

BRIEF REPORT

Patient Perspectives on Delayed Specialty Follow-Up After a Primary Care Visit

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Background: Patients are often referred for important diagnostic tests or consultations after a concerning symptom or finding is identified at a primary care visit, but many referrals are delayed or not completed.

Methods: In this qualitative study, we reviewed electronic health record data to identify patients who did not have timely completion of a recommended referral at an academic primary care hospital-based practice and an affiliated community health center. Using semistructured interview guides, we interviewed 15 patients who did not complete a cardiac stress test within 28 days of a primary care visit associated with a diagnosis of chest pain, and 15 patients who did not complete a dermatology referral within 90 days of identification of a concerning skin lesion.

Results: Thematic analysis highlighted 3 areas: 1) Patients desired clear communication to inform, equip and empower them, 2) Clinician-patient communication regarding a referral's rationale and value is key, and 3) Referral appointment processes were often challenging and/or delayed. Patients wished to understand why they were being referred, the specific value and reason for the referral, and what to expect. We developed a conceptual model describing how the initial clinician-patient communication may influence referral completion.

Conclusions: Failure to close diagnostic loops may be more likely when a patient is not given sufficient meaningful information, particularly if there is health system "friction" that reduces the patient's ability and ease to obtain a timely diagnostic referral appointment. Clinicians should use accessible language to communicate why a diagnostic referral is useful and important for the patient's health, and include a specific optimal time frame. The initial communication and the ease of the subsequent appointment booking both matter, and may compound or mitigate each other's effect. To reduce diagnostic referral failures and delays, clinicians should advocate for consistent appointment booking processes that systematically inform, equip, and empower patients with clear and meaningful referral information and timely appointments. (J Am Board Fam Med 2025;00:000–000.)

Keywords: Communication, Continuity of Patient Care, Diagnostic Errors, Diagnostic Tests, Doctor-Patient Relations, Health Disparities, Health Education, Health Literacy, Patient Care Team, Patient-Centered Care, Patient Engagement, Patient Safety, Practice-Based Research, Primary Health Care, Process Measures, Qualitative Research, Quality Improvement, Quality of Care, Referral, Risk Assessment, Shared Decision-Making

Introduction

Patients often are referred for diagnostic tests or consultations after a concerning symptom or

finding is identified at a primary care visit. Diagnostic errors, defined as failures to establish an accurate and timely explanation for a patient's

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health or communicate that explanation to the patient, affect an estimated 12 million patients annually in the US.^{1,2} Many diagnostic errors emerge as a result of failure to “close a diagnostic loop,” when a diagnostic test or specialty referral is ordered, but delayed or not completed.^{3–5,6} Many factors are known to play a role in a patient’s likelihood to complete screening and specialty referrals, including wait times, distance,⁷ trust in physicians/health care system, insurance and income,⁸ type of practice,⁸ bias,^{9–11} health literacy and preferred language,¹² and staff shortages.^{7,13}

We sought to explore how patients whose diagnostic referral was delayed or not completed experienced the referral process.^{14,15} We hypothesized that the initial clinician-patient communication informs a patient’s path to pursue the steps required for a timely referral and may influence patient motivation.^{16–19} Exploring patient experiences of delayed diagnostic evaluation is essential to the design of systems that achieve better quality and safety.

Methods

Study Design

The study was conducted at 2 primary care clinics affiliated with a large academic medical center in the Northeast US. We reviewed electronic medical record data to identify all patients with delayed or never completed referral orders for dermatology or cardiology as follows:

1) Dermatology referral for a skin lesion identified by a primary care clinician as specifically concerning for melanoma or other high-risk skin cancer, and 2) Cardiac stress test ordered after a primary care visit for chest pain. With input from patient advisors, we designed semistructured patient interview guides (Appendix) to understand these “open” loops, focusing questions on 3 areas: 1) Referral communication; 2) The process of arranging the referral appointment; and 3) Overall barriers and facilitators.

Study Participants, Setting, and Recruitment

Patients received care in 1 of 2 adult primary care clinics: an academic hospital-based clinic and a hospital-affiliated community health center. Staff physicians were mostly internists and a few family physicians. Time frames for closed loops were based on clinical consensus with specialists.

We identified 2 groups with open loops:

1. Dermatology referrals: Patients with a primary care order for urgent dermatology consultation for a concerning lesion, with no completed appointment in hospital system within 90 days.
2. Cardiac stress test referrals: Patients who had a primary care visit with a diagnosis of chest pain (ICD-10 codes R07.9, R07.1, R07.89) with a primary care clinician order for an exercise or chemical stress test with no completed test in hospital system within 28 days.

We obtained consent to contact each patient from their primary care physician. We excluded patients who spoke a language other than English or Spanish. Patients were invited via letter, offered a gift card for participation, and randomly selected for additional phone outreach.

Data Collection and Analysis (See Appendix for Additional Details)

Individual telephone interviews were conducted July to November 2022 (DR, MA, LF); they were recorded and transcribed using Zoom or MS Word and deidentified. Spanish interviews were conducted by a bilingual clinician and professionally translated. Our initial codebook was developed deductively, based on the literature. Using NVivo12 software, we coded transcripts to explore key themes regarding referral communication and processes.²⁰ The core research team reviewed several transcripts and iteratively added and modified codes, reaching consensus for a finalized codebook. One researcher coded all 30 interviews. A second, blinded coder independently reviewed 20% of the transcripts (reliability kappa 0.89, see Appendix.) Emergent themes were developed and discussed iteratively by the research team and used to develop a conceptual framework.

Results

We identified 162 patients with delayed or not-completed dermatology referrals, and 143 patients with delayed or not completed stress tests (Table 1) and interviewed 30 subjects from the 2 groups (Table 2) whose preferred spoken language was English or Spanish (Figure 1). (Only 1 was from CHC). (Figure 1 and Table 2.) Thematic analysis of interviews highlighted that: 1) Clear communication equips and empowers patients as they negotiate referrals 2) Clinician-patient communication about the referral is key, especially regarding its rationale 3)

Table 1. Demographics of Patients with Dermatology and Stress Test Referral Open Loops* (Total n = 305)

	Dermatology Open Loops (n = 143)	Stress Test Open Loops (n = 162)
Mean age, n (SD)	57.9 (15.7)	55.8 (11.7)
Gender, n (%)		
Male	78 (55.5)	65 (40.1)
Female	65 (45.5)	97 (59.9)
Race, n (%)		
White	112 (78.3)	78 (48.1)
Black	15 (10.5)	54 (33.3)
Asian	5 (3.5)	11 (6.8)
Other/Mixed race	6 (4.2)	16 (9.9)
Unknown	5 (3.5)	3 (1.9)
Ethnicity, n (%)		
Hispanic	11 (7.7)	21 (13.0)
Non-Hispanic/Not indicated	132 (92.3)	141 (87)
Preferred spoken language, n (%)		
English	132 (92.3)	138 (85.2)
Spanish	2 (1.4)	9 (5.6)
Cape Verdean	2 (1.4)	5 (3.1)
Other	6 (4.2)	10 (6.2)
Unknown	1 (0.7)	
Education, n (%)		
Less than high school	6 (4.2)	11 (6.8)
High school	44 (30.8)	67 (41.4)
College	71 (49.7)	63 (38.9)
Unknown	22 (15.4)	21 (13.0)
Health insurance, n (%)		
Commercial	68 (47.6)	73 (45.1)
Medicaid	26 (18.2)	47 (29.0)
Medicare	46 (32.2)	31 (19.1)
Unknown	3 (2.1)	11 (8.6)
Site of care, n (%)		
Hospital based clinic	136 (95.1)	147 (90.7)
Community health center	7 (4.9)	15 (9.3)

*Dermatology referrals for lesions suspicious for skin cancer not completed at 90 days, and stress test referrals for chest pain not completed within 28 days based on EHR clinician orders and EHR documented appointments.

Abbreviations: SD, standard deviation, EHR, electronic health record.

Referral appointment processes were often challenging and delayed. Domains and Themes are summarized in Table 3.

Cross-Cutting Theme of Clear Communication as Empowering

A dominant theme was that patients wanted to be better equipped to navigate a diagnostic referral by having

clear meaningful information: understanding more would help them feel in control, less anxious, and more empowered. Most wanted more practical information regarding what to expect and understand health information better with use of “regular” language.

The Importance of the Initial Clinician-Patient Communication

Patients generally “agreed” with being referred. They understood that the clinician was seeking

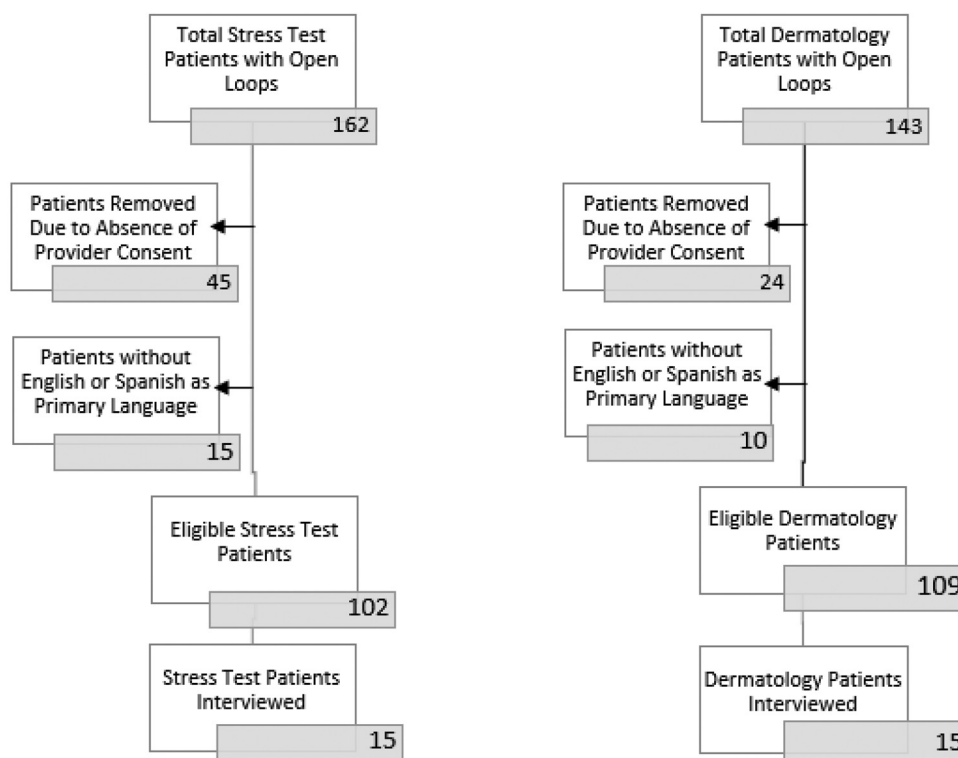
Table 2. Demographics of Interviewed Patients (Recruited from Patients with Open Loops)

	Dermatology Open Loop (n = 15)	Stress Test Open Loop (n = 15)
Mean age, (SD)	65.0 (11.9)	55.0 (9.8)
Gender,* n (%)		
Male	9 (60.0)	7 (46.7)
Female	6 (40.0)	8 (53.3)
Race-Ethnicity* n (%)		
White	14 (93.3)	6 (40.0)
Black	–	3 (20.0)
Asian	1 (6.7)	–
Other/More than one race	–	1 (6.7)
Hispanic	–	5 (33.3)
Language Spoken at Home* (some patients spoke more than one), n		
English	15	10
Spanish	–	6
Cape Verdean/Kriolu	–	1
Other language	2	3
Education,* n (%)		
Some high school	–	–
High school	–	1 (6.7)
Some college	5 (33.3)	5 (33.3)
College	2 (13.3)	4 (26.7)
Post-college	8 (53.3)	4 (26.7)
Primary insurance, n (%)		
Commercial	4 (26.7)	7 (46.7)
Medicare	7 (46.7)	4 (26.7)
Medicaid	4 (26.7)	4 (26.7)
Confidence filling out forms, n (%)		
Not very confident	–	–
Confident	8 (53.3)	5 (33.3)
Very confident	7 (46.7)	10 (66.6)
Site of care, n (%)		
Hospital based clinic	15 (100.0)	14 (93.3)
Community based clinic	–	1 (6.7)

*Elicited during interview.

Abbreviation: SD, standard deviation.

Figure 1. Qualitative interview enrollment flow chart.



additional information for a more definitive diagnosis, but some did not know the specific diagnoses being considered, for example, that concern about skin cancer motivated the dermatology referral. Many wanted more transparency about risks. Some were unfamiliar with medical terms and jargon, such as “stress” test.

Patients reported some uncertainty surrounding the urgency or recommended time frame for the referral. Some inferred nonurgency because the test was not booked immediately. Some believed a referral was no longer necessary if symptoms resolved. A few recalled feeling anxiety about potentially serious diagnoses and delays. Many described strong and trusting relationships with their primary care doctor. Several expressed less trust in health system reliability.

Challenges Related to Arranging a Referral Appointment

The process of scheduling appointments was described as challenging, and delays were universal. Patients reported long call holds and limited appointments. On concluding primary care visits,

many were given multiple and variable instructions: some tasks required them to initiate a call, and others to await one, causing uncertainty. Remembering to call was difficult for some, some were “not contacted,” and “life got in the way.” Some said the health system seemed overburdened and unreliable.

Referral Conceptual Model

Based on literature^{21,22} and our findings, we developed a conceptual model (Figure 2). Patients “construct” meaning from what they hear in the initial communication through a lens that is affected by their broader context, the relationship with their clinician, and health literacy. They interpret and construct meaning and valence for the referral, which informs their behavior as they confront barriers. When a clinician shares the referral rationale in empathic and clear language, explores concerns, and explains risks and benefits (A), the patient is more equipped and motivated to persist through subsequent difficulties (B). Conversely, a poor explanation combined with a difficult appointment-booking system may result in an open loop (C).

Table 3. Domains, Major Themes, and Representative Quotes Regarding Diagnostic Referrals

Domain	Theme	Illustrative Quote
Cross-Cutting	Clear Communication as Empowering	<i>They sometimes (ask): ‘Do you have any questions?’ But some people don’t really know what to ask. . . , about (the topic). I say, no, I don’t have no question, because I don’t know what to ask. And when I get home, some people ask me questions. I say, bmm. . . it’s true: I should have asked that. You know . . . they should give more information.</i>
Importance of Clinician-Patient Communication about the Referral	Agreement with Referral	<i>My primary care physician took a look at it and said she would feel much better having a dermatologist look at it, and we both agreed that she would make a . . . referral</i>
	Unclear Rationale for Referral	<i>They said they needed to do a stress test to see what was going on. To define what was going on. But they didn’t explain what the test is, what they were going to do, nothing. I just got there and I went to the machine and you’re going to do this, you’re going to do that, that’s it. She felt that she couldn’t tell me exactly what was going on and that the expertise of a dermatologist would probably be better.</i>
	Ambiguous Urgency and Time Frame	<i>I felt that they never thought it was a life-threatening situation. So it was more like: Is (it) convenient for you to have this done? I kind of had a sense that it wasn’t extremely urgent, or else he would have said, like go to the emergency room right now.</i>
	Desire for Transparency and Clear Language	<i>I would ask them to be 100% transparent and communicate to the best of their knowledge how risky the condition is, to allow me to figure out how much concern I should or should not have. If someone could have said: “Well, here’s the process that we go through. You’ll be examined, your physician will be so and so, followed by discussion of what the physician perceives to be the cause of my skin outbreaks and comment about how concerned I should be about them.” But I didn’t get any of that stuff. I would’ve appreciated more information about it. . . in layman’s terms”</i>
Challenges in Arranging the Referral	Emotional Context- Fears, Concerns, and Anxiety	<i>My worry was the injection they were going to give me (for the stress test) (translated from Spanish) In other words, as soon as you run the test I’m scared. The essential thing is that the distance between point A and point B be as short as possible, even if B is bad news. I just can’t handle the wait. My primary said that probably is nothing to be scared of. I was calm, you know, but I feel scared, because when it’s the heart it’s the heart. You don’t know. . . ”</i>
	Health System Delays and Challenges	<i>They tell you (that) you may have skin cancer, and it’s taken forever to get an appointment” It just seems like the medical professionals are overwhelmed and short staffed. There’s a long wait, you know. . . it shouldn’t be that way.</i>
	Trust in Physician and Health System	<i>They sometimes act like they don’t believe what you’re saying</i>
	Logistical and other Barriers	<i>The only problem (is distance) and it’s our fault because we live far away. . . So it’s logistics. So I’m definitely going to pursue it. It’s just you know, life got in the way. (. . .)Dermatology calling me would have made it easier.</i>
	Inconsistent Referral Processes, Diffuse Responsibility, and Uncertainty	<i>I thought that he was gonna take care of booking it, and then I found out later that he (. . .) wanted me to actually do the booking, . . . the call. There were. . . at least five things that I was responsible to get taken care of. I guess it wasn’t clear enough. . . All the other things were taken care of by the office.</i>

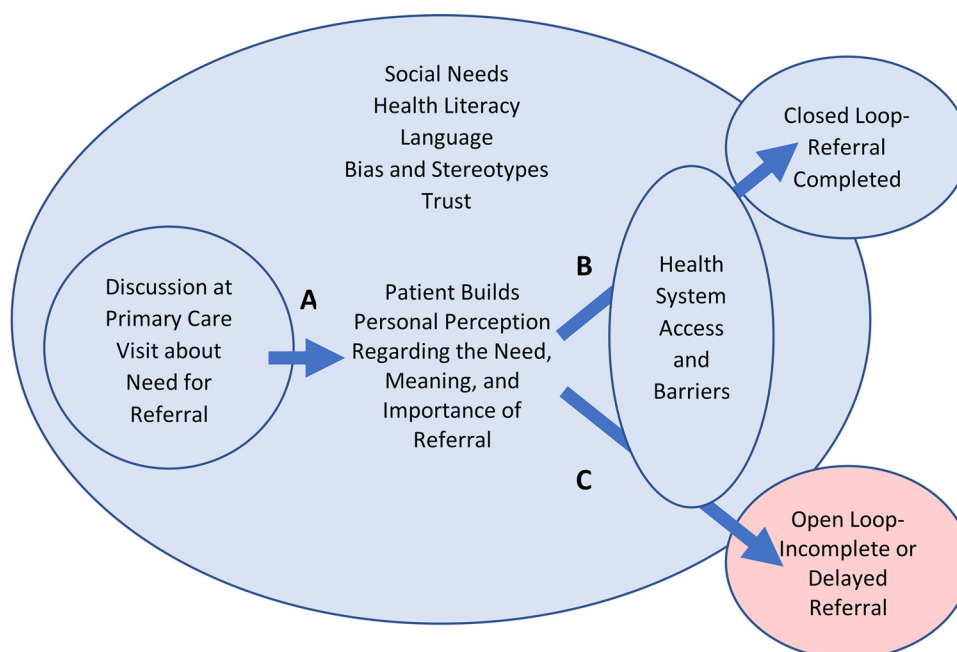
Discussion

This qualitative study highlights the importance of empowering patients with clear communication regarding a diagnostic referral’s rationale and how to schedule it. Patients may not always receive meaningful information as they weigh a referral’s priority. While most understood there was diagnostic uncertainty, some were unsure how a timely referral might matter, which may impact their

decision to pursue it. Studies about decisional conflict show that enabling decision making is heavily dependent on feeling informed, certain, and supported, and being clear about one’s values to feel like an effective decision is being made.^{21,22}

Our findings have implications for future interventions and should be considered in the broader context of systems design, engineering and improvement.^{23–26} Patients need to know what the stakes are.

Figure 2. Conceptual model for patient experience of diagnostic referral communication.



Notes: Patient interprets the clinical communication through the lens of trust, health literacy, lived experience of structural barriers, and their broader social and cultural context. Patient then constructs their own meaning, valence, and value of the referral, which they carry with them as they confront subsequent barriers.

Indeed, the initial communication is key: the clinician is uniquely positioned to help the patient interpret the “value” of the referral. But the current approach to referrals relies too heavily on a busy clinician who may not always sufficiently explain the rationale, and the patient may not recall the details.¹⁶ In addition, clinicians may not know the logistics and availability for all referrals. Completion rates may improve by creating referral processes that reliably equip the patient with main reason for referral, level of urgency and recommended time frame, how to book, and what to expect. In addition, easier booking, self-scheduling, appointment assistance and reminders may help. Finally, enabling more patients to access their notes may remind some why they were referred and thereby improve completion.¹⁴ Future studies should explore clinician perspectives, and how patients weigh referrals against other priorities.

This study took place during the COVID-19 pandemic era, influencing patient experiences. All had open loops; volunteer bias may have influenced responses. Most interviewed patients were from a single clinic. Patients with less education, who

speak other languages, or who identify as Black were less represented in dermatology interviews. Timing of interviews potentially limited recall, and were only in English and Spanish.

Conclusion

Among patients who experienced failure to close a timely diagnostic loop in dermatology or cardiac stress testing, most wished for better communication and easier appointment booking. Diagnostic loop failure may be more likely when a patient is not given sufficient meaningful information, particularly if there is health system “friction” that impairs the patient’s ability to complete a referral.^{18–21} Clinicians should use accessible language to communicate why a diagnostic referral is useful and important for the patient’s health, and include a specific optimal time frame. The initial communication and the ease of the subsequent appointment booking both matter, and may compound or mitigate each other’s effect. To reduce diagnostic referral failures and delays, clinicians should advocate for consistent appointment booking processes that systematically inform, equip, and empower

patients with clear and meaningful referral information and timely appointments.

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To see this article online, please go to: <http://jabfm.org/content/00/00/000.full>.

References

- Singh H, Meyer AN, Thomas EJ. The frequency of diagnostic errors in outpatient care: estimations from three large observational studies involving US adult populations. *BMJ Qual Saf* 2014;23:727–31.
- Singh H, Schiff GD, Graber ML, Onakpoya I, Thompson MJ. The global burden of diagnostic errors in primary care. *BMJ Qual Saf* 2017;26:484–94.
- Pagani K, Lukac D, Olbricht SM, et al. Urgent referrals from primary care to dermatology for lesions suspicious for skin cancer: patterns, outcomes, and need for systems improvement. *Arch Dermatol Res* 2023;315:1397–400.
- Forrest CB, Shadmi E, Nutting PA, Starfield B. Specialty referral completion among primary care patients: results from the ASPN Referral Study. *Ann Fam Med* 2007;5:361–7.
- White T, Aronson MD, Sternberg SB, et al. Analysis of radiology report recommendation characteristics and rate of recommended action performance. *JAMA Netw Open* 2022;5:e2222549.
- Campbell KA, Sternberg SB, Benneyan J, et al. Completion rates and timeliness of diagnostic colonoscopies for rectal bleeding in primary care. *J Gen Intern Med* 2023;39:985–91.
- Patel MP, Schettini P, O’Leary CP, Bosworth HB, Anderson JB, Shah KP. Closing the referral loop: an analysis of primary care referrals to specialists in a large health system. *J Gen Intern Med* 2018;33:715–21.
- El AyadiDesai HA, Jones RE, et al. Referral rates vary widely between family medicine practices. *J Am Board Fam Med* 2021;34:1183–8.
- Hoffman AS, Lowenstein LM, Kamath GR, et al. An entertainment-education colorectal cancer screening decision aid for African American patients: a randomized controlled trial. *Cancer* 2017;123:1401–8.
- Kne A, Zierhut H, Baldinger S, et al. Why is cancer genetic counseling underutilized by women identified as at risk for hereditary breast cancer? Patient perceptions of barriers following a referral letter. *J Genet Couns* 2017;26:697–715.
- Mwansa H, Lewsey S, Mazimba S, Breathett K. Racial/ethnic and gender disparities in heart failure with reduced ejection fraction. *Curr Heart Fail Rep* 2021;18:41–51.
- Landon BE, Onnela JP, Meneades L, O’Malley AJ, Keating NL. Assessment of racial disparities in primary care physician specialty referrals. *JAMA Netw Open* 2021;4:e2029238. Published 2021 Jan 4.
- Agunwamba AA, Zhu X, Sauver JS, Thompson G, Helmueller L, Finney Rutten LJ. Barriers and facilitators of colorectal cancer screening using the 5As framework: a systematic review of US studies. *Prev Med Rep* 2023;35:102353.
- Bell SK, Amat MJ, Anderson TS, et al. Do patients who read visit notes on the patient portal have a higher rate of “loop closure” on diagnostic tests and referrals in primary care? A retrospective cohort study. *J Am Med Inform Assoc* 2024;31:622–30.
- Amat MJ, Anderson TS, Shafiq U, et al. Low rate of completion of recommended tests and referrals in an academic primary care practice with resident trainees. *Jt Comm J Qual Patient Saf* 2023;50:177–84.
- Weinstein E, Ragazzoni L, Burkle F, Allen M, Hogan D, Della Corte F. Delayed primary and specialty care: the coronavirus disease-2019 pandemic second wave. *Disaster Med Public Health Prep* 2020;14:e19–e21.
- Akanuwe JNA, Black S, Owen S, Siriwardena AN. Communicating cancer risk in the primary care consultation when using a cancer risk assessment tool: qualitative study with service users and practitioners. *Health Expect* 2020;23:509–18.
- Zuckerman KE, Nelson K, Bryant TK, Hobrecker K, Perrin JM, Donelan K. Specialty referral communication and completion in the community health center setting. *Acad Pediatr* 2011;11:288–96.
- Dahm MR, Cattanaach W, Williams M, Basseal JM, Gleason K, Crock C. Communication of diagnostic uncertainty in primary care and its impact on patient experience: an integrative systematic review. *J Gen Intern Med* 2023;38:738–54.
- Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. *PLoS One* 2020;15:e0232076.
- Turcotte S, Guerrier M, Labrecque M, et al. Dyadic validity of the Decisional Conflict Scale: common patient/physician measures of patient uncertainty were identified. *J Clin Epidemiol* 2015;68:920–7.
- Pecanac KE, Brown RL, Kreamsreiter HB. Decisional conflict during major medical treatment decision-making: a survey study. *J Gen Intern Med* 2021;36:55–61.
- Nehls N, Yap TS, Salant T, et al. Systems engineering analysis of diagnostic referral closed-loop processes. *BMJ Open Qual* 2021;10:e001603.

24. North F, Nelson EM, Buss RJ, Majerus RJ, Thompson MC, Crum BA. The effect of automated mammogram orders paired with electronic invitations to self-schedule on mammogram scheduling outcomes: observational cohort comparison. *JMIR Med Inform* 2021;9:e27072.
25. Matulis JC, McCoy R. Patient-centered appointment scheduling: a call for autonomy, continuity, and creativity. *J Gen Intern Med* 2021;36:511–4.
26. Schiff GD, Kroenke K, Lambert BL, Sanders L, Sheikh A. Ten principles for more conservative, careful diagnosis. *Ann Intern Med* 2019;170:823–4.

Appendix

Full Set of Identified Codes

Risk Communication
Agreement
Attention
Ideas for Improvement
Less Serious Explanation Offered
Main Cause of Open Loop
Other Causes of Open Loop
Rationale
Symptom Resolution
Uncertainty and Confusion
Urgency
Fears, Concerns, Anxiety
System Barriers
COVID
Ideas for Improvement
Main Cause of Open Loop
Other Causes of Open Loop
Patient Perception of Appointment Booking Process
Patient Did Not Successfully Book Appointment <ul style="list-style-type: none"> • <u>Forgot</u> • <u>Could not reach provider's office</u> • <u>Was not contacted by provider's office</u> • <u>Unclear about steps needed to book</u> • <u>Needed someone else's input/proxy medical decision maker</u> • <u>Delay</u>: general mention of the process being delayed/stalled or there being an issue getting an appointment in a timely manner <ul style="list-style-type: none"> ○ <u>Internal Delay</u>- set-backs from the providers office, lack of sooner appointments available ○ <u>Personal Delay</u>

Physician and Healthcare Trust
Social Determinants of Health
Transportation/Logistics Getting To/From Appointment
Uncertainty and Confusion
Utilization of the Patient Portal

Interview Guides

Stress Test Referral Interview Guide

Thank you for taking the time to meet with me. This interview will take about 30 minutes or less. I will take notes and record the conversation so we can transcribe it accurately. Is that ok? I will not use your name or any information that can identify you in this research. The recording will be deleted within 3 months after the interview. You can ask me to skip or move on if I ask you any question that you would prefer not to answer. You are also welcome to ask us to go back into the recording and delete anything you would prefer not to be recorded. Is it okay with you if I begin recording now? [Turn on recorder]

Today's date is _____.

Our research team is interested in learning from your experience with a medical symptom with (rectal bleeding, or chest pain) at (insert site name) and the plans for follow up. First, we will discuss what happened after you reported a particular symptom or concern. Then, we will ask about your experience with any testing, communication, and any recommended follow up. At the end, we will close the interview with some demographic questions.

INITIAL EVALUATION

In the past year, (share month/year) you had a visit in which you and the Doctor or NP talked about abdominal pain/chest pain/ rectal bleeding

- a. Did you think the medical team did a good job evaluating your symptom?

RISK COMMUNICATION:

- a. CAUSE:
 - i. Did they explain to you what they thought was causing your symptoms?
 - ii. Was the explanation clear or confusing?
- b. FURTHER TESTING RATIONALE:
 - i. Was any further testing recommended? Did they say **why** you needed another test?
 - ii. Did they explain things in ways that made sense to you/you could understand? Did you feel you were told enough to help you make a decision about getting any follow up tests?
- c. FEARS AND CONCERNS and TRUST:
 - i. Did you have any fears or concerns about the follow up tests? How were they addressed?
 - ii. What would have helped you or someone else manage fears or concerns about the follow up tests?
- d. UNCERTAINTY:
 - i. Did you feel there was any uncertainty in the doctor's/nurse's assessment?
 - ii. What does it mean to you if a doctor says they are not sure what is causing your symptoms? How does that make you feel?
- e. SERIOUS MEDICAL CONCERNS:
 - i. If a doctor is worried that there is a possibility that something serious is causing a patient's symptoms, how much should they explain and talk about it with a patient?

ACTION STEPS:

- f. Did you feel you understood **clearly what you needed to do** after the visit to get the follow up test?
- g. **Who** explained the next steps? Did anyone explain how you would find out the results of any tests? Did they give you any written instructions, or was it just said verbally?
- h. Was it clear **how** to get the follow up test/colonoscopy/visit? Who was supposed to book it?
- i. **Was it easy** to get the follow up? Were there any barriers to getting the follow up? What would have made it easier? Did language/communication barriers influence your experience?
- j. Did you get a sense of how **urgent** it was for you to get the follow up? Days? Weeks? Months?
- k. Were you referred to a specialist, and if so, did you see the specialist? Why or why not?

FACTORS FOR DECISION:

Does anyone help you make medical decisions?

If so, did their perspective affect your decision regarding follow up?

Can you explain how?

If you did not get a follow up test/referral/Colonoscopy, what was the main reason you didn't get that follow up?

(Interviewer circles the one that is most appropriate to answer, can circle 2 if both given in response to this question or prompt)

- I didn't know I needed to follow-up/get colonoscopy/test
- I didn't understand why I needed to follow up/get test/colonoscopy
- I had fears or concerns about the doing the test/colonoscopy
- I was worried about getting bad news
- It was difficult to book the appointment or travel there
- I planned to follow up, but then forgot
- I was going to follow up, but had not gotten to it yet or missed the appointment
- Something else (write in what pt said)

4) IDEAS FOR IMPROVEMENT:

What might have been a better way to help you get the follow up that was recommended to you? What would help you the most to get a needed follow up?

(Interviewer circles the voiced answers)

- More explanation about why I need the test/opportunity to ask more questions
- Have follow up appointment booked for me by someone else/at the visit
- Receive reminders about the appointment
- Be able to book online
- Sooner appointment for follow up test/colonoscopy
- Someone to help me get through it
- Something else (write in what pt said)

A. Demographic Information

As mentioned, we want to ask some demographic questions so that we can understand more about our respondents. If you prefer not to answer any of these questions please feel free to let me know that you prefer not to answer.

1. What is your gender identity? Female Male NonBinary Prefer not to share
2. How do you identify, in terms of race and ethnicity?
3. What languages do you speak at home?
4. What is the highest level of school/education you completed?
5. When you go to a doctor's office, how confident are you in filling out medical forms by yourself?

Thank you for speaking with me.

Dermatology Referral Interview Guide

Thank you for taking the time to meet with me. This interview will take 30 min or less. I will take notes and record the conversation so we can transcribe it accurately. Is that ok? I will not use your name or any information that can identify you in this research. The recording will be stored for 3 months: after that it will be destroyed. You can ask me to skip or move on if I ask you any question that you would prefer not to answer. You are also welcome to ask us to go back into the recording and get rid of anything you would prefer not to be recorded. Is it okay with you if I begin recording now? [Turn on recorder]

Today's date is _____.

In this interview I will first ask you some questions around your experience with dermatology referral at [insert site] and then transition into demographic questions. Our aim is to learn more about your experience with hearing that you need a referral to dermatology, the process for getting a dermatology appointment, and any barriers that you encountered.

A. Dermatology Referral

I understand that you were referred to a dermatologist for skin abnormality. Do you recall being referred to a dermatologist? We wish to understand the process.

Can you tell us more about why a referral was recommended? What were they worried about? Did they explain why they recommended the referral?

Did you have any fears or concerns about seeing the specialist? Did you agree that a referral was a good idea? Why or why not?

Did they explain how soon the appointment needed to happen, whether it was urgent?

Can you tell us about what your PCP said about how the appointment would get booked? What happened after the PCP told you that you needed to see a specialist? Was there any delay? What prompted that delay? What was the process that was followed?

Possible prompt questions:

- i. How did the appointment get scheduled? Did it get scheduled by someone in the practice or did you have to schedule it yourself? Language or communication barriers? (Did you feel that you could explain to the person on the phone why you needed the appointment?)
- ii. Was it difficult to schedule, or were there obstacles to getting it scheduled? What would be the best way to do this in your view?
- iii. How long did you have to wait for the appointment? Did the time you have to wait until the appointment affect you in any way?
- iv. Was the specialist conveniently located for you?
- v. Did you have any concerns related to your insurance?

Is there anything else you think we should know about what might make it harder or easier for someone like you to get a follow up appointment?

B. Demographic Information

As mentioned, we want to ask some demographic questions so that we can understand more about how our respondents. If you prefer not to answer any of these questions please feel free to let me know that you prefer not to answer.

6. What is your gender identity?
7. How do you identify in terms of race and ethnicity?
8. What languages do you speak at home?
9. What is the highest level of school/education you completed?
10. When you go to a doctor's office, how confident/comfortable are you filling out medical forms by yourself?

If you did not have a Dermatology visit, what was the main reason you didn't get follow up?

(Interviewer circles the one that is most appropriate to answer, can circle 2 if both given in response to this question or prompt)

I didn't know I needed to follow-up/get colonoscopy/test

I didn't understand why I needed to follow up/get test/colonoscopy

I had fears or concerns about the doing the test/colonoscopy

I was worried about getting bad news

It was difficult to book the appointment or travel there

I planned to follow up, but then forgot

I was going to follow up, but had not gotten to it yet or missed the appointment

something else (write in what pt says)

4) IDEAS FOR IMPROVEMENT:

What might have been a better way to help you get the dermatology that was recommended to you? What would help you the most to get a needed follow up?

(*Interviewer circles the appropriate answer(s) that the patient names)

- A. More explanation about why I need the test/opportunity to ask more questions
- B. Have a follow up appointment booked for me by someone else
- C. Receive reminders about the appointment
- D. Be able to book online
- E. Sooner appointment for follow up test/colonoscopy
- F. Someone to help me get through it
- G. Something else (write in what pt says)

Thank you for speaking with me.

Inter-Rater Reliability with Blind Coder

Transcript	Inter Rater Reliability
A	0.87
B	0.93
C	0.88
D	0.9
E	0.92
F	0.92
G	0.83
Average	0.89