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# Direct-to-patient disclosure of results of mismatch repair (MMR) screening for Lynch syndrome via electronic personal health record (ePHR): A feasibility study

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## Abstract

**Purpose—**The adoption of universal mismatch repair (MMR) screening of colorectal (CRC) and endometrial cancers (EC) has the potential to improve detection of Lynch syndrome (LS) and health outcomes among cancer patients and family members. Electronic patient health records (ePHRs) represent an innovative, resource-efficient route to deliver results directly to patients that could be enhanced by multi-media interventions to improve critical downstream outcomes. The current study examines feasibility and acceptability of this approach.

**Methods—**Patients hospitalized for resection of CRC or EC were recruited to receive their MMR result via institutional ePHR. Baseline and follow-up assessments were conducted.

**Results—**74% (49/66) of eligible patients consented, and 81% (29/36) participants who had a result posted to their ePHR completed follow-up, surpassing feasibility thresholds, with 14% (5/36) receiving an abnormal result. Ratings of the study approach surpassed the acceptability threshold–97% had a mean score of ≥4 on a 7-point scale–and were high regardless normal or abnormal result. Ineligibility was more common among non-White (p=0.009) and ≥65 (p=0.035) participants due to low Internet use/no access.

**Conclusion—**ePHR-based result disclosure for MMR screening is feasible to study and acceptable to patients, but minority and elderly patients may experience greater barriers to participation.

### Keywords

Lynch syndrome; universal testing; mismatch repair; electronic patient health record

## INTRODUCTION

Lynch syndrome (LS) is among the most common adult hereditary cancer risk syndromes[1]. Carrier frequency for mutations in the mismatch repair (MMR) genes associated with LS is



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1/300 in the population[2]. Approximately 3% of colorectal cancers (CRC) and 2% of endometrial cancers (EC) are related to germ-line mutations in the MMR genes *MLH1*, *MSH2*, *MSH6*, and *PMS2* as well as in the *EPCAM* gene[1–3]. LS raises lifetime risk of CRC to 60–80%, EC to 40–60%, and lifetime risks of several other cancers[1–3]. Intensive CRC screening, prophylactic hysterectomy and salpingo-oophorectomy, and high-dose aspirin chemoprevention are proven to reduce CRC incidence in LS[4–6], yet most carriers are unaware they have LS, leading to many preventable cancers and deaths annually. Improving identification of LS is a public health imperative[7].

Research has supported new approaches to improve detection of LS. A 2008 study established the feasibility and cost-effectiveness of universal (i.e. all cases) MMR screening of CRC whereby tumors are routinely tested for deficient MMR by immunohistochemistry (IHC)[8,9]. A subsequent study reported an uptake rate of 71% for MMR screening at comprehensive cancer centers, but lower uptake in the community. Substantial variability in procedures to inform patients of their MMR screening results was also observed, but downstream outcomes were not assessed[10]. Among the concerns raised regarding universal MMR screening is the risk that patients may not pursue genetic counseling and testing when appropriate, diminishing anticipated preventive benefits of screening. A recent retrospective analysis examined three methods to return MMR results to patients and found that an unscheduled clinic approach by a genetic counselor (during a medical/surgical oncology appointment) led to the highest subsequent uptake of germ-line testing[11].

Effective, resource-efficient methods to disclose routine genetic screening results to patients are needed. Further, developing interventions that improve uptake of genetic services among patients and their families following MMR testing is critical to support broad-based implementation of universal MMR screening for LS. Web-based electronic patient health records (ePHRs) are an increasingly common, low-cost adjunct to health care, and are in-line with patient-centered health care as outlined by the Institute of Medicine[12]. ePHRs have been positively received by patients, and have demonstrated success in facilitating patient-provider communication and improving access to medical information[13–16]. Whether it is acceptable to allow patients direct access via ePHR to a genetic screening result is unknown. Experience from research and commercial testing suggests patients have favorable views of online access to genetic results[17,18].

The current study was developed with the goal of assessing the feasibility and acceptability of a larger study in which routine MMR screening results would be provided via ePHR, accompanied by a multimedia intervention. No previous studies have examined this approach.

## METHODS

### Universal MMR tumor screening at Fox Chase Cancer Center (FCCC)

Immunohistochemical (IHC) staining for MLH1, MSH2, MSH6, PMS2 expression is conducted on all surgically resected CRC and EC pathologic specimens per institutional standard, and all patients receive a hand-out describing universal MMR screening procedures that includes a toll-free number for the Department of Clinical Genetics. Once

testing is complete, a personalized result letter is prepared and provided to the patient's physician, who is then responsible for reviewing it with the patient. All screened patients are tracked prospectively in a clinical database to monitor MMR test completion, provider notification, and follow-up.

## MyFoxChase.com ePHR and study-specific modifications

All Fox Chase patients are given the option to open a MyFoxChase.com account (Figure 1a—Supplementary Material). Patients may use the portal to examine their schedule, laboratory results, and to send communications to staff. Patients receive an automated message sent to a linked email account when new results are available. For the study, several ePHR enhancements were made. The automated email message was adapted to indicate that the result of the universal MMR screening test was available. A dedicated electronic results page was also developed to accommodate study needs (Figure 1b–c—Supplementary Material), containing information about LS, as well as contact information for Clinical Genetics to receive information, schedule an appointment, or speak to a counselor. Adjacent to the result, a "More Information" hotlink allowed participants to obtain more detailed information about LS. Finally, an application to monitor PHR use was created through which study personnel could track visits to the result page and activation of the "More Information" hotlink.

## Recruitment

A schema of study procedures is seen in Figure 2. Patients undergoing resection of a CRC or EC adenocarcinoma were identified using operating room schedules. Patients ≥18 years were approached by study personnel 48–72 hours post-operatively. Internet access and use requirements were screened with three questions, "Do you have Internet access at home, at work, at another location, or through a personal Smartphone?", "Do you use the Internet ≥1 time/week?" and "Do you have an email account that you access ≥1 time/week?" and were required to all be positive before proceeding. Patients meeting Internet requirements were briefly introduced to the study using a prepared script, and were made aware that they would receive a routine genetic screening result for hereditary cancer risk evaluation via their ePHR if they agreed to participate.

## Study procedures

Interested patients provided informed consent, completed a baseline survey, and had a MyFoxChase.com account activated if they did not already have one. Once MMR screening by IHC was completed, the result was posted to the patient's ePHR. Within 36 hours of viewing the result, participants completed a distress measure by telephone. Those who did not view within 3 days received email notifications of a pending result. Within 1 month of result posting, participants completed a follow-up survey. Remote monitoring of result viewing and activation of the "More Information" hotlink continued for 2 months after posting.

### Participant surveys

All participants completed a baseline survey at enrollment. Demographic characteristics including age, gender, race, ethnicity, marital status, educational attainment and household income were queried. Family history among 1st and 2nd degree relatives was collected, including known cancer syndromes. At baseline, within 72 hours of result viewing, and at follow-up, distress was assessed using the *Hospital Anxiety and Depression Scale* (HADS)[19]. *Intention to log-in and view* the MMR result was assessed with one Likert-type item. *Location of log-in* (e.g. home, work) and *surgical provider discussions* of the MMR result were also examined. Internet privacy preferences were measured using a single item, "How concerned are you about the privacy of personal information on the Internet?" with responses ranging from "not at all" to "very concerned". *Perceived risk of hereditary cancer* was assessed by two items adapted from prior research, one asking participants to compare the risk of cancer in family members to an average person, and one examining patient perceptions of carrying an altered gene that caused their cancer[20,21]. Finally, seven Likert-type items (Cronbach's alpha 0.74) assessed *acceptability of the study*, while s*atisfaction with MMR screening* (Cronbach's alpha 0.81) was measured with a 10-item scale, both adapted from our prior research[22–24].

### Statistical methods

We summarized characteristics of all patients, consented patients, and analyzable patients using percentages and frequency tables. We looked for differences between patient groups (those who were not eligible or did not consent versus consented patients; consented but not analyzable versus analyzable patients) using Fisher's exact test. Survey data were summarized using frequency tables, proportions, means, and standard deviations. Feasibility and acceptability thresholds were set by the investigators and were informed by prior behavioral intervention research in cancer patients and low-risk primary care patients[22–25]. ***Feasibility*** was determined by the consent rate among eligible patients, with a rate of ≥50% deemed feasible to complete accrual of a 2–3 center trial within 3 years and by the rate of completion of all study components, with a rate of ≥75% deemed acceptable to support the successful analysis of outcomes in a future study. ***Acceptability*** of the study approach and procedures was determined by a subjective 7-item acceptability measure (see above) adapted from our prior research[22–24]. A mean acceptability rating of 4 or greater in ≥75% participants was deemed a minimum necessary threshold.

## RESULTS

### Recruitment

A recruitment flow diagram is seen in Figure 3, and characteristics of the population available for recruitment (total pool), who signed consent (consented), and who had a result posted to their ePHR (analyzable) are seen in Table 1. Over 6 months, 131 patients with CRC and EC were identified, and 91% were successfully approached during their hospitalization. Overall, 65 (54%) were ineligible at recruitment, over half (34/65, 54%) because of no Internet access or use of the Internet/email <1 time/week. Non-White patients were more likely than White to be ineligible (p=0.009), and those ≥65 were more likely to be ineligible (p=0.035). Other reasons for ineligibility included no diagnosis of cancer

(n=26) and prior MMR screening for LS (n=5). Of the remaining 66 patients, 26% refused participation in the study, many indicating low interest. Patients either refused actively (n=10) at recruitment, or did not contact personnel after taking an informational flyer (n=7). Patients ≥65 years were more likely to refuse participation than those <65 (p=0.003).

### Consented population

The mean age of consented participants was 59 years, and 76% were female. Nearly all were White (Asian ancestry, n=1), and 6% reported Hispanic ethnicity. Educational attainment and income levels were diverse—29% had a high school diploma or less, while 53% were college graduates. The median annual household income was $50–100,000, but was < $50,000 for 22%. Over two-thirds (68%) had ≥1 first-degree relative with cancer–1 participant reported a family history of LS. Perceived risks levels were low to moderate, with nearly 90% estimating CRC risk in relatives as “the same” or “a little higher” compared to others, and over half (61%) estimating the chances that an altered gene had caused their cancer as “not at all” or “a little”. Finally, 69% were “moderately” or “very concerned” about Internet privacy, but there were no differences in degree of concern by demographic factors.

### Feasibility and acceptability

The feasibility thresholds for consent rate and completion rate were met. Overall, 49/66 (74%) eligible patients consented to the study, surpassing the first feasibility benchmark of ≥50% consent rate. From these 49 participants, 13 (27%) were later removed from the study —10 due to insufficient tumor to complete MMR screening, while the first 3 participants enrolled were later removed due to technical failure of the ePHR results display–leaving 36/49 (73%) participants who had their MMR screening result posted to their ePHR. From this group, 31/36 (86%) viewed it, and 31/36 (86%) completed the follow-up surveys [of note–29/36 (81%) both viewed their result and completed the follow-up surveys]. At 81%, this completion rate exceeded the second feasibility threshold of ≥75%. Notably, 5/36 (14%) participants had an abnormal result.

Participant-rated acceptability of the study was high–97% had a mean score of ≥4 on a 7-point scale (Table 2). There was no difference in acceptability by MMR result [normal: mean 6.4 (SD 0.6); abnormal: mean 6.2 (SD 1.4), p=0.7]. Acceptability was higher among married participants (p=0.01). Satisfaction with MMR screening was also high for those receiving either a normal (mean 3.08, SD 0.51) or abnormal result (mean 3.12, SD 0.80). Acceptability (p=0.08) and satisfaction (p=0.006) were borderline and significantly higher among participants who, at baseline, reported higher perceived risk of carrying an altered gene that caused their cancer.

### Analyzable population outcomes

All patients viewed their MMR result by ePHR at home. Married participants (p=0.05) and those with an abnormal result (p=0.06) were more likely and borderline more likely to view their result multiple times [range 2–6 times]. The majority viewed their result <24 hours after posting (22/31, 71%), while others took up to 18 days. The *More Information* hotlink was activated by 25/31 (81%) including 4/5 with abnormal results. Among those with a

normal result, married participants were significantly more likely to activate the *More Information* hotlink (p=0.004). The only participant with an abnormal result who did not activate the *More Information* hotlink had a family history of LS. ePHR use can be seen in Table 3.

Overall 55.6% and 60% of participants receiving normal and abnormal results respectively reported a discussion of their result with their doctor. Among those with an abnormal result: 3/5 contacted Clinical Genetics and 2/3 scheduled an appointment, were counseled and tested—the remaining 2/5 received counseling concurrent with a medical oncology appointment, and 1 pursued further testing, while the other, a 23 year-old with CRC and a family history of LS, has yet to pursue testing. None who received a normal MMR result have pursued genetic evaluation at FCCC.

### Anxiety monitoring

No differences were seen overall between baseline and 72-hour anxiety or for those receiving a normal versus abnormal result. Anxiety levels at follow-up were significantly lower than at baseline (p=0.003).

## DISCUSSION

Under-recognition of LS leads to thousands of preventable cancer diagnoses annually[2,3,7]. Universal tumor-based MMR screening of CRCs and ECs has shifted the paradigm for identifying LS among cancer patients, but it remains uncertain how to efficiently inform patients of the result from this routine screening test for hereditary cancer risk. In order to maximize dissemination potential, novel methods to disclose genetic results to patients must consider resource/time constraints, patient preference, and, the effectiveness of the method in promoting positive downstream behavioral outcomes[2,3,8–10].

The current study examines the provision of granting patients access to universal MMR screening results via ePHR, and was designed to primarily evaluate the feasibility and acceptability of a future clinical trial to evaluate the impact of this novel approach, when *additionally enhanced* by a multi-media educational intervention, on psychological and behavioral outcomes. Secondary goals included assessment of how participants used the ePHR result interface, anxiety related to receipt of the result, and exploratory assessment of psychological factors that may impact desirable downstream behaviors (e.g. uptake of genetic counseling and testing). We demonstrate that a future study is feasible, with a robust consent rate (74%) and study component completion rate (81%) surpassing target thresholds. We nonetheless acknowledge that universal testing protocols at some centers may include a more comprehensive testing approach than the one examined in our pilot study. For example, many centers additionally conduct testing for the *BRAF* V600E mutation in CRC specimens that demonstrate loss of the MLH1 and PMS2 protein staining by IHC, as presence of this mutation is strongly and negatively associated with LS. To improve generalizability of our pilot approach to the community-based cancer setting where onsite molecular pathology facilities may not be available, we chose to focus on the results of the IHC test. However, we believe centers with more comprehensive universal MMR testing protocols could develop ePHR-based notification modules similar to the one

examined here that compile and report results of all elements of testing performed in a summary format. While the reporting of these additional tests may increase the complexity of the final report, patients could be given access to both immediate online supports through *More Information* hot links as was done in the current study as well as clinical support as needed through their providers.

Our findings suggest potential age- and race-related recruitment barriers to studies involving Internet interventions. Non-White, predominantly African American, patients (p=0.009) and patients ≥65 (p=0.035) were more likely to be ineligible for this study due to inadequate Internet access or use. Recent figures from the Pew Research Council show that Internet use is steadily growing among older Americans and minority households, but remains lower than that recorded for younger adults and Whites[26]. Age-related differences in Internet access/use among CRC and EC patients are likely to diminish in the coming years as web-savvy young adults enter middle adulthood. Moreover, high Smartphone use among young, non-White adults further supports the transiency of age- and race-related barriers[27].

Eligible patients ≥65 were also more likely to refuse study participation, and many indicated low interest as their reasoning. Here, low interest is challenging to elucidate, as it may indicate low interest in any research or specifically Internet-based or genetics research. Older patients have been shown to be less likely to participate in therapeutic clinical trials, but this often reflects stringent eligibility criteria and provider biases[28,29]. Interestingly, Internet privacy preferences and acceptability did not vary by age—however, it remains possible that older patients refused participation out of concern for privacy or due to age-related barriers to ePHRs[30,31]. Poor understanding of genetics and negative attitudes towards genetics may also have diminished interest among older patients[32,33].

A growing body of research has begun to examine disclosure of genetic test results via the Internet[34–37]. Our study is innovative in that it examines, in a manner largely impossible to replicate in a high-risk clinic, disclosure of a routine genetic screening result for hereditary cancer predisposition following a cancer surgery in an unselected, average risk population with low awareness of MMR testing and LS. Like a growing number of cancer centers, universal MMR screening at FCCC is performed automatically and does not require informed consent[10,38], and thus the total patient pool for recruitment was unbiased by perceptions of risk or attitudes towards genetics. Further, in an effort to reduce selection bias rooted in perceived risk, our recruiters emphasized the goal of examining a novel route (ePHR) to deliver a standard-of-care genetic screening result (i.e. non-diagnostic).

Patient perceptions of ePHRs are positive and studies have shown robust use, despite concerns about Internet privacy[39,40]. It remains unclear nonetheless whether any genetic results are appropriate for ePHRs, and the research described here breaks new ground in examining a routine genetic screening test for hereditary cancer. Further supporting feasibility, several findings are likely reflective of shifting public attitudes toward genetics and privacy: 86% viewed their MMR result via ePHR, and acceptability ratings were high despite low to moderate perceived genetic risk of cancer, and regardless whether a normal or abnormal result was received. Expanding use of the Internet in the population and favorable public attitudes toward Internet-based medicine and genetics also support the notion that

ePHRs could be dually harnessed to deliver MMR results as well as to facilitate subsequent steps in a patient's evaluation. For example, direct-to-provider messaging and/or scheduling functions embedded in the ePHR could permit patients to request or initiate a consultation with a genetic counselor. In the future, greater integration of ePHRs into clinical practice may also increase efficiency in the transmission of genetic risk information to patients. Patients receiving a normal screening result will benefit from the information that appropriate screening for LS was performed on their tumor but will be less likely to require a lengthy discussion of this result with their provider, as many will have reviewed information made available to them through the ePHR prior to the clinical visit. Those patients receiving an abnormal screening result will, alternatively, have the opportunity to review the materials made available through resources like *More Information* links, supplementing their preparation for the discussion with their provider and allowing for a more focused discussion of their result and suggested next steps.

The study has several important limitations. As discussed earlier, center-specific protocols for universal MMR screening may be different from the one examined here—for example, additional testing for *BRAF* V600E and MLH1 methylation may be reflexively performed after IHC–and thus our approach would need to be carefully adapted to the standard procedures at a given institution. Secondly, our rate of ineligibility was higher than anticipated, resulting in a sample size inadequate to test for race- or ethnicity-based or other subgroup differences in acceptability and outcomes, although these were not primary goals of this research. Thirdly, because of the novelty of the approach and the genetic nature of the information, in-person recruitment and informed consent were felt to be critical, while recognizing that this approach was not fully representative of a real world setting. Indeed, outside of a study, one potential option would be that patients activating an ePHR account would have the ability to establish personal preferences related to access to particular types of information—thus they could elect to either view or not view results that may be considered sensitive like universal MMR screening. The limited information provided about the study during recruitment and informed consent may also have biased the consented population towards patients with greater concerns about hereditary cancer risk. Finally, FCCC is a tertiary care cancer center, and thus the surgical population is not generalizable to a community-based setting; however, the education and income levels among study participants demonstrate notable heterogeneity.

In conclusion, our study supports the notion that routine genetic screening results may be made available to cancer patients via web-based patient-oriented ePHRs. Patients are interested in receiving genetic screening results online, and view this approach as valuable whether they receive a positive or negative result. As the number of genetic markers and tests in medicine grows, further research to study the Internet as a means to provide patients direct access to their genetic results is needed. Based on our findings, a future randomized clinical trial will examine whether a web-based educational intervention, when coupled to the MMR result, may improve critical downstream outcomes of MMR screening including uptake of genetic testing among patients and family members at-risk for LS.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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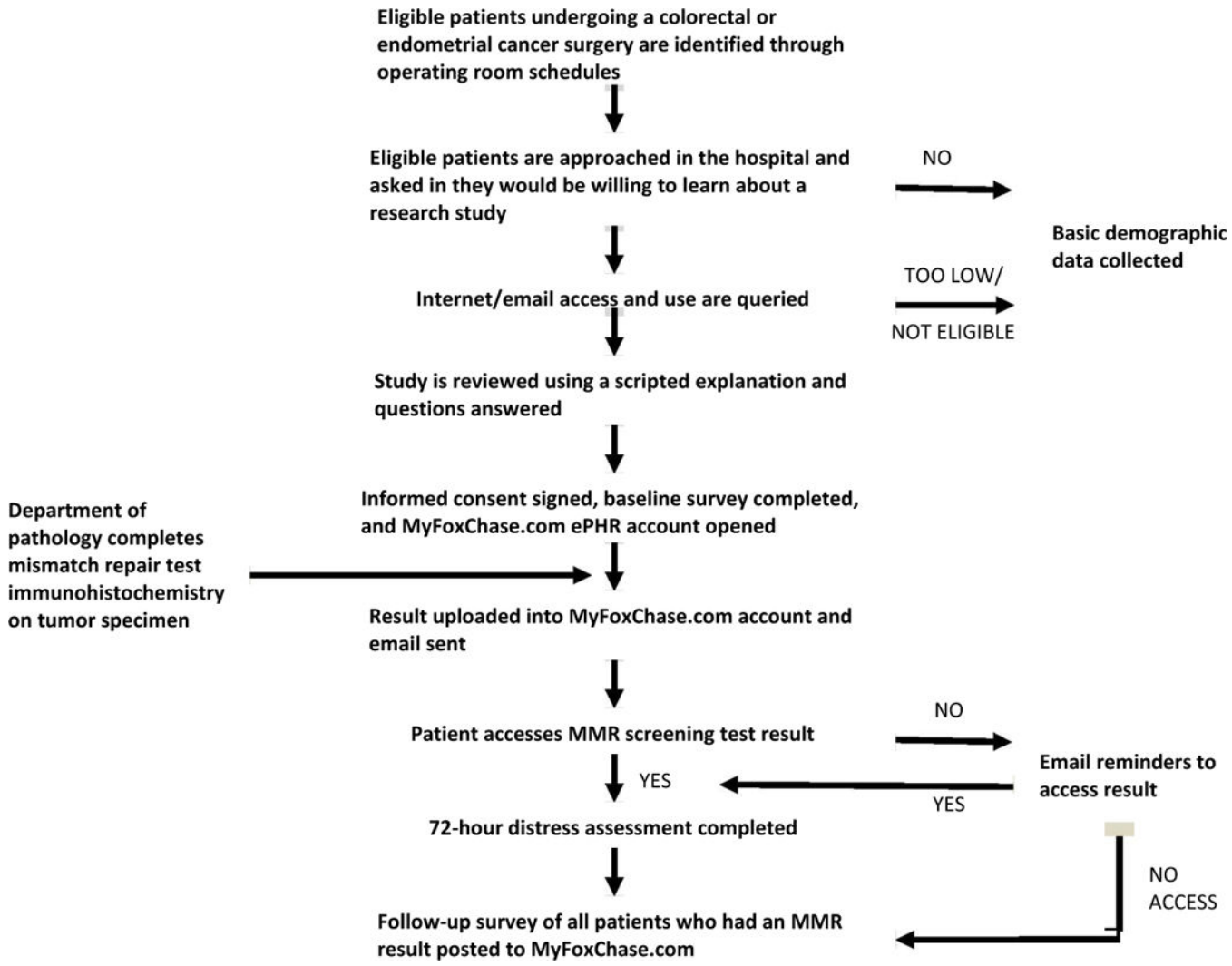


**Figure 2.**
Schema of study procedures

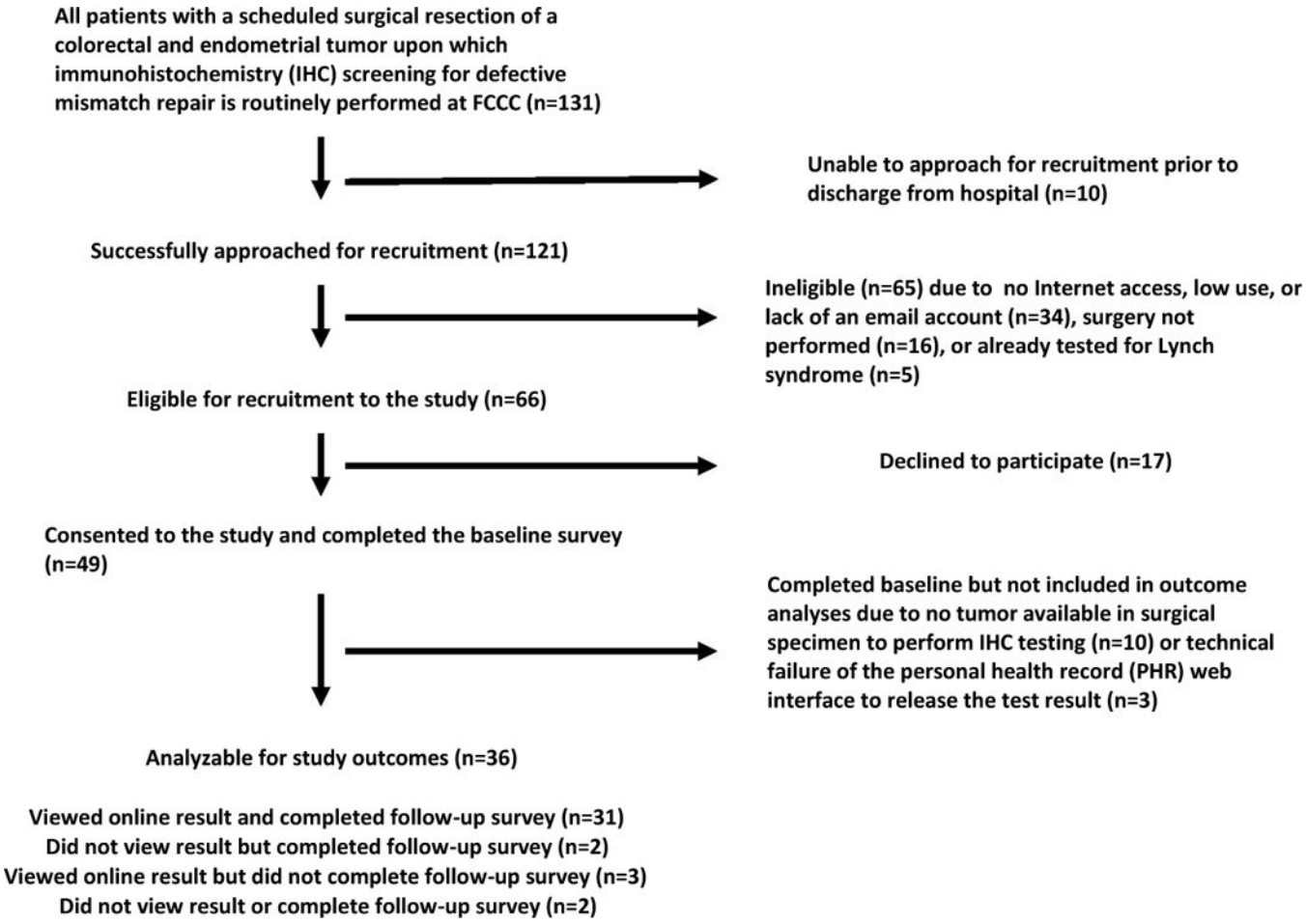


**Figure 3.**
Flow diagram of recruitment

## Table 1

Characteristics of post-operative endometrial and colorectal cancer patients undergoing MMR screening and comparison of non-consented versus consented populations

| Characteristic | Population undergoing clinical MMR screening [total pool] (n=131) | Population agreeing to study participation [consented] (n=49) | Population with a result successfully posted online [analyzable] (n=36) | P-value* Non-consented vs consented |
|---|---|---|---|---|
| | N (%) | N (%) | | |
| **Mean age (SD)** | 61.9 years (12.4) | 57.6 years (12.0) | 57.1 years (12.2) | |
| Age < 65 | 73 (55.7) | 38 (77.6) | 28 (78.8) | <0.001 |
| Age ≥ 65 | 58 (44.3) | 11 (22.5) | 8 (22.2) | |
| **Sex** | | | | |
| Female | 107 (81.7) | 37 (75.5) | 27 (75.0) | 0.17 |
| Male | 24 (18.3) | 12 (24.5) | 9 (25.0) | |
| **Race** | | | | |
| White | 110 (84.0) | 48 (98.0) | 35 (97.2) | 0.002 |
| African American | 17 (18.0) | 0 (0.0) | 0 (0.0) | |
| Asian | 4 (3.0) | 1 (2.0) | 1 (2.8) | |
| **Ethnicity** | | | | |
| Hispanic | 3 (2.3) | 3 (6.1) | 2 (5.6) | 0.046 |
| Non-Hispanic | 129 (97.7) | 46 (93.9) | 34 (94.4) | |
| **Marital status** | | | | |
| Married | NA | 30 (61.2) | 25 (69.4) | |
| Other | NA | 19 (38.8) | 11 (30.6) | |
| **Educational attainment** | | | | |
| High school or less | NA | 14 (28.6) | 11 (30.6) | |
| Some college | NA | 9 (18.4) | 7 (19.4) | |
| College degree | NA | 26 (53.1) | 18 (50.0) | |
| **Annual household income** | | | | |
| <$50,000 | NA | 11 (22.4) | 6 (16.7) | |
| $50,000–$100,000 | NA | 22 (48.9) | 17 (47.2) | |
| >$100,000 | NA | 16 (32.7) | 13 (36.1) | |
| **Family history** | | | | |
| 0 FDR with cancer | | 16 (32.7) | 12 (33.3) | |
| 1 FDR with cancer | NA | 18 (36.7) | 15 (41.7) | |
| ≥ 2 FDR with cancer | NA | 15 (30.6) | 9 (25.0) | |
| Lynch syndrome | NA | 1 (2.0) | 1 (2.8) | |
| **Internet privacy concerns** | | | | |
| “Moderate” or “high” concern | NA | 34 (69.4) | 26 (72.2) | |
| **Tumor pathology** | | | | |
| Colorectal cancer | 63 (48.1) | 30 (61.2) | 23 (63.9) | 0.030 |

| Characteristic | Population undergoing clinical MMR screening [total pool] (n=131) | Population agreeing to study participation [consented] (n=49) | Population with a result successfully posted online [analyzable] (n=36) | P-value* Non-consented vs consented |
|---|---|---|---|---|
| | N (%) | N (%) | | |
| Endometrial cancer | 68 (51.9) | 19 (38.8) | 13 (36.1) | |
| **Perceived risk** | | | | |
| Comparative risk of colorectal cancer for family members | | | | |
| Less | NA | 0 (0.0) | 0 (0.0) | |
| The same | NA | 18 (36.7) | 13 (36.1) | |
| A little higher | NA | 36 (53.1) | 19 (52.8) | |
| Much higher | NA | 5 (10.2) | 4 (11.1) | |
| Chances that an altered gene caused my cancer | | | | |
| Not at all | NA | 4 (8.2) | 2 (5.6) | |
| A little | NA | 26 (53.1) | 19 (52.8) | |
| Somewhat | NA | 15 (30.6) | 12 (33.3) | |
| Very likely | NA | 4 (8.2) | 3 (8.3) | |

*Comparison of those in the total pool who were not consented (N=82) vs those who were consented (N=49). There were no significant (P<0.05) differences between the analyzable cohort (N=31) and those who were consented by not analyzable (N=18).

## Table 2

ePHR use among participants who had an MMR screening result successfully posted to their electronic health record (analyzable population)

| Study component | All participants who had a result posted N/total (%) | Participants who received an abnormal result N/total (%) |
|---|---|---|
| **Result posted to ePHR (n=36)** | 36/36 (100) | 5/5 (100) |
| Result viewed online | 31/36 (86.1) | 5/5 (100) |
| **Result viewed online (n=31)** | **N=31** | **N=5** |
| Viewed 1–2 times | 18/31 (58.1) | 1/5 (20.0) |
| Viewed 3 or more times | 13/31 (41.9) | 4/5 (80.0) |
| **Activation of *More Information* tab** | 25/31 (80.6) | 4/5 (80.0) |
| Did not activate | 6/31 (19.4) | 1/5 (20.0) |
| Activated 1 time | 14/31 (45.2) | 0/5 (0.0) |
| Activated 2–4 times | 11/31 (34.5) | 4/5 (80.0) |
| **Discussion of result with provider** | 20/31 (55.6) | 3/5 (60.0) |

## Table 3

Acceptability and satisfaction among participants completing the follow-up survey, stratified by MMR screening result (n=31)

| Survey items | Normal result N=26 Range 1–7 Mean (SD) | Abnormal result N=5 Range 1–7 Mean (SD) | p |
|---|---|---|---|
| **Acceptability of the study approach** | | | |
| "Did you feel worried or anxious after reading your result on the MyFoxChase.com website?" | 6.7 (0.6) | 6.2 (1.8) | 0.24 |
| "Did you regret that you chose to receive your result on the MyFoxChase.com website?" | 6.8 (0.5) | 6.2 (1.8) | 0.14 |
| "How easy was it to log into the website?" | 6.4 (1.3) | 6.4 (1.3) | 0.99 |
| "Was the information on the website easy for you to understand?" | 5.9 (1.5) | 6.6 (0.9) | 0.32 |
| "Having the MMR screening test is valuable to me." | 6.6 (0.7) | 5.8 (1.6) | **0.07** |
| "Having the MMR screening test result available to me on the Internet is important." | 6.2 (1.0) | 5.8 (1.6) | 0.46 |
| "I would like more of my medical results to be available to me on the MyFoxChase.com website." | 6.2 (1.6) | 6.6 (0.9) | 0.59 |
| Average acceptability | 6.4 | 6.2 | 0.7 |
| **Satisfaction with MMR screening** | | | |
| Average satisfaction | 3.08 (0.05) | 3.12 (0.80) | 0.89 |