

Universal Screening for Familial Colorectal Cancer Syndromes at Seattle Cancer Care  
Alliance: Qualitative Study of Providers involved in Implementation and Patients  
Experience with First Wave of Testing

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Abstract

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**Introduction:** In 2013 the Seattle Cancer Care Alliance (SCCA) implemented universal screening procedures for people who present with colorectal cancer in order to help identify high risk families for which Lynch Syndrome testing would be effective. This qualitative thesis reports on patients experience with the first round of universal screening procedures at the SCCA including their thoughts about colorectal cancer. Provider interviews about the implementation process are used as key informant interviews to explore barriers and facilitators to implementation. **Methods:** Qualitative interview procedures were utilized for both patient and provider interviews. Patient interviews were coded using Nvivo software to extract themes and analyze data. **Results:** Providers indicate that implementation of universal screening procedures for Lynch Syndrome are successful. Despite this, the majority of patients did not remember the purpose of the testing or its implications for the health of themselves or their families. Patients also report openness about sharing health information among their families citing varying degrees of support and communication. **Conclusion:** Public health interventions can target patients and families to ensure uptake of knowledge and sharing of health information among family members for familial diseases like colorectal cancer.

**Introduction:**

The American Cancer Society (ACS) expects an estimated 134,490 new cases of colon or rectal cancer to be diagnosed and 49,190 deaths attributed to colorectal cancer (CRC) in 2016 (1). The ACS projects colorectal cancer to be the third leading cause of cancer related death in the United States in the coming year for both men and women (1). Screening for CRC beginning at age 50 is an effective method of early detection (2). Colonoscopy, considered by many to be the best method of early detection, can greatly reduce mortality of colorectal cancer (3). In one study colonoscopy reduced mortality by up to 53% (4). A consistent decline in CRC mortality in the past several decades is attributed to an uptake in screening measures like colonoscopies and the public health push to increase these behaviors, in addition to improved treatment options, and changes in dietary habits (1,5). However, compliance to invasive screening methods such as colonoscopy can be low. In 2010, only 59% of people over the age of 50 reported having colorectal cancer screening despite recommendations (6).

Approximately 5-7% of CRC cases are attributed to a known genetic predisposition (7). The most common form of hereditary colorectal cancer, Lynch Syndrome, is a disease that previous research has linked to several mismatch repair genes: MLH1, MSH2, MSH6, and PMS2. When these genes function properly, their products are responsible for repairing bases which have been misincorporated during normal DNA replication (8). Mutations in these genes hinder DNA repair processes and can lead to carcinogenesis (8). Up to 3-5% of all colon cancers are thought to be caused by Lynch Syndrome (9), which is also associated with an increased risk of endometrial, ovarian, and other cancers (10,11).

Table 1 shows the lifetime risk and average age of developing Lynch Syndrome-related CRC by gene, compared to the population average non-hereditary, sporadic CRC.

<b>Gene Mutation Carriers</b>	<b>Risk (%)</b>	<b>Average Age of Diagnosis (y)</b>
Sporadic CRC	5.5	69
<i>MLH1</i> and <i>MSH2</i>	22–74	27–46
<i>MSH6</i>	10–22	54–63
<i>PMS2</i>	15–20	47–66

Table 1: Lifetime Risk and Average Age of CRC development by Gene (7)

Awareness of colorectal cancer risk is especially important for families of people who have developed CRC because even without a *known* genetic predisposition, close family members of CRC patients are about twice as likely to develop the disease (12,13). This is due to several potential factors including shared environmental risks or yet to be discovered hereditary links (14). One study, by Forsberg et al., highlights the importance of screening behaviors in family members of people with colon cancer. It showed 22% of people with 2 close relatives, and 24% of people with 3 close relatives with colorectal cancer had adenoma findings on a colonoscopy. In the same groups 6% and 7% of relatives had advanced adenoma findings respectively. Only 10% had adenoma findings and only 3% had advanced adenoma findings in a control group (no close relatives with colon cancer) (15). From these data, it is clear that family members of patients with known Lynch Syndrome and relatives of CRC patients should be aware of possible genetic susceptibility and increased risk *and*, that this knowledge should inform their own screening behaviors.

There is a consensus among several influential policy recommending entities that universal screening for Lynch Syndrome is recommended in patients who present with colorectal cancer as public health policy to reduce colorectal cancer mortality. The

Evaluations in Genomics Applications Practice and Prevention (EGAPP) Work Group (16) has recommended universal tumor screening for Lynch Syndrome, and the National Comprehensive Cancer Network (NCCN) (17) recommends universal screening for patients under the age of 70. Healthy people 20/20 (18), a public health call to action, specifically mentions the uptake of the universal screening procedures for Lynch Syndrome as a public health goal for the current decade. Universal screening for colorectal cancer using a combination of microsatellite instability analysis and immunohistochemistry has been shown to be more effective than the previous clinical diagnosis procedures, namely the Amsterdam II (19) or Bethesda criteria (20), for identifying people who have a hereditary colorectal cancer syndrome in their family (16). Universal screening procedures have also been shown to be cost effective, especially when multiple, at-risk family members are tested for the disease (21).

Universal screening is accomplished using two methods, Microsatellite instability analysis (MSI) and immunohistochemistry (IHC). Use of both is recommended for highest sensitivity and specificity of screening (16). Microsatellite instability, seen in approximately 90% of Lynch Syndrome related colorectal tumors is a hallmark of the disease (22). Microsatellite instability is an abnormal number of short repeated sequences of DNA called microsatellites. Microsatellites are prone to DNA replication errors and an abnormal number of repeats, as seen in Lynch Syndrome, indicates defective MMR proteins (23). Sensitivity for this analysis depends on the gene mutation but can be as high as between 80%-90%, with specificity as high as 90% (16). IHC testing looks for the presence or absence of protein products of previously mentioned mismatch repair genes. A reduction in the amount of these protein products indicates that they are not functioning

properly. IHC analysis has approximately 84% sensitivity and 89% specificity for detecting Lynch Syndrome (16). At the time of recommendation, EGAPP could not identify any studies with an ideal study-design to test either MSI or IHC's clinical validity, so sensitivity and specificity for these analyses are still under debate (16). These procedures are minimally invasive because they utilize tumor tissue from excised cancers and are more cost effective than initially using targeted germline mutation analysis on CRC patients, which often follows the initial testing for MSI or IHC as a confirmatory test (16).

Dineen and colleagues (24) found that a successful improvement of their universal screening program identified an additional 20 cases of Lynch Syndrome in the study population. Stemming from these cases, they were able to identify an additional 202 first-degree relatives who would potentially benefit from a potential public health intervention to increase screening behaviors or further genetic testing for the disease. This makes Lynch Syndrome screening an important public health measure for CRC patient's families. In order to get family members screened for Lynch Syndrome, it is important to understand what patients experience first-hand during the process of universal screening. By studying how patients think about current procedures, we can gain insight into potential gaps that may exist between providers and patients in conveying information about colorectal cancer as a family disease. Furthermore, we must study how patients think about their diagnosis of colorectal cancer and how they share their diagnosis and the results of genetic testing with their families and social network to understand how to best fill these information gaps and improve public health policy more broadly. We can utilize the synthesis of this information to improve current universal screening procedures and to encourage both an

increased awareness of risk and uptake of screening behaviors in family members of colorectal cancer patients.

Many factors must be taken into consideration when implementing these procedures from a system standpoint, related to different provider roles and the procedural steps involved in the process (25). Engaging the various stakeholders involved in this process will help us to fill in gaps in services by understanding the role that each individual stakeholder plays in the implementation of these procedures and therefore, target areas of need for future improvement. Thus it is important to understand both the lived-experience of patients undergoing universal screening procedures for Lynch Syndrome and of the providers of these services. Some research has been conducted about providers' views prior to implementation of universal screening (26) but nothing is available that collects data from providers and patients together.

The aims of this qualitative pilot study are two-fold: 1) to explore how patients think and talk about universal screening and colorectal cancer in order to inform public health decision-making about colorectal cancer screening, diagnosis, and treatment as a family disease and; 2) to understand provider views about implementing universal screening into their health care setting.

**Setting:**

The Seattle Cancer Care Alliance (SCCA) (27) is a consortium of cancer care and research facilities that includes The Fred Hutchinson Cancer Research Center, University of Washington Medicine, and Seattle Children's Hospital. The colorectal cancer specialty clinic (CCSC) at the Seattle Cancer Care Alliance, established in February 2013, was viewed as an

ideal setting for the implementation of universal screening for Lynch Syndrome using MSI and IHC. Cohen et al. outline the implementation of these procedures (Figure 1) in (25), which occurred in July 2013. At the time of data collection, over 40 patients had undergone Universal Screening procedures at the SCCA. The Fred Hutchinson Cancer Research Center Institutional Review Board approved both provider and patient interviews.

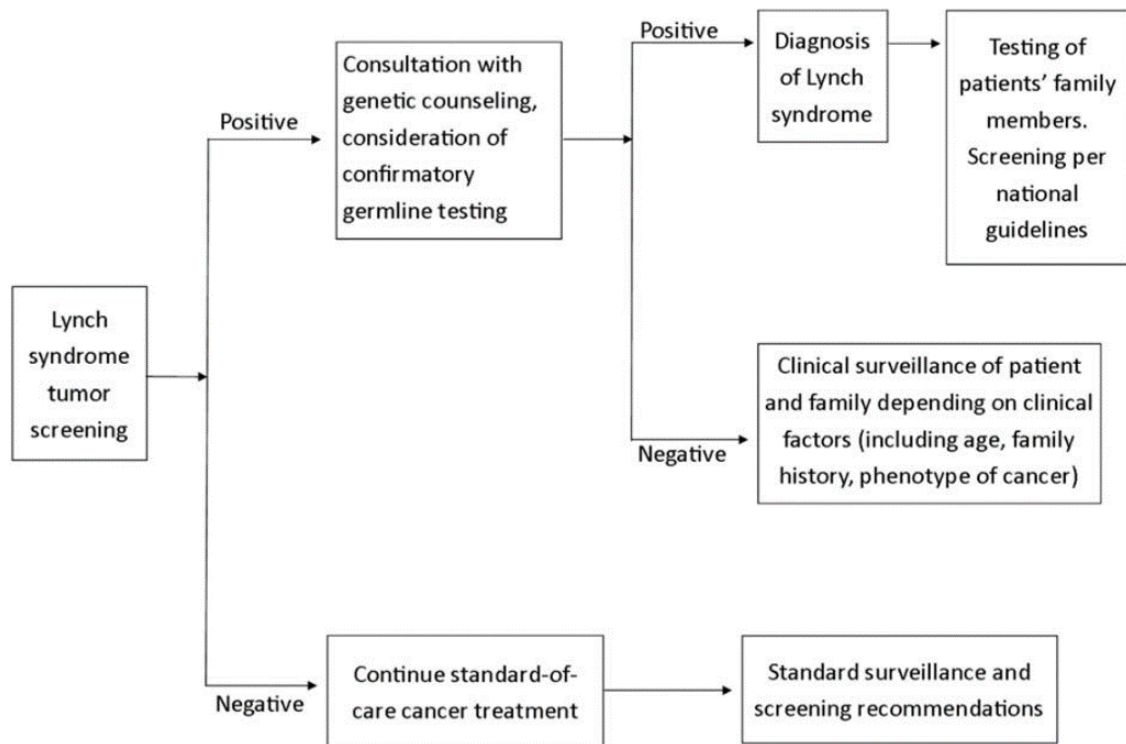


Figure 1: Flow Diagram for Universal Screening Procedures (25) at the SCCA CCSC

**Aim 1: To explore how patients think and talk about universal screening and colorectal cancer in order to inform public health decision-making about colorectal cancer screening, diagnosis, and treatment as a family disease**

**Methods:**

Research staff contacted patients (18 years old and older) who received their care at the SCCA CCSC clinic as part of their colorectal cancer treatment in order to recruit them into the study. These patients all had MSI/IHC testing as part of universal screening at the SCCA. We excluded patients diagnosed at SCCA CCSC with anal cancer, those who had MSI/IHC testing at another institution or had a known genetic condition. Participants received a recruitment approach letter, a follow-up phone call to determine interest, and, upon response, study staff scheduled participants for an interview with the study interviewer (DG). Study recruitment was completed by September 30<sup>th</sup>, 2014.

Demographic data for study participants can be found in Table 2.

Study ID:	1J	2I	3S-B	25	26	8	10	13	22	23
Age	n/a	72y	60y	44y	71y	60y	37y	n/a	52y	n/a
Sex	n/a	F	M	F	F	M	M	n/a	F	n/a
Race/ Ethnicity	n/a	Not Hispanic or Latino	Not Hispanic or Latino	Not Hispanic or Latino	Not Hispanic or Latino	Not Hispan ic or Latino	Not Hispan ic or Latino	n/a	Not Hispa nic or Latino	n/a
Received Genetic Counseling?	n/a	N	N	Y	N	Y	Y	n/a	N	n/a
Diagnosed w/ Lynch?	n/a	N	N	N	N	N	N	n/a	N	n/a

Table 2: Demographic information for study participants N=3 Missing Data

Participants consented verbally and then participated in an approximately hour-long semi-structured interview. Study staff de-identified interviews by redacting names and assigning a study ID number that was then stored on a secure database. Interviewers asked participants a variety of questions about their experience with universal screening

and topics related to their colon cancer, family relationships and communication, and physical and emotional closeness with the participant's family (Appendix 1).

The primary coder (TH) reviewed the transcribed interviews, then utilized questions and emerging themes to create a codebook. A second coder, CE, also reviewed interviews and separately coded them using the agreed upon codebook.

A percent agreement score was calculated and interview coding was reconciled until an acceptable level was met. During this time, the original codebook was modified and finalized (Appendix 3) in order to encompass both coders interpretation of data. Acceptable percent agreement was set at a moderate level of .85 to allow for a range of interpretations of these data. Qualitative data was coded using Nvivo v10 coding software by the primary coder and by hand for the secondary coder. 10 interviews with patients were completed before saturation was determined. Percent agreement for these interviews averaged 89%.

## **Results:**

Several themes emerged throughout our interviewer's conversations with participants about universal screening and communication about their cancer with members of their social network:

### **Difficulty Remembering Conducting or Purpose of Tests**

Patients had an extremely difficult time recalling discussions about IHC or MSI which involved testing on either biopsy or surgery specimens. The majority of patients

(6/10) did not remember these tests being conducted at all while 4/10 vaguely remembered, meaning that they were able to recall that some sort of genetic testing was conducted. However, they could not specify which tests were conducted. None of the participants could relay the exact purpose of the tests or identify them by name.

Interviewee: So, I did and found it that I didn't have any of the markers for that, so it wasn't any sort of genetic predisposition towards it.

Interviewer: ...Do you remember anyone talking to you about MSI or about tests DNA-based test that would determine your risk for cancer?

Interviewee: I don't remember anything like that.

Interviewer: And do you remember anyone talking to you about test that would help to determine which chemotherapy would be best for you?

Interviewee: I don't remember that. No.

Several (3/10) participants identified that the deluge of information received during the beginning stages of their cancer diagnosis acted as a barrier to recalling specifics about tests being performed.

Interviewee: I'm not sure. I remember when I first went in there I met an unbelievable large quantity of people! I was meeting with so many different specialists and doctors. I'm pretty sure that one of the people I met with was some kind of a genetic counsellor. I filled out a questionnaire. I'm not sure if they got a sample from me or not.

### **Openness about Health Topics within Social Network**

Participants had varying levels of comfort talking about health topics with their social network. All interviewees (10/10) mentioned at some point during the interview that they were at least somewhat open to talking with certain people in their social

network about their health. This was especially true if the information could have a positive influence on that person's health:

Interviewer: For you, what seemed important to share with your family and friends about your cancer?

Interviewee: Anything that would alert them to— if something happened to them and I also wanted to be reassuring them that I was in a good position to get better from it.

For some participants, this openness extended beyond their immediate family and into non-genetically related members of their social network. Respondents reported sharing information about their cancer with close friends, step-siblings, in-laws, and co-workers. (6/10) Participants indicated that certain topics tended to be taboo, or off limits to talk about within their family. These included sexual health, like sexually transmitted diseases and sexual dysfunctions, mental health, and topics related to death. Some participants indicated difficulty sharing their diagnosis of colorectal cancer with certain family members. The main reason given for this was that they did not want to cause undue worry. This was especially true of participants with elderly, living relatives:

Interviewee: Well, with the cancer... the last people I wanted to tell was my family. I told my— you know, my immediate family obviously, my husband and my dad. I told my sisters that I couldn't bring...myself to tell my grandmother and my aunt and the like...I thought about picking up the phone and calling and I would just say, "How do you tell your grandmother who would be 100 years old— 101 that you have cancer?"

Most people tended to believe that there were either spoken or unspoken 'rules' or 'norms' about health within their family. These ranged from diet and exercise to smoking

and drinking habits, and in some families this included things like screening for cancer. (8/10) interviewees mention that these health norms exist in their families though (7/10) indicated that these norms varied throughout their family.

Interviewee: ...I think that [health prevention] is kind of a rule. But I think they're all pretty well aware but they need to stay up to date with everything and I think they pretty much they do that.

### **Communication within Family and Champions of Health Information**

Participants identify several methods of communication that they use to speak to their family members about health information. Methods of communication about health topics that participants mentioned included phone (10/10), e-mail (8/10), text messaging (6/10), in person (3/10), and letters (2/10). Participants seemed to indicate that they preferred more personal communications for serious health discussions, although sometimes this was not possible due to temporal or geographic constraints.

Interviewee: Well, in that case, I probably e-mail more because it's-- they can see it in their-- if it's their schedule, they have time to read it. But they would just as well will have a phone call to really kind of-- If it's, you know, kind of a serious ongoing health issue, it's probably about 50/50.

Of note, most people (8/10) were able to identify somebody within their family who acted as a champion to communication about health topics within the family; sometimes this was the interview participant but most of the time it was another person in their family. Often times, the person that was identified had a profession in the health sciences (for example, physician or nurse) enabling them to act as a gatekeeper and vehicle for health related information:

Interviewee: Yeah. I would say that applies particularly to my middle daughter who is a nurse. She had lots of information and came to see me and [my husband] [and?] understood the medical side of it probably much better than others did.

The majority of interviewees (7/10) indicated that they tended to talk to their close family members when in the process of making important medical decisions for their health, though only a few actually included their family in the decision making process. 4/10 also mention that there is sometimes tension when these decisions are brought up because family members do not always agree on the best course of action for each medical decision.

Interviewee: And when I did make the decision to go with SCCA, I then had another decision of whether I was going with the standard care or I had discussions about clinical trials. And so we talked about that, what their thoughts were. I guess any time there was any kind of a change, or decisions to make, we talked about it.

### **Support and Effects of Cancer Diagnosis on Family Members**

Throughout the interviews, participants indicate different levels of closeness and affection in regards to their family. (10/10) interviewees mention that at least some members of their family get along well, while others (3/10) mention that there are certain people in their family who do not get along very well or at all. These people tended to mention the disconnects in their family multiple times throughout the interview, indicating that this distance might play a major role in their family dynamics.

Interviewee: Yeah. When I'm in my dad's side of the family, there was a real split in the family...And so, the ones that were more in my age or I hadn't seen so long...they never got in contact with me, but I

figured, you know, I offered. I let them in and if they didn't wanna come, that's fine.

Participants spoke about varying degrees of support within their families. Many (8/10) felt that family members relied upon one another during times of medical necessity such as their cancer diagnosis. For example, family members offered physical assistance with care after a surgery, or offered to drive patients to medical appointments when they could not do so themselves?. This is in contrast with several interviewees who mentioned that specific members of their family did not require or want assistance unless it was necessary. This seemed to be reflective of those individual's personality traits rather than a theme among the family as a whole. (4/10) Interviewees mention that there is a familial 'obligation' that exists in their families to offer assistance when needed, even if that assistance would carry a significant time commitment or burden.

Interviewee: And I don't know how you will ever state this but because they are 3 sisters I had-- my one sister that live-- because [my sister?] had my mom with them from the time that mother has been older so that she hasn't been able to take care of herself. My sister has had her all the time. I just thought that it was my turn. So I came over Southern Montana and Idaho to take care over here at Oregon... And I think that particularly that sister feels really obligated to help others.

Along with support from family members, some participants noted that family members were even affected by their diagnosis of CRC in ways such as increased awareness of their own health behaviors like diet and exercise. Several (2/10) mentioned that their families have gotten closer since their diagnosis due to the in depth discussions about health and wellness that their cancer incited. (6/10) participants' family members have had screenings like colonoscopies after the participant was diagnosed with CRC. The

majority state that this was after a conversation with these family members about their own risk.

Interviewer: It sounds that, your diagnosis has influenced your brothers [to get screening]?

Interviewee: Yes. My brothers have both had colonoscopies...and my younger brother had polyps....probably what I had. So it was a bit of an eye opener for us.

### **Discussion:**

Participants in this study have very little recollection of the screening procedures for Lynch Syndrome that were conducted on them. Another study (28) found that it can be common for patients to have difficulty remembering diagnostic tests in the context of prostate cancer. This is likely compounded by the stress of the beginning stages of cancer diagnosis and treatment. The participants' lack of knowledge about tests conducted on them is an important public health consideration, especially when discussing a disease like colorectal cancer since, as previously mentioned, regardless of a known genetic predisposition, family members of CRC patients are at a greatly increased likelihood of also developing cancer. Further research must be conducted on patients who test positive for Lynch Syndrome to investigate whether they understand the implications of their positive test results and feel able to communicate about shared risk with family members.

Previous research has shown that people who participate in genetic testing in a research or clinical setting are open to sharing their results with their family members and doctors (29,30). Furthermore, other qualitative literature has also shown that people are open to talking about their colorectal cancer, genetic risk and the need for CRC screening among family members (31). Data from this project reinforce these ideas as all

interviewees mention that at least some members of their family are open to sharing and communicating health information. This information even led to an increased awareness of family members' own health and an uptake of screening behaviors in some family members. The beneficial effect that family members can have on each other's health, especially when discussing diseases like cancer, which can be more common among family members, is a key target to consider for family level interventions.

Participants indicate varying levels of closeness and support throughout and even within families. The majority of people seemed to feel that their family was there to support each other in times of medical need. Research data indicates that we must be sensitive to certain types of information and should assess individual families comfort levels with this information and also varying family structures before attempting to facilitate an open discussion about these topics. Many participants are able to identify members of their family whom they consider to 'take the lead' on healthcare information knowledge and dissemination. Identifying these people was a seemingly straightforward task for the majority of participants, which may mean that identifying these people for intervention would not pose a significant burden for researchers and clinicians. This is also reflected in the literature where people can identify (31) members of social networks who are champions of health information. Champions represent a powerful tool for communication within a family and greater social network and can be targeted for facilitation of this communication.

## **Aim 2: To understand provider views about implementing universal screening into their health care setting**

### **Methods:**

We chose providers to interview from a list of 'key players' in the implementation of universal screening at SCCA, which included GI specialist physicians, genetic counselors, administrators, and others. We asked experts at SCCA who most contributed to the implementation of universal screening across disciplines in order to understand who the key stakeholders, both positive and negative, were in this process. We sampled providers based on relative importance for achieving the goals of universal screening procedures. Provider interviews represented multiple points of contact for patients along the process of universal testing. Research staff contacted providers via email and requested an in person or phone interview.

After providers were consented verbally, they engaged in an approximately 30 minute long discussion about their role in the implementation of universal screening for Lynch Syndrome at the SCCA. The interview guide was created using constructs in the Consolidated Framework for Implementation Research (CFIR) (32). The constructs contained within the CFIR can be utilized to map the implementation of universal screening procedures for Lynch Syndrome, highlighting the different aspects of the people involved, the organization and the intervention that are important for successful implementation. Selected CFIR constructs (Table 3) for this project were chosen based on their relation to the lived-experience of patients undergoing universal screening procedures. These constructs were inputted into the CFIR 'interview guide' tool (32) and output was then

modified (Appendix 2) in order to fit the context of universal screening for Lynch Syndrome at the SCCA.

CFIR CONSTRUCT	CFIR DOMAIN	DESCRIPTION (13)
1. ENGAGING	PROCESS	Attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities.
2. EXECUTING	PROCESS	Carrying out or accomplishing the implementation according to plan.
3. REFLECTING/ EVALUATING	PROCESS	Quantitative and qualitative feedback about the progress and quality of implementation, accompanied with regular personal and team debriefing about progress and experience.
4. STRUCTURAL CHARACTERISTICS	INNER SETTING	The social architecture, age, maturity, and size of an organization.

Table 3: CFIR Constructs Related to the Lived Experience of Universal Screening Procedures

Four interviews were conducted with providers (genetic counselors, the chief of GI pathology, and the chief of GI surgery) who were pivotal in both the implementation process and day-to-day function of screening procedures. These interviews act as key informant interviews, which give context to the patients' lived experience of universal screening procedures.

### **Results and Discussion of Key Informant Interviews:**

Providers spoke about implementation both from a systems standpoint and from a patient centered standpoint, both of which could influence the lived experience of patients undergoing the first round of universal screening procedures at the SCCA post-

implementation. They mentioned a number barriers to implementation from the system standpoint including creating direct lines of communication between usually separate divisions, overcoming the difficulty of embedding these tests into the electronic medical record system, creating procedures for physicians ordering these tests, and overcoming the standard of care which did not originally include universal MSI or IHC testing. Many of these barriers reflect previously published work on this subject, in this setting and others, and can be looked at further in (25,26). Although these were important barriers to overcome during the implementation process, providers indicated that the upstream implementation procedures were, for the most part, successful and that it was patient outcomes had yet to be looked at.

From the patient standpoint, providers felt there were several factors that might influence the lived experience of this first wave of universal screening. The first of these was that some patients may have problems with obtaining insurance coverage or paying for the tests. One provider felt strongly that if a patient were to get a bill in the mail, they ought to know exactly why they are receiving it. This makes true 'universal' screening difficult. In this case, a system was built into the process by which the best decision is made for each individual patient's financial situation.

Providers also indicated that patients often have a long list of tests and procedures that they must keep track of. This can make it difficult for patients to know exactly what procedures are being conducted and when they are being conducted. Multiple providers noted that this seemed to be due to the stress as well as the overwhelming nature of a cancer diagnosis and treatment process rather than a general lack of faculty. One provider

noted that there was usually not much explanation to the patient of what these tests entail before they are conducted because they are not diagnostic and that the tests were added into regular standard of care for patients who come into SCCA with colorectal cancer. The detailed explanation of the meaning and implications of these tests, in the system that was set up for this institution, comes after a positive screening result in consultation with genetic counselors. This sentiment is reflective of patient interviews which showed that participants in universal screening did not remember specific details about any of the tests that had been performed on them, likely since none of them tested positive for these results.

There have been several published works outlining the successful implementation of universal screening procedures (25,33,34) for Lynch Syndrome. Implementation of universal screening procedures at the SCCA CCSC was a process that took a significant amount of effort and collaboration between clinicians, administrators, laboratory staff and other key players within the organization. From our key-informant interviews, and previously published work (9) it is clear that the implementation of these measures was successful from a system standpoint. All providers indicated that the procedures have been integrated effectively into the standard of care for CRC patients at SCCA. Despite this, there seems to be a disconnect between the apparent success of the program and the patient's understanding of the program, the tests being conducted, and the implications of potential results. Providers indicate that they believe that this disconnect exists, in part, by the overwhelming nature of the medical process for cancer diagnosis and treatment. The issue may also exist in our ability to discuss all of the tests being conducted in detail to patients with a limited amount of time when there are many important topics to cover during a

clinical visit. In this system, the genetic counselors take the responsibility of explaining what a positive result implies and how to proceed should further tests be necessary, as was not the case for the patient population studied in this project.

### Public Health Implications:

Figure 2 shows the flow of knowledge throughout professional, familial and social networks. There are important steps along this pathway that interventions can target to ensure that knowledge is both absorbed by patients, and then communicated throughout their social network efficiently and effectively.

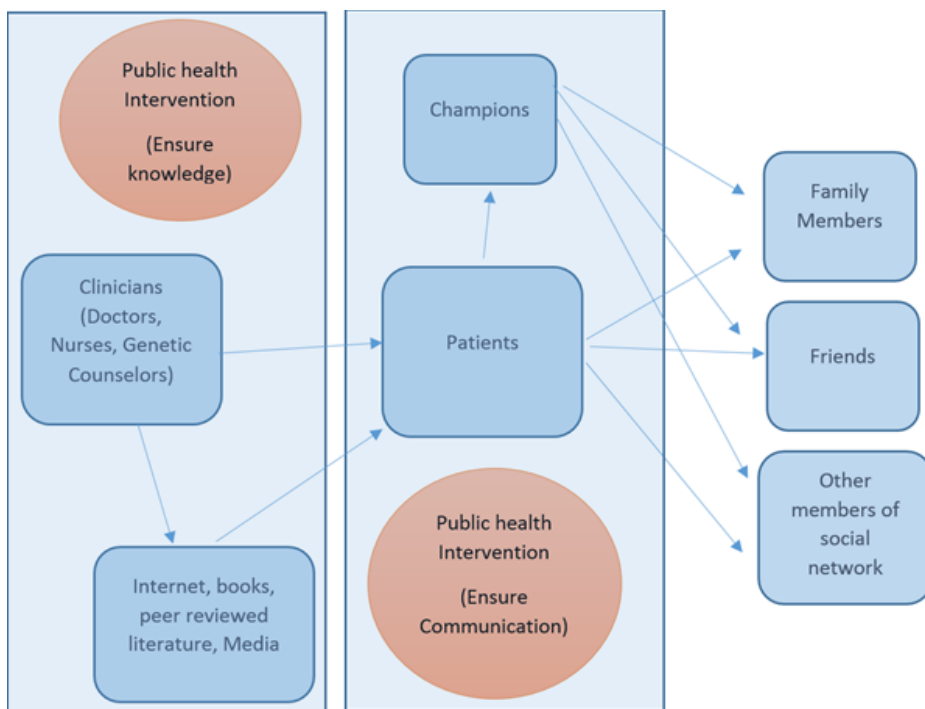


Figure 2: Diffusion of knowledge throughout a social network

The first of these steps takes place in the clinical setting and it is to ensure that knowledge easily accessible and understandable to the patient. Successful interventions at

this stage require that any potential service gaps that might hinder or halt the education process be addressed. This step addresses the findings in aim 2 and the universal screening portion of aim 1 of this project. In this context, this could occur at the time that patients learn about universal screening procedures for Lynch Syndrome or, more likely, after a positive screening test during their discussion with a genetic counselor. This step is made more challenging by varying degrees of health literacy among patients and among the members of the social network that these patients must communicate with. These important considerations lay outside simply determining if a new program, such as universal screening for Lynch Syndrome, is effective. We must further investigate the patient perspective, how readily they are able to understand the information that is presented to them, and how well they are able to retain this information. The 'reflecting and evaluating' portion of the CFIR process constructs must be given extra weight, especially when evaluating implementation from the patient's perspective.

The second step is to intervene once the patient has gone home and started to integrate the new health information into his or her own life. Interventions at this stage can enable, encourage, and facilitate the communication of this information among members of the patients' social network. At this stage, we can recruit champions of health information and utilize their status in the social network to aid in dissemination of health information. Many diseases like colorectal cancer are family diseases. However, universal screening for only some of these diseases is recommended as good public health practice. Even so, these diseases can cause a significant amount of burden within a family and facilitating a conversation about them is good practice to help families remain vigilant and improve their own health. Tools can be created in order to assist in this communication and enable

patients to become advocates for themselves and their families. More research must be completed in order to determine the best ways to help families and social networks talk about disease risk in the most effective and efficient manner.

A comprehensive plan for ensuring proper education of patients about the tests conducted on them, the implications for these tests along with facilitating a conversation within families about shared risk could prove a difficult but valuable endeavor for a health system. For example, in cases of Lynch Syndrome along with other family diseases such as breast cancer (BRCA) or even hypercholesterolemia, it is possible to build policy to conduct cascade genetic testing. Cascade testing seeks to target high-risk family members of patients who test positive for highly penetrant variants and screen them for shared risk (35). Successful and efficient cascade testing requires the screening and education procedures for the initial patient to be effective while also making educating and engaging the correct family members important in order to reduce disease burden in a family.

### **Limitations**

This study presents several limitations that must be addressed when discussing the implications of results. First, no participants that we interviewed tested positive for Lynch Syndrome. One or more interviews with participants who received positive results would have given perspective and insight into how patients undergoing universal screening procedures incorporated a positive screening result into their lives and how they would have communicated this impactful information to their social network. In addition, the small sample size of this study and the lack of knowledge about universal screening procedures made it difficult to ascertain clearly the lived-experience of patients undergoing

the first wave of testing. That being said, the majority of people noted that all of their concerns were addressed throughout their medical care experience with SCCA.

### **Future Directions:**

It is important to further study the experience of patients undergoing these screening procedures in a population who have positive screening results. Due to the difference in follow-up with these patients, they may better understand the implications of a positive test result when compared to patients who do not have extensive follow up with genetic counselors. Current, unpublished research attempts to create a system by which families can learn about and talk about colorectal cancer among members of their family and greater social network in an attempt to track this communication and downstream health behavior changes. Eventually, we can incorporate these practices into standard healthcare procedures for familial diseases like CRC. We must consider multiple factors that were uncovered during this project, including: how implementation success might affect the lived experience of patients, assessing variable sensitivity to certain health topics in families, utilizing champions as communicators, and different communication methods for each unique network of people.

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## Appendix 1

### Universal Screening for Microsatellite Instability and Immunohistochemistry at the Seattle Cancer Care Alliance Colorectal Cancer Specialty Clinic

#### Interview Guide: Research Participants

April 19, 2014

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#### INTRODUCTION

Thank you very much for taking the time to speak to me about your experience as a patient at the Seattle Cancer Care Alliance Colorectal Cancer Specialty Clinic.

Your participation in this interview is voluntary. You can refuse to answer any questions, and end this interview at any time. I will digitally record the interview to enable in-depth analysis for the study. These recordings will not be shared with anyone outside of the research team and all transcribed data will be made anonymous and secured.

Does that all sound reasonable? Do you have any questions before we begin?

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#### Section 1: Knowledge about Colorectal Cancer

- 1) Some people have ideas about what caused them to develop colorectal cancer and some people are pretty unsure why they got it. I'd like to ask you about your thoughts concerning why *you* developed cancer.  
Thanks for your answer. I am interested in finding out what made you feel this way.

##### Probes:

- 1) Disease factors, such as where in the colon the tumor was located?
- 2) Family conversations?
- 3) Discussions with physicians or other health care provider?
- 4) Other information seeking, Internet, etc?
- 5) Other ways you have gathered or been exposed to colorectal cancer information?
- 6) Did you have a colonoscopy or were recommended to have one a few years prior to being diagnosed with cancer?

- 2) Now I'd like to ask you your thoughts about whether you could get colorectal cancer again.

Thanks for your answer. Again, I want to find out anything that has influenced your thoughts about this.

##### Probes:

- 1) Medical factors?
- 2) Family conversations?

- 3) Discussions with physicians or other health care provider?
  - 4) Other information seeking, Internet, etc?
  - 5) Other ways you have gathered or been exposed to colorectal cancer information?
  - 6) Another person with cancer – family member or friend
- 

## Section 2: Knowledge about tests conducted during treatment

- 1) I'd like to ask you about one of the tests performed during your colorectal cancer care.

It is a policy of the SCCA and of most large hospitals nationally to test colorectal cancer tissue for a possible hereditary cause of cancer. We perform two tests: microsatellite instability (also called MSI) and immunohistochemistry (also called IHC).

- A. MSI is a DNA based test. These tests help to determine which chemotherapy would be best for you and also whether a genetic susceptibility to cancer may be present.

Have you ever heard of this test?

**Probe:** Did your medical provider discuss performing additional tests on your tumor to help learn information on how to treat you?

What do you remember of this test?

Did you get the information you needed about this test?

What about the results?

Did you talk about them with your family?

Who and how did you bring it up?

What did you talk about with them?

- B. The immunohistochemistry or IHC testing looks for four proteins on the colorectal cancer tissue. These are called MLH1, MSH2, MSH6 and PMS2. This test determines whether these proteins are present or absent. It also can provide information about genetic susceptibility.

Have you ever heard of this test?

What do you remember of this test?

Did you get the information you needed about these tests?

What about its results?

Did you talk about them with your family?

Who and how did you bring it up?

What did you talk about with them?

---

### **Section 3: Genetic Counseling**

Now, I'd like to ask you about your experience with genetic counseling.

As part of your care at the SCCA CCSC, were you referred to see a genetic counselor?

If No

Go to the next section

If Yes

Did you make an appointment?

How was this experience for you?

What do you remember being discussed during your consultation with the genetic counselor?

**Probes:** Was MSI and IHC testing discussed?

What types of genetic testing was discussed with you?

Were any other tests recommended? Tumor tests?  
Blood tests?

What was your motivation to see the genetic counselor?

Doctor/provider recommendation?

Family member request?

Other?

How did the genetic counseling visit help you understand and/or make a decision about genetic testing?

Did you pursue genetic testing?

If Yes/No – what were the reasons for your decision?

---

### **Section 4: Family Communication**

Let's talk about the ways you think of or are thinking of involving your family in discussion about your cancer and possible risks for family members.

For you, what seems important to tell them?

Who have you told already and what did you tell them?

Do you think it is important to involve your family in the information? If no/yes, why?

Are there members of your family that you want for sure to be involved in terms of knowing the information and why?

Are there members of your family that you don't want to be involved in terms of knowing the information and why?

**Let's talk about family a bit.** First of all, everyone seems to have a different definition of family.

1. When you think of family who comes to mind immediately/pops into your head? When you think harder about the definition of family who else comes to mind?
2. Is there a difference between "family" and "relatives" to you? What is it? Is there "family" that are not relatives? Are there relatives that are not part of your "family" definition?

**Probe:** Does "family" includes individuals outside the immediate family? Grandparents? Grandchildren? In-laws? Aunts/Uncles? Cousins? Or "step" individuals? Stepparents? Stepchildren? Stepsiblings? Why or why not? Individuals who are not related by blood, but are very close? Ex. some people might think of a best friend or neighbor as their closest "family." While not relevant to genetics, I think it is useful to bring up if you are going to define this so particularly.

3. Are there people who fit your definition of family but who you left out when answering my first question? If so, can you tell me what makes them different?

**Probe:** Is it where they live? A rift? Communication patterns?

4. What about people who are no longer living but might have fit your definition of family if they were alive? How do you think about them being part of your family?

## II. Family Interaction & Health

Let's talk about the ways in which your family interacts about health. The next sets of questions all have to do specifically about things your family does and/or says.

### A. Closeness & Affection

1. Does your family generally get along? Do you generally like each other? Are there any members of your family from whom you feel distant?

2. Families are different in the ways they talk about health and illness. What would you say your family is like? Do people talk about how they feel physically? How to stay healthy? Is it okay to express health worries and concerns with each other or is health considered a very private matter? Overall, how hard or easy is it to talk about health?
3. Are certain health topics off limits with certain family members? **Probe:** For example everyone talks about one family member's health issue and their concern about it except to the actual individual.)
4. Can you describe an instance when you recently talked about a health issue with your family? I am interested here in what was discussed, the context for the discussion, what you were thinking and how you felt in the situation. What was the outcome?
5. Are there any topics that are taboo or not appropriate to mention with all or some family members?
6. Are there different family members who are more open about health matters than others? Why do you think that this?

#### **B. Type & Frequency of Contact**

1. Is there a person that takes the lead on health issues (family health informant)? What does he/she do? Is it helpful?
2. Is this person a hub or family head in other areas of family life as well?
3. Can you describe a situation where you decided not to talk to a family member about a health topic? How did you make that decision? Why did you make the decision?
4. Are there specific rules for talking about an illness in your family? About health? How about lifestyle behavior (such as exercise, sun exposure, diet)

#### **C. Agreement in Opinions, Values and Orientations**

1. Do you find that your family has a lot of agreement on health issues? What are the issues where there is no agreement, amongst who, and why? Is agreement on these health issues important, or not, and why?
2. Can you describe a situation where family members disagreed on a health topic? Please tell me the story. : describe who said what and the outcome of the discussion.
3. Does your family agree on what family members should do to "stay healthy"? How about when a family member is ill? Do more or less family members tend to agree on health issues during a family health crisis? Are there certain family members that tend to agree more with the majority of the family? Do certain family members always disagree or agree?

#### **D. Practical Assistance**

1. Do you rely on your family to help you through health issues? What about the rest of your family – do they rely on each other? For what specifically? Is there anything that is seen as not appropriate to get help from your family?
2. Can you think of a recent instance when someone in your family has relied on you or another family member for practical help with a health problem? Please tell me about it. How about when you have relied on another family member for help with a health issue?
3. How about help in order to maintain good health, such as a workout buddy or diet partner? Is this different from when someone might be sick or have a disability and need some help?

### **E. Sharing Norms, Having Obligations**

1. Would you say that there are certain beliefs or opinions about health that most of the family share? Can you name these? Are there some things about which some of you have different opinions – like what constitutes “healthy eating?”

**Probe:** I’d like to describe some health norms we have heard from other families.

Other individuals have said the following:

I want to know all of the information and make my own decision vs. I want my doctor to tell me what to do.

We try to make sure we get regular check-ups to protect our health, including cancer screening like mammography and colonoscopy

We don’t like to get unnecessary medical tests – why look for trouble?

2. How important is it to you and other family members to follow these family norms or beliefs?
3. Has your family recently experienced an illness or crisis that has required the family to step in and help? How did that go? Do you think everyone behaved the way your family thinks is correct?

**Probe:** What about having to help other family members out? What is the family rule about being there when family members need your help or each other’s help around health issues? What if someone gets sick? Loses their job and health care?

4. After your cancer, did things change in your family? How? Did your family’s behavior change, such as: changing what they eat or trying to get screening? Have any other experiences with a family member’s illness shaped your family norms about prevention or health? If so, how?
5. Do you feel obligated or that it’s your duty to take care of members of your family in health-related situations? (Filial duty?). Please elaborate.

### **F. Geographic**

1. How close does your family live to each other? Are you spread geographically across the United States, the World?
2. How often does your family get together?

Not sure survivor contact is relevant here

3. What means of communication does your family mostly use (Telephone? Email? Letters?). Is it different for different people or generations? How does your family communicate most often?
4. Does your family use email/instant messaging to communicate health issues? If so, how do you feel that the email/instant messaging influences your family? Your family's health decisions? Are there certain family members that use email/instant messaging to communicate about health issues more often? Are people more open communicating through the Internet? Are there health issues communicated via email that would not be communicated over the phone or in person? Has the Internet increased your family's communication on health-related issues? On communicating about colon cancer, prevention, and risks?
5. Does the mode of communication on health-related issues change depending upon the health issue (such as the severity of the health issue), the family member (the family member's age, generation, or location), or your proximity to the family member? If so how? What type of communication do you use for what type of situation and/or family member?

Do you have anything else you would like to add?

#### **WRAP-UP**

Thank you very much for your time today.

I appreciate your insights – you've been very helpful!

- **Are there any last thoughts you would like to share?**

*[Thanks again, goodbye]*

## APPENDIX 2 SCCA PROVIDER INTERVIEW GUIDE

### INTERVIEW GUIDE

*Universal Screening for Microsatellite Instability and Immunohistochemistry at the Seattle Cancer Care Alliance Colorectal Cancer Specialty Clinic*

Hello, my name is \_\_\_\_\_. We are conducting a study through the University of Washington to understand issues arising in developing programs to screen patients with colorectal cancer for Lynch Syndrome. The goal of the interview is to get the factors that have been important in implementing screening your institution, as well as any additional factors you would recommend that others consider.

*At outset:*

- *Reiterate/document: \_voluntary participation, \_stop at any time, \_decline any question*
- *Confirm time availability*
- *Confirm ok to audio record, reiterate that participant can ask to turn it off any time*

*Start of interview:*

1. What is your roles with respect to screening colorectal patients for Lynch syndrome?
2. (From above perspective) Has the intervention been implemented according to the implementation plan?
  - [If Yes] Can you describe this?
  - [If No] Why not?
3. Did you have to make any changes in order to implement lynch screening of all colorectal cancer patients?
  - Changes in scope of practice? Formal policies? Information systems or Electronic records systems? What barriers did you have to overcome?
4. Who were the key influential individuals in establishing screening of colorectal patients for Lynch Syndrome at your institution?
  - What role(s) did they play?

- Do they continue to have a role?
5. Other than the formal implementation leader, are there people in your organization who are champions for Lynch screening?
- Were they formally appointed or is it an informal role?
  - What position do these champions have in your organization?
  - How have they contributed?
6. (This question will depend on the roll—may omit) What is your communication or education strategy related to Lynch screening?
- Have you developed brochures, email communications or other strategies?
7. (This question will depend on the roll—may omit) Does the Lynch screening program include measures to reach out to family members, if Lynch Syndrome is diagnosed?
- If yes, how is this done?
  - If no, why not?
  - Is information about Lynch screening collected during the process?
  - Which measures do you track? How do you track them?
  - How will this information be used?
8. Will you receive feedback reports about the implementation process, (screening outcomes), (implementation success)?
- What will they look like? Content, mode, form?
  - What are your thoughts about strengths and weaknesses of the approach?
9. To what extent has your organization/unit set goals for implementing Lynch screening?
- What are the goals? How and to whom will they be communicated?
  - How do you measure success?
  - If you determine that goals are not being met, what actions can be taken? By whom?

### Appendix 3: Codebook

- 1) Knowledge about colorectal cancer
  - a) Thoughts about why you developed colon cancer
    - i) Personal attribution of risk
    - ii) Genetics or heredity
    - iii) Lack of vigilance by medical provider
    - iv) Unsure
  - b) Sources that influenced knowledge
    - i) Internet
    - ii) Own advocate or self motivated
    - iii) Print info
    - iv) Other sources
  - c) Think they could get CRC again?
    - i) Yes
    - ii) No
    - iii) Do not know
- 2) Knowledge about tests being conducted
  - a) Recollection of MSI and IHC
    - i) Remembers testing specifically
      - (1) Can define purpose of test
        - (a) Knows what the tests are specifically
        - (b) Vaguely knows
        - (c) Does not recollect
      - ii) Vaguely remembers tests
      - iii) Does not remember at all
    - ii) Vaguely remembers tests
    - iii) Does not remember at all
  - b) Reasons for not remembering
    - i) Too many things going on
    - ii) Doctors not clear
  - c) Feelings about this info
    - i) Could be a burden
    - ii) Potentially useful
  - d) Trust in doctor
- 3) Genetic counseling
  - a) Yes
  - b) No or does not remember
  - c) Concerns answered
- 4) Family communication
  - a) Important things to share with family
    - i) Communicating health topics
      - (1) Open
        - (a) All health information
        - (b) Information that could negatively influence health
        - (c) Support
        - (d) Responsibility
      - (2) Not open

- (a) Not sharing with certain people
      - (i) Do not want to worry them
    - ii) People included in family who shared with
      - (1) Mother/father
      - (2) Siblings
      - (3) Children
      - (4) Grandchildren
      - (5) Spouse
      - (6) Distant relatives
      - (7) People outside blood relatives
      - (8) Deceased relatives
    - iii) Difficulty sharing with family
- 5) Family interaction and health
  - a) Closeness and affection
    - i) Family gets along
    - ii) Family does not get along or is distant
    - iii) Champions/hubs of health info
  - b) Type of contact
    - i) Phone
    - ii) Writing
    - iii) Email
    - iv) In person
    - v) Texting
  - c) Practical assistance
    - i) Family relies on one another
    - ii) Family rarely relies on one another
    - iii) Independence noted
  - d) Sharing norms and obligations
    - i) Taboo health topics
      - (1) Sensitive
      - (2) Off limits
        - (a) Death
        - (b) Sex
        - (c) Mental health
    - ii) Health and treatment decisions
      - (1) Discuss and consult
      - (2) Tension
    - iii) Health rules and norms
      - (1) Exist
      - (2) Vary
      - (3) Do not exist
  - e) Geographic
    - i) Family lives close
    - ii) Family lives far
  - f) Family effected by results
- 6) Illustrative quotes