Comprehensive Cancer Networks guidelines (NCCN, Version 1.2022) for managing hereditary colorectal cancer. These guidelines assist in the decision-making process of individuals and the healthcare team involved in their cancer care. The guidelines are updated frequently to report the most up to date information for managing cancer risks; the lifetime cancer risks reported above and cancer screening guidelines below are subject to change as more information is gathered about people with Lynch syndrome and effective cancer screening practices.

Colon and Stomach Cancer Screening and Management

- Screening: Colonoscopies are recommended to begin anywhere from 20 to 35 years of age, however the age at which they are recommended and frequency of them varies based on which Lynch syndrome gene is mutated and the ages of diagnosis for any family members with colorectal cancer. Upper endoscopy recommendations also vary by gene mutation and family history but generally begin from 30 to 40 years of age every 2 to 4 years.

- Medication: The use of aspirin has recently shown the potential to decrease the risk of developing colorectal cancer in people with Lynch syndrome. The decision to begin aspirin therapy should only be made with your doctor once it is deemed appropriate for you.

Uterine (Endometrial) Cancer Screening and Management

- Surgery: The most effective way to reduce the chance of developing uterine cancer is to have your uterus removed. The decision to remove your uterus should be individualized and based off of factors such as which Lynch syndrome gene is mutated, whether or not childbearing is complete, and any other factors that could be increasing your risk of developing uterine cancer.
- Symptom Awareness: Education about symptoms associated with uterine cancer can help make people be more proactive about their gynecological health. For uterine cancer these symptoms include abnormal vaginal discharge or bleeding, postmenopausal vaginal bleeding, unexplained weight loss, changes in bowel habits, and/or abdominal pain. If you are experiencing any of these symptoms, talk with your doctor or other healthcare professional to see what the next best steps for your medical management should be.
- Medication: Oral birth control pill use has been associated with a decreased risk of developing uterine cancer. Talk with your doctor about the risks and benefits of oral contraceptive use to see if it is appropriate for you.
- Screening: Version 1.2022 of the NCCN Guidelines states that the practice of routine screening for uterine cancer does **not** have a proven benefit. Endometrial biopsies can be used to diagnose someone with uterine cancer but their effectiveness as a screening test has not yet been proven. Similarly, transvaginal ultrasounds may or may not be performed by certain doctors since their results are often unreliable in premenopausal women. Talk with your doctor or another healthcare professional and learn more about the risks and benefits of each to see if they are appropriate for you.

Ovarian Cancer Screening and Management

- Surgery: The most effective way to reduce the chance of developing ovarian cancer is to have your ovaries removed. The decision to remove your ovaries should be individualized and based off of factors such as which Lynch syndrome gene is mutated, whether or not childbearing is complete, menopause status, and any other factors that could be increasing your risk of developing ovarian cancer.
- Symptom Awareness: Education about symptoms associated with ovarian cancer can help make people be more proactive about their gynecological health. For ovarian cancer these symptoms include pelvic or abdominal pain, bloating, increased abdominal girth, unexplained weight loss, difficulty eating, early satiety, or increased urinary frequency and/or urgency. If you are experiencing any of these symptoms talk with your doctor or other healthcare professional to see what the next best steps for your medical management should be.
- Screening: Version 1.2022 of the NCCN Guidelines states that the practice of routine screening for ovarian cancer is **not** recommended due to a lack of evidence that ovarian

cancer screening reduces the risk of developing ovarian cancer. The decision to undergo transvaginal ultrasounds and/or CA-125 blood tests for ovarian cancer screening is often made by doctors who may or may not feel comfortable performing these screening tests on their patients. Talk with your doctor or another healthcare professional and learn more about the risks and benefits of each to see if they are appropriate for you.

If you have any further questions about genetic testing or cancer screening, you can also visit the National Society of Genetic Counselor's website at **nsgc.org** and navigate to the Find a Genetic Counselor section of the website to see if there is a genetic counselor near you who you could schedule an appointment with to discuss these topics in greater detail.

APPENDIX B: Complete List of Participant Comments

I am the only woman in my family with a known MSH2 mutation. I have no family history of gynecological cancer and likely wouldn't pursue these screenings without my mutation. Since I have already had a hard time finding providers knowledgable about Lynch, I worry that my gynecologist (appointment scheduled for tomorrow) will not take the mutation seriously OR will recommend that I get a hysterectomy immediately, which I am not ready for.
The decision to have a hysterectomy is difficult for me. I have PMS2 which has the lowest of the Lynch syndrome genes for gynecological cancers. It's a life changing decision and I'm not sure there's enough research on PMS2 to understand if it's worth it for me.
I was the first in my family history to be diagnosed with cancer (breast). I told my family to get tested and no one did. My sister then was diagnosed with stage 4 endometrial cancer the following year and tested positive for LS after her cancer diagnosis. Had she gotten testing earlier her cancer might have been prevented.
The fear is always there, we feel like the proverbial ticking time bomb when we're told we have, say, an 85% chance of developing some form of cancer. Anything that helps us feel like it's not yet started helps us get through the next day/month/year.
I almost always have to educate my medical professionals regarding Lynch Syndrome, and I have to self-advocate for my screenings, some of which my gynecologist felt were "overkill". My main medical support regarding Lynch Syndrome comes from my genetic counselors.
Gynecologist wants endo biopsy but pcp says normal pap, normal transvaginal ultra sound and normal CA125 level, she doesn't feel it's necessary. Who do you listen to? Naturally I would like to Listen to PCP because I've been told the biopsy is painful. Seems like not everyone is on the same page for lynch related gynecological cancers/screenings.
I had an incredibly difficult time getting diagnosed with uterine cancer. I researched the internet for 9 months and found about Lynch as for father and grandfather passed young from colon cancer. Couldn't get anybody to take my gyn symptoms seriously so I found a great genetic counselor that tested me and then finally I was taken more seriously and diagnosed with endometrial adenocarcinoma.
I learned I have PMS2 mutation when I sought genetic testing after I was diagnosed with breast cancer. There is a lot of confusing information out there about Lynch and breast cancer - I know the state of research is unsettled, but patients online are terribly confused about it and would benefit from better information. Also, I didn't meet with a medical oncologist until almost 3 months after my breast cancer diagnosis/2 months after discovering my Lynch. My breast surgeon had no helpful information about it, so I've been on my own for several months until I could finally get in wiht a medical oncologist, who helped me understand Lynch and all the screenings I'll need. That was too long to wait. It's been stressful trying to learn all this on my own in the interim - while also dealing with breast cancer and recovering from a double mastectomy.

No cases of Lynch in my family that we know of. 2 maternal aunts had breast cancer. Father died of bile duct cancer at 81. I have two sisters and one has tested negative for the gene so far. Getting a second genetic test done to make sure this is real for me. Have had a pelvic ultrasound, uterine biopsy, breast MRI, Colonoscopy, dermatology scan, and Endoscopy. All have come back clear. Uterine biopsy was done with NO deadening or pain medicine. Was excruciating. They should put women under for it. Totally barbaric. Genetic test results should be gone over once received with a genetic counselor and gynecologist present so that everyone understands/is on the same page. This is life-altering news.
Doctors/Specialists here in San Diego have no clue about Lynch .
It was difficult to find a Lynch specialist who could coordinate a care plan.
Since I have 4 children I wasn't really given options other than surgical removal of my uterus. I was told by the gynecologist oncologist that I could keep my ovaries which would require me to have frequent ultrasounds BUT there was a risk of having a clear u/s and having stage 3 cancer the next scan a few months later.
I notice Mayo Clinic suggests Lynch patients keep pelvic area screened while having uterus and ovaries removed. I have not had a gynocologist recommend this.
I was told by both Northwesters and Boston to have the surgeries so I did... but I do not feel enough education is provided before or after the surgeries. I also don't feel that they know what to do with the symptoms after the surgery... hot flashes, night sweats... and do not provide help with this if you can't take hormone replacement. I am glad I had the surgeries because they did find pre-cancer in my uterus. I feel like your study. Should've included questions about what was found if you had your uterus and ovaries removed... so that you would have percentage of how many surgeries prevented cancer that was starting to grow.
The nature of ovarian cancer symptoms makes it so difficult to detect (i.e. indigestion, pain, spotting, etc.). Coupled with the lack of definitive and reliable screening tests, I don't feel that it's good enough. It feels hopeless and almost futile sometimes. I've literally been told "it's better than nothing". So the best bet is for me to get a hysterectomy and go into menopause in my 30s, or wait every 6 months in fear of my invasive test results that don't really tell me anything definitively? Last year I was diagnosed with medical PTSD regards to my Lynch diagnosis (specifically around GYN) as a result, and am undergoing treatment for it. I'm really angry at the lack of research and general concern the medical community has about gynecological cancers (and GYN health overall), especially considering the subtlety of the symptoms. As a woman in general, I constantly feel gaslit by the medical community anyways. Even though I'm highly monitored, I feel so let down by this area of medicine, especially when you juxtapose it next to the definitive nature of a colonoscopy. We need to do better, and I often feel like no one is paying enough attention because it's women's reproductive health, and that's historically the case...
Lynch syndrome is a very scary thing to have. However, I regret having both ovaries removed. This has impacted my quality of life. I feel gynecologists are reacting to quickly with these surgeries.
No discussion of post-hysterectomy regarding ongoing screening for ovarian cancer.

My gynecologist oncologist was pretty forceful about me getting a hysterectomy in the year after I got diagnosed, even though the research wasn't nearly as strong for risks of pms2. She also recommends the 6 month screening with biopsy, ultrasounds, and ca125, even though they are not proven to decrease cancer deaths. It's interesting that they do not seem to follow the science, but are trying to find anything proactive they can do to prevent or catch cancer. I hope we find better options soon. I am grateful for my hysterectomy but I'll wait till I am closer to menopause to get my ovaries out because there are other risks to loosing them and I don't believe the ovarian cancer risk is greatly elevated in pms2. These were tricky decisions yo make. My sister and I made them together which was comforting to have a buddy.
I am unsure if I should have a pap test yearly , as this year my gyn did not do one and I was not aware she didn't do one at my annual exam until I read the office visit notes. I am unsure of what screening to have done after hysterectomy and oopherectomy as well, because I have heard some women still get cancer after the procedure of their vaginal cuff that was discovered after annual pap smear of the vaginal cuff. I am unsure what screening to have if you are having uterine type pain resembling that of a fibroid m, as I am having that currently and currently am on HRT which I wonder if that has precipitated that. and if a fibroid is found, how are we certain it is a fibroid rather than cancer? It is my understanding that a CA125 test isn't a good screening tool? I always have small ovarian cysts, likely hemorrhagic, which have been ongoing for atleast 10 years to 13 years. Should this be a concern? I was told by a Lynch specialist Gyn Oncologist in Seattle that I do not have to have yearly endometrial biopsies unless I have symptoms but the only symptoms I was asked about at my annual were if I had intermenstrual spotting, which I never do.
I wish there were more Doctors informed of Lynch syndrome.
Most doctors are unaware of Lynch Syndrome
In general I have felt that the impact of surgical menopause has been poorly communicated or downplayed by the genetic counsellors and gyn-oncologists who I've consulted.
it is unconscionable that doctors will perform endometrial biopsies without providing patients with a block or other pain mitigation
It has made me aware that ovarian cancer screenings are not particularly effective. At some point I will likely have a preemptive ovarian removal.
I had everything removed with the exception of my ovaries. My risk is slightly elevated but I also have heart issues in my family. When I had my hysterectomy they found fibroids and andomosis (can't spell it but it the cousin of endometriosis). I had constant irregular paps since 2015 without HPV. My biopsy showed mild chronic inflammation. Once I had my hysterectomy it become clear that the screenings are not where they need to be. Part of me wishes I had my ovaries removed.
I have two close family members on my dad's side who had ovarian cancer, but that is associated with a BRCA2 mutation which I do not have. On my mom's side, where my Lynch gene came from, she is the only close relative with a Lynch-associated cancer. I may decide to get more aggressive with screening as I get closer to my 40's or if the recommendations for PMS2 get stronger, but at the moment I'm pretty comfortable with the wait and see approach.

I like to use an interdisciplinary approach when it comes to my decisions regarding my Lynch syndrome care and what that could mean for my future. As a nurse I feel as though I have a big advantage over a lot of others as to the meaning of a lot of things and what the potential long term effects are. This also means that, in my opinion my doctors are more open and honest with me about my options are and what possible implications may come with each option in regards to my care. I have built a team of doctors behind me that I feel work within my wants and needs and the recommendations available for Lynch patients and their families. I have made it a priority to seek out doctors who will allow what I view as the bare minimum (transvaginal ultrasounds once a year) to be preformed for screening purposes. They also work well within my comforts and limits based off other medical factors to ensure I am doing all I can to prevent cancer for as long as I can.
I had undergone IVF to have both of my children. My daughter was a baby when I decided to have a hysterectomy, both fallopian tubes and one ovary removed. I knew I was done having children. After my surgery they confirmed pre-cancer in my uterus. I was 37. I'm forever thankful to Moffitt and the genetic counseling team for staying on top of my screening needs so I can be here for my babies.
My father had multiple types of cancer. His derm found something suspicious dx Muir' tire. I encourage my father to get genetic testing and found msh6 . It helped me start the process of getting tested. Right away started preventative testing colonoscopy, skin checks and was referred to gyn onc . Decided to have a complete hysterectomy which I do not regret. I was finished with kids. Con put me into menopause but able to manage. I never was dx with cancer. I had my 3 kids tested at 18 yr 2 out of 3 kids are positive but not old enough to start preventative testing colon, biopsy etc This topic I find extremely important and there is not enough information provided to health care staff and their patients. I live in Pittsburgh and I have been grateful to have a gi provider Dr Brand who specializes in Patients dx with Lynch. He actually worked with Dr Lynch years ago.
Diagnosed with Lynch syndrome, scheduled hysteterectomy- then symptoms appeared- biopsy (VERY PAINFUL) was negative, but pathology at surgery showed cancer. Very grateful to genetic counselor
You will note that I answered that I did not receive genetic counseling. You will also note that I answered that I received information from a genetic counselor. I was tested because my sister tested positive. My sister's genetic counselor gave me the diagnosis over the phone or via a Zoom call and that was the only time we communicated. So while I was given the diagnosis by a genetic counselor, I don't feel like I was counseled by them. Also I may have entered the incorrect year I was diagnosed- my initial appointment to order the genetic test was Dec 14th 2021- but I believe the actual results came back in Jan or Feb 2022. To clarify.
My mutation was found while removing a squamous cell skin cancer. My dermatologist requested my report, which then showed positive and I myself went to an oncologist gynecologist I was not referred.
I was adopted and found 7 siblings all positive for Lynch. I was informed and told to contact a genetic counselor and be tested. once I found out I was positive for MLH1, I informed my 2 sister and she told me that my other sister had passed from Ovarian cancer and that I needed to see a gynecologist right away. I did and we agreed to have my ovaries. cervix, and fallopian tubes removed. That was 15 years after my hysterectomy.
Post surgical report indicated I had endometrial neoplasm

I began researching ovarian cancer risks after I developed severe endometriosis and ovarian cysts. I tested negative for BRAC 1and 2 and knew another genetic reason was the cause with significant family history. I also took Lupron for 3 months but needed emergency surgery for ruptured cyst. My pathology was donated for research.
I have decided to wait to undergo a hysterectomy due to my age and not being 100% sure whether I want kids or not. I had only been married for a year when I received my diagnosis and my husband and I have not made a decision over whether to have kids. Right now we are not in a position to have kids financially.
I had a bilateral salpingectomy completed at the time of my hysterectomy. I am currently in the process of moving forward with scheduling my bilateral oophorectomy.
Very interested in learning how someone with Factor V Leiden can benefit from estrogen without raising risk of blood clots. Have pituitary tumor. Have had pre-cancerous skin lesions removed. Awaiting results of colon polyp removal. These issues make me more inclined to remove both ovaries & Fallopian tubes this year. Was REALLY hoping I could just remove the fallopian tubes to remove risk. My mom does not have BRCA1 nor BRAC2, thus I do not by default. Per study(ies) I've read, there is no known ovarian cancer risk reduction (as of yet!) for someone like me whose mother had ovarian cancer twice due to MSH6. Mother is still alive after chemo age 50 and chemo age 51 due to estrogen patch causing cancer to return as theorized by her oncologist. She moved to a high faith, high plant based diet, no estrogen and turns 76 this month. These are factors impacting my decision when to have complete hysterectomy. Thank you for your work.
I knew that if I tested positive for lynch syndrome that I would have prophylactic surgery so there was never any emphasis on screening for uterine or ovarian cancer. If I hadn't had the surgery I would have expected to receive information on screening and symptoms of gynecological cancers.
I chose to do my hysterectomy after several years of research and wrestling emotionally with the decision. I spoke to top Lynch expert docs at several cancer centers before making my decision. And in the end I chose to remove uterus, both Fallopian tubes, and one ovary, and to keep my other ovary to retain my natural hormones to maintain overall health. I am confident in my decision. I am willing to take the (hopefully now somewhat reduced risks) of ovarian cancer in order to main the benefits of my natural hormones to my overall health. I will continue to get annual transvaginal ultrasounds until I remove my last ovary at the time of natural menopause. I made this decision with my gynecologic oncologist's support at Cleveland Clinic.
Tbh I was in shock when I received my LS diagnosis. Only two possible cancers in my family history (cervical and lung). I don't exactly remember what information I was given and in what format. I was done having kids and I knew that having both my uterus and ovaries removed would get rid of those cancer risks. It was an easy decision for me to make. I'd much rather deal with hot flashes than go through chemo again.
Because I was entering menopause and was finished having children my choice to have surgery was easier to make. I feel many young women are being pressured to have surgery too early.
I'm happy with my decision to have a hysterectomy and oopherectomy. I'm having more trouble with getting good information about bladder issues.

Some of the numbers are not very accurate here since I don't remember things from that long ago! I had a hard time making a decision about the hysterectomy but when I had it and they found endometrial cancer (stage 1A) I was very glad I decided to do it. I had no symptoms.
I was sure from the beginning of diagnosis that I wanted hysterectomy.oopherectomy but it took 8 months to go through steps to get surgery
I was diagnosed with PMS2 in October. My gyn/onc advised immediate surgery for complete hysterectomy. I went to Dana Farber Lunch Center and was advised I can keep my ovaries until the age of 50. I have surgery scheduled for March and will most likely keep one ovary. I will meet with Dana Farber yearly to to stay update on new studies and findings. My great grandmother had ovarian cancer at age 60. My mother passed from colon cancer at age 41.
I'd like to know more about other variables and their impact on cancer incidence in conjunction with Lynch Syndrome, like smoking, drinking, diet and exercise.
I think you need to mention risk of getting cancer if you've had pelvic radiation for other cancers. many people end up with multiple types of cancers due to lynch.
I did have a great grandmother on my mother's side with "female" cancer. no other information is known.
More studies need to be done for PMS2. The rate of breast cancer diagnosis is much higher than what's portrayed in a positive PMS2 genetic testing results. Meaning the FB group which I belong too has a high number of PMS2 diagnosis performed after breast cancer diagnosis, which would show the that Colom and cervical cancers are not the only ones at the top of the list.
my mother was dxd with synchronous ovarian and endometrial CA at age 45. option was not available in your Q.
On the question about having uterus and ovaries removed before diagnosis, there was no place to put removed after diagnosis
I would like to know which Lynch mutations have a higher correlation w certain cancers.

APPENDIX C: Complete List of Free Response Answers Throughout Survey

What is your relationship status?

- Divorced and have a current partner I'm living with.
- in a long term committed relationship, not yet married

My periods stopped because of:

- Ablation
- birth control
- birth control implant
- endometrial ablation
- Mirena IUD
- uterine ablation

Hysterectomy and oophorectomy: What was the reason for your hysterectomy?

- endometriosis and abn pap
- excessive bleeding
- ovarian cysts/endometriosis
- Terrible bleeding and painful long periods more often than normal cycle

Hysterectomy and oophorectomy: What was the reason for removing your ovaries?

- ruptured cyst 26/endometriosis

Which of the following options best describes your reason(s) for undergoing both a hysterectomy and oophorectomy before uterine or ovarian cancer developed?

- prevention
- severe endometriosis/fibroids/ovarian cysts
- Was already in peri menopause

Of the options you selected above, what would you say is the main reason for undergoing these surgeries?

- It was supposed to be a prophylactic surgery but they found endometrial cancer stage 1A as a result of the surgery.
- severe endometriosis/fibroids/ovarian cysts

Hysterectomy only: What was the reason for your hysterectomy?

- Endometriosis & Iron Deficiency
- Placenta accreta

Which of the following options best describes your reason(s) for undergoing a hysterectomy before uterine cancer developed?

- Pregnancy complication of placenta accreta necessitated a hysterectomy
- This procedure was also gender-affirming, although this was not my primary reason for a hysterectomy

Which of the following options best describes your reason(s) for not undergoing a hysterectomy and/or oophorectomy?

- Factor V Leiden means HRT is not an option? Exploring transdermal estrogen route vs risk of blood clots. Have been hopeful that the Mirena IUD might protect not just endometrial lining, yet hopefully protecting the ovaries as well.
- Fear of significant weight gain, hormonal/emotional challenges
- I have it scheduled just haven't had it yet
- I just found out that I have Lynch Sydrome. Will likely pursue hysterectomy.
- My surgery date is 12/14/22. Planning a hysterectomy and oophorectomy on that date. Still healing from double mastectomy on 10/20/22, so needed to wait for the 2nd surgery.
- no family history
- Surgery planned Aug 2023
- Will be having a hysterectomy and possible oophorectomy

Of the options you selected above, what would you say is the main reason for not undergoing these surgeries?

- I just found out that I have Lynch Syndrome. Will likely pursue hysterectomy.
- Inability to take HRT once ovaries are removed due to Factor V Leiden
- Planned Aug 2023
- Planning on surgery
- Waiting on surgery date.
- Will be having it

When are you planning on undergoing one or both of these surgeries?

- 12/14/2022

- 8/23/2023
- 1 year
- 1-2 years
- after age 40
- After I've had more time to explore estrogen patch and risk of blood clots due to Factor V Leiden. Estrogen has caused some family members to get DVT and other clots.
- asap - I'm not planning on having more children
- At age 40, or if something even slightly concerning is found before then
- Before, but closer to menopause and possibly after having a child or two
- Depending on age
- Doctor advises I reach the age of 40 before undergoing surgery
- Hysterectomy age35 oophorectomy after menopause
- I am waiting as long as possible and am fearful of surgical complications and surgical menopause
- I'm a couple months
- In the near future
- In the next few years, when I can have assistance recovering
- Next month
- Plans on undergoing hysterectomy at age 35 or after childbearing is complete without oophprectomy based off the scientific research at the time and my doctors recommendations.
- Summer time when I am not working (teacher)
- This summer
- when I have more support during recovery.

What is your reason for taking oral birth control pills?

- I was required to be on birth control while taking another medication (Accutane)
- menopause
- stop period
- Those are the reasons why I took them. I haven't taken them in years.

What is your main reason for taking oral birth control pills?

- I took oral birth control pills originally to regulate my periods, I had to stop taking them 6 years ago after being diagnosed with a hepatic adenoma, that required surgery to remove, due to their use.
- I was required to be on birth control while taking another medication (Accutane)
- Menopause

Which of the following resources have you used to receive information about symptoms of gynecological cancers?

- high risk cancer center
- I am a nurse so I did learn a lot about symptoms in nursing school.
- Oncologist that works with Lynch Syndrome

Where did you first receive information regarding these symptoms?

- don't remember
- Gastroenterologist
- GI doctor
- I don't remember
- Nursing school
- Oncologist
- Oncologist that works with Lynch Syndrome
- school

In what format was this information about gynecological cancer symptoms given to you the first time you received it?

- don't remember
- Online
- online info seeking, doc never told me symptoms

Which of the following resources have you used to receive information about gynecological cancer risks for Lynch syndrome?

- Lynch Syndrome Center at Dana Farber
- Lynch syndrome specialist (physician)
- Medical oncologist
- medical school
- Oncologist that works with Lynch Syndrome
- Regular oncologist

Where did you first receive information regarding these cancer risks?

- Internet
- myself

In what format was this information about gynecological cancer risks given to you the first time you received it?

- Online

Which of the following resources have you used to receive information about gynecological cancer screening options for Lynch syndrome?

- Lynch syndrome specialist (physician)
- medical oncologist
- Oncologist that works with Lynch Syndrome

Where did you first receive information regarding these screening options?

- Myriad Genetics Lab after diagnosis

In what format was this information about gynecological cancer screening options given to you the first time you received it?

- ?
- Online