Supplementary material:

**Supplementary Table 1. Demographic characteristics of the LSI participants (n=170)**

<table>
<thead>
<tr>
<th>Sex, n (%)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>18</td>
<td>10.6</td>
</tr>
<tr>
<td>Female</td>
<td>152</td>
<td>89.4</td>
</tr>
<tr>
<td>Median age, years (range)</td>
<td>50</td>
<td>18 - 76</td>
</tr>
<tr>
<td>Annual Household Income in U.S., n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30,000</td>
<td>20</td>
<td>12.3</td>
</tr>
<tr>
<td>30,000-75,000</td>
<td>57</td>
<td>35</td>
</tr>
<tr>
<td>&gt;75,000-125,000</td>
<td>49</td>
<td>30.1</td>
</tr>
<tr>
<td>&gt;125,000-250,000</td>
<td>28</td>
<td>17.2</td>
</tr>
<tr>
<td>&gt;250,000</td>
<td>9</td>
<td>5.5</td>
</tr>
<tr>
<td>No response</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Education, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤High school</td>
<td>21</td>
<td>12.5</td>
</tr>
<tr>
<td>Some college</td>
<td>72</td>
<td>42.9</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>37</td>
<td>22</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>38</td>
<td>22.6</td>
</tr>
<tr>
<td>No response</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Cancer, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>49</td>
<td>29.3</td>
</tr>
<tr>
<td>Endometrial/other</td>
<td>40</td>
<td>24</td>
</tr>
<tr>
<td>No cancer</td>
<td>78</td>
<td>46.7</td>
</tr>
<tr>
<td>No response</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Mutation, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pathogenic DNA MMR mutation</td>
<td>141</td>
<td>83.9</td>
</tr>
<tr>
<td>Never tested</td>
<td>15</td>
<td>8.9</td>
</tr>
<tr>
<td>Variant of unknown significance</td>
<td>3</td>
<td>1.8</td>
</tr>
<tr>
<td>True Negative</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>Not sure</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>No response</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: MMR, mismatch repair.
**Detailed process flow steps for FamilyCONNECT**

1) The mutation positive IP identified in the clinic receives an email sent by the study coordinator via FamilyCONNECT with information about FamilyCONNECT and a link to join if interested. A link to an informational video about FamilyCONNECT and LS is included in the email invitation to allow participants the opportunity to make an informed decision about using FamilyCONNECT. 2) Upon clicking the link in the email for joining FamilyCONNECT, the IP is directed to a screen where he or she can create a secure account to log in to FamilyCONNECT after an authentication step (although for the IP we have no doubt that they are the right person receiving the email invite, authentication by the relative is based on validation of two/three pieces of personal information provided by the IP about them including the name, gender, and phone number, to ensure the account is created by the person it was intended for). 3) Upon logging into FamilyCONNECT, the index patient is presented with a consent form to join FamilyCONNECT, accepting that it is for the purpose of communicating securely with relatives, providing the relatives with a copy of the index patient’s genetic test results, and allowing invited relatives to view and grow the family tree. 4) The index patient can view and print the mutation test results available within FamilyCONNECT in the event he or she wishes to share them directly. 5) Upon reading and (electronically) signing the consent form, the index patient can review his or her personal and family history, authorize release of genetic test result to relatives, and add any additional relatives to the family tree. 6) The index patient can view and print the updated pedigree. 7) Lastly, the index patient is presented with a screen at which he or she can provide contact information for relatives to whom FamilyCONNECT will send email invitations (those relatives selected by the index patient to receive information through FamilyCONNECT). 8) On submitting the completed online forms, the IP is directed to an informational website that has in-depth information about Lynch syndrome and resources such as finding a genetic counselor nearby. 9) The IP also receives an email link that allows them to return to their account by logging in with their user name and password to update information about their family members and invite additional family members in the event that they may need time to obtain contact information for some of their at-risk relatives. The relatives’ navigation through FamilyCONNECT is similar to the steps followed by the index patient and includes authentication of identity, account creation, informed consent, viewing/printing a copy of the index patient’s mutation report, reviewing the family history, adding additional relatives, viewing/printing an updated pedigree, and inviting other at-risk relatives not yet invited.

**Process flow and technical configuration of FamilyCONNECT**

Each new patient provides family history through a patient history intake form (an instrument originally designed by MDACC epidemiologists, dubbed the ePHDB or electronic Patient History Database) completed prior to their visit. During their initial visit with their healthcare providers, this information is reviewed by the clinic nurse and then imported into EPIC where it becomes a part of the history and review of systems. The family history field is configured into a pedigree and can be edited by providers by means of recent upgrades to EPIC itself. For patients who have a genetics referral, family history and other clinical data are reviewed and updated by the genetic counselor in EPIC. These data can be imported directly from EPIC into the clinical version of Progeny’s family history questionnaire (FHQ) database (Progeny Genetics LLC, Aliso Viejo, CA, www.progenygenetics.com). Data points stored in Progeny include testing data that was ordered, what lab did the test, which test was done, the results of the test, the mutation found in the test, as well as patient contact information, pedigree, and cancer history. FamilyCONNECT is built on the same core software as the clinical version of Progeny. This allows FamilyCONNECT to import data directly from Progeny into the research database for patients that meet approved criteria for the study. This import feature was custom built for MD Anderson Cancer Center.
(MDACC) by Progeny. In theory, all of the above could be done within EPIC or other EMRs, without the need for exportation into a separate database. However, EPIC and other EMRs are not designed to enable outreach to relatives, and at least for now any consideration of doing so would have to be considered beyond the scope of this effort.

**FamilyCONNECT data import process:** Authorized accounts for any user such as the Navigator/Study coordinator are created in the Clinical FHQ database and FamilyCONNECT and the credentials must match both databases. If the credentials match, the import process will proceed. The coordinator normally searches for an IP/proband using their medical record number (MRN) then clicks 'Import'.

The clinical file is then copied into the research database as is the pedigree and becomes searchable in FamilyCONNECT. Once the pedigree and associated data are imported into FamilyCONNECT, a Navigator/Study Coordinator reviews the data to ensure that the relevant data for the index patient are imported, including the pedigree and the mutation report.

**Invitation process to join FamilyCONNECT:** FamilyCONNECT Progeny is configured to work back and forth with REDCap via REDCap’s API as well as custom middleware developed at MDACC to allow the two systems to communicate throughout the participant's experience. When the patient record is imported into FamilyCONNECT, or data entered by personnel in the clinic, that patient can be sent an invitation to participate in the study. The invitation is programmed to be generated in FamilyCONNECT, but an intermediary is required. The FamilyCONNECT-generated email is not what is sent to the participant. When the FamilyCONNECT database submits an invitation, all of the appropriate tables are updated and the data is generated to 'say' one was 'sent' in the Progeny database. Part of our system integration uses the dummy invitation to trigger a next step. At this point, custom middleware is checking the FamilyCONNECT database for dummy invitations that were 'sent'. This is an audit to ensure that Genetic Testing Results documents are being passed to those invited. If there are no Genetic Testing Report documents uploaded or imported into FamilyCONNECT, then the invitation process is paused until that task is completed by the Coordinator. The FamilyCONNECT custom middleware (FCCM) will update REDCap and send the aggregated data of a family to a form created in RedCap called the 'DataForm' (forms can be named as needed). The 'DataForm' is considered completed when all of the required fields have values. This form is configured to accept the system-generated data into the REDCap database via the REDCap API.

There are 3 forms created in REDCap that handle 3 separate jobs. The 'receiving process' is handled by the one form that we named 'DataForm', and the 'sending process' is handled by two additional forms we called ‘ConsentForm' and the 'ConsentRelativeForm'. To ensure data integrity, specific field types were chosen when designing these forms (FamilyCONNECT database id, MRN, gender, email address, last name, Progeny invitation links -shortened and full). On the 'DataForm', each of these fields requires there to be a real value, or else the survey will not trigger the beginning of the next form. Upon the creation of the record in REDCap by the system-generated data, the 'ConsentForm' is configured to generate an Automated Invitation.

The logic to automate the invitation process is based on several factors filled in the 'DataForm':

For Probands, the required values are: 1) FamilyCONNECT database id: for system integration purposes; 2) MRN: to validate as MDACC patient; 3) Email Address: for communication 4) Gender: for authentication of identity; 5) First Name: for authentication of identity; 6) Is this Person a Proband: Yes; 7) Link to FamilyCONNECT's questionnaire: e.g. https://familyconnect.mdanderson.org/WEB/FHQ-7; 8) Invite Status: Invite Ready to Send.
For Relatives, the requirements are: 1) FamilyCONNECT database id: for system integration purposes; 2) Email Address: for communication; 3) Gender: for authentication of identity; 4) First Name: for authentication of identity; 5) Is this Person a Proband: No; 6) Link to FamilyCONNECT's questionnaire; 7) Invite Status: Invite Ready to Send.

REDCap is authorized to send email on behalf of MDACC. It is configured to use 'familyconnect@mdanderson.org', an MDACC authorized email address. Participants receive an invitation email that includes an embedded video that explains what FamilyCONNECT and Lynch syndrome are about.

The email also includes contact information about the study and an embedded email link to 'familyconnect@mdanderson' which is a monitored mailbox. The email finally closes with a REDCap link to join FamilyCONNECT.

**Authentication of identity**: Data imported from the FamilyCONNECT database into REDCap provides REDCap with clinically validated information that is used to confirm that the invitation is received by the individual it was intended for. The invitee provides gender and first name in the authentication step and if validated by the system, is redirected to the registration page for the Progeny-based questionnaire and family-builder which is pre-populated with pedigree information from clinical Progeny.

**The Family Builder**: This consists of 3 sections: My Family, My Mother's Family, and My Father's Family. Participants (both the proband and any invited relative) can 'Add Family Member' and must select details such as: 'To which family member do you want to add a relative?', 'What relative do you want to add to' this family member?, 'What is the first name of this person?', and 'What is the age, cancer diagnosis if any, and mutation status of this person (if known)?' Answering these questions gives the application the necessary datapoints for placing the person correctly into the family, relative to the Proband in the family. After validating or adding additional relatives to the family, there is an option to view the pedigree graphically, and download or print it.

The final step in the family builder is the Family Invite Module, which allows the participant to provide email address/es (or phone number if email is not available) of relatives he or she intends to invite. Once the ‘Invite’ check box is checked by the participant, the FamilyCONNECT platform initiates all steps described above to send an email to the person invited.

The link will be unique to only that person, and there is no sharing of a link amongst relatives. The uniqueness of the link is intrinsic to the Progeny application that uses system-generated alpha-numeric keys for each individual’s invitation. In the case of sharing, since the link is designed to only work with the invited individual, a second party cannot use their username and password to access FamilyCONNECT. That second party will need to find their invitation email and use the link unique to them. The design of the system is to provide everyone their own chance to enter/update/correct their own information if necessary and expand the pedigree if possible.

Once a participant has completed their session, they click the Submit button. The person is then redirected to a Lynch syndrome educational/resource website, which is hosted on an IIS Server at MDACC.

**Implementation**: The implementation of the FamilyCONNECT Platform exists based on system availability. There was limited flexibility in the systems involved because no one system had everything necessary to accomplish the goal. With the project constraints involved, from HIPAA to network security, budget and personnel, programming data integrity, and the evolving clinical processes, the steps we took
to integrate the systems available at the time at MDACC required they be configured and interact in the following ways.

- Install Progeny
- Leverage REDCap (for authentication)
- Leverage Institutional Information Security
- Show an educational website
- Develop a data pipeline from FHQ to FamilyCONNECT to REDCap back to FamilyCONNECT (see Workflow Diagram: Technical)

FamilyCONNECT (Progeny) was established as a stand-alone database. It still had 3 front-end versions to manage: the clinical, the patient, and the administrator. However, they all tie back to one database. Progeny provides a web-based, HIPAA-compliant CRM system that can be further customized by technical personnel. They also provide a desktop administration client to edit the front-end (in some places).

This is not the cloud-version of Progeny. MDACC has a local installation of Progeny. Each installation of Progeny (FHQ and FamilyCONNECT) are installed on their own web servers with their own database servers.

The personnel who were working on this project were Microsoft experienced so all web hosting leaned toward IIS when possible. We developed the educational website as normal, which would still be supported by IIS and .Net 3.5 framework, but we had to work with the network engineering group again to customize a unique firewall script to manage our traffic.

REDCap was readily available because the institution hosts it. It has a feature that allows unique invitations to be sent to a participant, which was why we thought it would work with Progeny’s ability to generate unique invitations as well. That was the basis for the idea of joining the systems.

With FHQ and FamilyCONNECT and REDCap then established, we could make sure that users would trust all of the systems they were accessing. With the help of Progeny and our Network Engineering team, we were able to configure SSL to support the level of security involved with sharing health information across the Internet. Since Progeny runs on Apache Tomcat web server, we were limited with the other web offerings that a study like this would offer. All of the SSL certificates are managed by the institution on the firewall.

**Access and infrastructure:** REDCap access is controlled through an MDACC domain account. The virtual machines that host the Progeny software must be accessed with elevated MDACC domain account. That access would be designated at the beginning of the project and account info shared by Progeny.

The server hosting the middleware can only be accessed with an elevated service account on a separate service account created for the MDACC domain in order to run jobs behind the scenes.

The Coordinator account that accesses FamilyCONNECT Progeny and Progeny FHQ must have the password in sync or else importing from the FHQ to FamilyCONNECT fails.

Progeny administration access is proprietary to Clinical Cancer Genetics IT STAFF. The middleware application is hosted on a department VM running Windows 2008 R2 and the WCF service is coded in C#, hosted by IIS 6.1, and is scheduled to run every 5 minutes to ensure small windows of time between an invitation triggered in Progeny and it being sent from REDCap. Each one of these pieces likely exists
in any major cancer center or educational institution or can be purchased. REDCap is hosted and supported by MDACC.

Virtual Machines, Firewalls, and an institutional Email system are required infrastructure to implement FamilyCONNECT. All virtual machines involved in hosting these applications must be behind institutional firewalls.

Progeny can be purchased and configured to host a survey. Their database comes included and the formats of the survey can be created and implemented by their staff as a part of the license. They also helped to train our group to handle building questionnaires and configuring them to work with existing institutional infrastructure like email and network folders.

REDCap is readily available for research institutions to implement. Both systems need local hosting in order to be integrated into FamilyCONNECT. FamilyCONNECT Custom Middleware is custom built for MDACC. The working knowledge of all systems involved attributed to the functional prototype. This software can be packaged and shared with partner institutions and modified to fit the environment described here. The environment supports the application, but further customization per institution could be required.
Workflow Diagram: Technical

**THE COORDINATOR**
- Coordinator provided list of MRNs to Invite
  - Log into FamilyCONNECT Desktop App
    - Check if MRN is available to import
      - If there is a record...
        - Import the patient record
      - If there is NO record...
        - Log into FamilyCONNECT Web
        - Create the record
        - Send Invitation

**REDCap [BEHIND THE SCENES]**
- Receives Progeny data
- Sends invitation email
- Every 5 minutes, the Middleware is checking for invitations...
  - 1. Import invites from Progeny into Redcap
  - 2. Update database record that invites were sent to Redcap
  - 3. Export new Redcap consents/records into Progeny
  - 4. Import Mutation Report files from Progeny into Redcap
  - 5. Update database that mutation files uploaded into Redcap

**THE PROBAND/THE RELATIVE**
- Receive invitation email
- Redirected to Progeny
- Register for FamilyCONNECT
  - Completes Survey Questions
  - Completes Family Builder
  - Invites Relatives
- Personal Computer
- REDCap
- PROGENY

**THE MIDDLEWARE**
- Click invitation link
- REDCap Validation
- Consents Online
FamilyCONNECT feedback survey

FamilyCONNECT
We are asking LSI members and friends to help evaluate a novel on-line tool called FamilyCONNECT that will enable medical professionals to communicate with patients' relatives about their Lynch syndrome/HNPCC risk. We will walk you through the tool step-by-step then ask for your opinion about the process.

Why are we asking LSI members and friends to participate in this survey?

One challenge we face when caring for Lynch syndrome (LS) patients is being able to identify and communicate with at-risk family members of our patients. If they are not contacted, these family members may not get informed, tested or screened.

In routine practice, this is what usually happens:

1. Genetic counselor gives the LS patient written information about the disease and role of genetic-testing.
2. Patient gets tested and the specific genetic mutation in the mismatch repair (MMR) gene is identified.
3. Patient informs family members about the risk and the specific genetic mutation they should be tested for (medical professionals do not routinely contact relatives on the patient’s behalf).
4. Relatives contact their own physician, get genetic testing and any indicated screening procedures.

Unfortunately, only about half of the time do immediate relatives get notified of their risk for LS. Distant relatives are contacted even less frequently. As a result, these relatives are not tested or screened.

Over the past 2 years, the clinical cancer genetics team at MD Anderson Cancer Center has been working with our ethics committee and compliance lawyers to develop a process to make communication about genetic testing between LS patients and their relatives easier.

The online tool, FamilyCONNECT, will allow us to securely communicate with relatives that may be at risk, particularly the more distant family members that the LS patient may not be willing or able to communicate with directly. The system depends on the LS patient providing email addresses of family members and consent to contact them. The LS patient can also provide contact information of a relative who is most likely to be in touch with the family, like the family historian, and this person can in turn help reach out to extended family members who might be at risk.

We are trying to see if FamilyCONNECT is built so that its features are acceptable and people can use it easily. If you have trouble with parts of it, then it means other people will too, and we need to do more work to fix the tool.
We will ask for your feedback for each step (screen) of the FamilyCONNECT online tool by presenting you with screenshots to evaluate:

1. Email invite to patient's relatives to join FamilyCONNECT
2. Confirm identity of each invited relative
3. Online consent form to join, obtain and share genetic testing information with family members
4. Access to family's genetic testing report
5. Family History Questionnaire
6. Building or adding to the family tree (pedigree)
7. Provide email addresses of additional relatives and permission to contact them
8. Review an educational website for information about Lynch syndrome and FamilyCONNECT

Consent to participate:

Your participation in this survey is voluntary. The survey will take about 20-30 minutes and all information obtained will be kept confidential. The information that you provide will not be shared with any individuals or groups except in aggregate such that no one will be able to identify who participated in the survey.

I acknowledge that by answering the questions that follow, I am consenting to participate in this feasibility survey.

It is recommended that you complete the survey at one go. If you are unable to, you have the option to Save and Return Later to complete the survey. When you select Save and Return Later, remember to copy and save the return code provided. This will allow you to complete the remainder of the survey from where you left off. You will also be required to provide your email address to return to the survey.
Before you start, it is important that we know more about you so that we can better profile the responses that are collected.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your gender?</td>
<td>Male, Female</td>
</tr>
<tr>
<td>What is your age in years?</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>What is your education level?</td>
<td>High School or less, Some college, Bachelor's degree, Postgraduate education</td>
</tr>
<tr>
<td>What is your internet experience?</td>
<td>Beginner, Able to shop, browse, I am in the Internet technology field</td>
</tr>
<tr>
<td></td>
<td>(Place a mark on the scale above)</td>
</tr>
<tr>
<td>What is your yearly household income?</td>
<td>Less than $30,000, $30,000-75,000, $75,000-125,000, $125,000-250,000, More than 250,000</td>
</tr>
<tr>
<td>What is your Lynch syndrome (LS) gene mutation status?</td>
<td>I have a known, pathologic LS mutation, I am known to be negative for LS mutation, I have a variant of uncertain significance (VUS), Never tested for LS mutation, Not sure</td>
</tr>
<tr>
<td>What is your LS cancer status?</td>
<td>I am a colorectal cancer survivor, I am a survivor of endometrial or other LS cancer, No previous cancer (a &quot;previvor&quot;)</td>
</tr>
</tbody>
</table>
Family History Questionnaire - FHQ

Background about the FHQ: The basic tool for initial collection of family history from the patient newly diagnosed with LS is already in widespread clinical use (Progeny Family History questionnaire). Most LS patients will have completed the FHQ in Clinic or during genetic counseling.

A family tree or "pedigree" is generated from the family history provided by the LS patient.

Similar to the Clinical FHQ, FamilyCONNECT allows for completing the FHQ and building a family tree from the FHQ. In addition the LS patient has the opportunity to provide contact information (email addresses/phone) of family members that he or she would like us to communicate with. Checking a box marked "Invite" lets us know that we can contact the invited relative on the patient's behalf  to provide information about LS and the family specific genetic test results.

An email invite is sent to the selected family members through FamilyCONNECT.

This is how the family member contact information and permission to contact fields are set up in FamilyCONNECT

FamilyCONNECT screenshot of form used to provide contact information for relatives and permission to send email invite
Starting with this section and for the rest of the survey, consider yourself the FAMILY MEMBER of a person diagnosed with Lynch syndrome as you examine the screenshots that follow and answer questions related to each.

1. Email Invite

On behalf of your relative, you receive the email that follows to convey information about potential genetic cancer risk to you and other members of the family. Please read and provide your responses below.

FamilyCONNECT screenshot of email invite to relative

If you received an email like this from MD Anderson, with the contained content and form, would you feel comfortable clicking the embedded link to learn more and or participate in the registry (FamilyCONNECT)?

☐ Yes  ☐ No

What is your impression of the content in the email invite?

favorable/dislike Neutral Favorable/love it

(Place a mark on the scale above)
2. Authentication and creation of a secure account to access FamilyCONNECT

(a) Authentication

What if your LS relative entered your email address incorrectly and it accidentally went to the wrong person?

In order to make sure "the mail gets to the right address" it is necessary and required by HIPAA that the identity of the email recipient (you, as relative) is correct.

So we now ask you to review the authentication screen and answer questions that follow. The information entered will be matched to information provided by the relative that sent the email invite for successful authentication. Upon authentication you will be able to create a secure account within FamilyCONNECT.

FamilyCONNECT authentication screen

Would authentication such as this encourage you to create an account to access family risk information?

☐ Yes  ☐ No

Are the authentication instructions easy to follow?

☐ Yes  ☐ No

What do you think about the appearance of the authentication field?

Dislike  Neutral  Like

(Place a mark on the scale above)
(b) Creating a Secure Account:

After authentication, you will be able to create a secure account with a unique username and password to login to access FamilyCONNECT.

FamilyCONNECT screen for creating your username and password

We have provided for the usual creation of an account that will enable entry of online data and for subjects to easily return to FamilyCONNECT on a recurring basis.

Question: Does this field adequately explain the need for an "account field" and enable it to be easily used?

- [ ] Yes  - [ ] No
3. Online Informed Consent

After you have created a secure account in FamilyCONNECT, you are presented with the following Informed Consent document which tells you about FamilyCONNECT and benefits and risks related to joining FamilyCONNECT.

The consent form is somewhat long as a lot of the content is required by institutional regulatory requirements. You are encouraged to read the entire document, however, we have marked in red information that is important for you to review.

After you have read the consent, you are required to sign it before proceeding further.

[Attachment: "IC family member.pdf"]

Is this consent form generally readable, understandable and with content that helps you understand what you are being asked to do?

easy and helpful

not sure

difficult and confusing

(confusing)

(Place a mark on the scale above)

We have numbered each line of the consent form. This enables you to provide comments or criticism or to ask questions about any part of it that you have issues with.

Simply note at the left what line of the consent you are addressing and then enter your comment or question.
4. Access to family’s mutation test report

Mutation Test Report:

After you have completed the authentication field, you will be able to access the mutation report for your family. This report is posted only with the consent of the relative that has had a mutation detected and has provided us with your contact information. The name of the person tested is required in order that you and your provider can know the mutation really pertains to someone identifiable in your family. More importantly, if you are planning to undergo mutation testing, it enables your ordering physician to attach the mutation report to the test requisition so that the testing laboratory will know exactly what gene alteration is being tested for.

FamilyCONNECT screenshot of mutation test results of family member

Do you feel that inclusion of your relative's name on this report presents any potential for concern within your family?

☐ Yes  ☐ No

If you have any such concerns, explain here what those concerns are
By following the links on this page, you will be able to download and print a) the mutation report (to take to your provider); and b) a document briefly describing what is Lynch syndrome, cancer risk for people with Lynch syndrome and next steps for you. FamilyCONNECT screen where the mutation test report and information about the report and LS can be downloaded.
5. Family History Questionnaire
Family History Questionnaire (FHQ):

This is a set of questions used to capture your family history and genetic test results. Some of this information will already have been completed by the relative that sent you the invite but you are encouraged to review the information. You can make changes to your own information as well as add contact information for other relatives that are not already included on the family tree.

FamilyCONNECT screenshots of FHQ (Family History Questionnaire)
The information requested in these FHQ fields seems understandable and appropriate

☐ Yes  ☐ No

I have the following concerns, comments, questions about the FHQ fields

After your information is entered in the FHQ, you can View and Print your family tree and also edit your information. FamilyCONNECT screen where you can download and print your Family Tree and edit your information if you need to

How likely are you to view and print your family tree?
Not likely  Very likely

(Place a mark on the scale above)
6. Add to Family Tree

Pedigree: Build or add to Family Tree.

This is what a pedigree looks like in FamilyCONNECT

If you saw this picture, would you know that it is a family tree?

☐ Yes  ☐ No

What do the pink and blue symbols represent?

The developers of FamilyCONNECT consider it desirable to have pedigrees show ALL useful information for the use of relatives. Although we, as providers, will have access to all of this information, we understand that it is sensitive when included in a pedigree available to all relatives that join FamilyCONNECT.

Do you in general feel that it is OK to encourage family members to contribute their mutation and cancer information so that it can be viewed by other relatives? Keep in mind that this information is posted only with the consent of the person in question.

☐ Yes  ☐ No

Comments or concerns if any related to sharing of cancer and or mutation information with extended family?
7. Provide contact information and invite family members to join FamilyCONNECT

Provide email address of additional relatives and permission to contact them:

This feature allows you to a) grow the family tree (pedigree) further and b) reach out to other members of the family that might be at risk by checking the "Invite?" box. These relatives will be sent an email invite (Step 1.) and the whole process (Steps 1-7) can be repeated.

FamilyCONNECT screen where contact information for more relatives to invite can be added.

The above field would enable us to identify and reach out to other relatives, some of whom may not have been known to the original index case (LS patient) in your family.

Are you OK with the way in which this information is being requested?

- Yes  - No

Please provide any comments, concerns, or questions about the content or wording of this field.
Given a choice, what would you consider the appropriate time to send the email invite to additional relatives that might be at risk?

- Immediately
- After waiting a month
- After waiting 3 months

Would you consider reaching out to your relatives and letting them know about the genetic mutation and cancer risk in the family BEFORE letting FamilyCONNECT do it on your behalf?

- I would like to talk with ALL my relatives first
- I would talk to some relatives and let the remaining be contacted by FamilyCONNECT
- I would let FamilyCONNECT reach out to all my relatives
8. Informational Website

Informational Website: Next you will review a website about FamilyCONNECT, Lynch Syndrome, and communication in families. This website will also provide a link to join FamilyCONNECT.

Screenshot of informational website for LS and FamilyCONNECT

Does the appearance of the FamilyCONNECT website have the look and feel of a website you would respond to if sent here by following a link in an email sent on behalf of a relative of yours?

Not at all  Somewhat  Ideal

(Place a mark on the scale above)

The tabs on the ribbon at the top and on the left side of the page are links that provide more information about the topics listed.

Please provide your suggestions if you would like to see additional topics listed or if you have any other comments.