Preparing for Personalized Medicine: Improving Genetic Screening Resources for Primary Care Providers

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Abstract

Preparing for Personalized Medicine: Improving Genetics Screening Resources for Primary Care Providers

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Due to the expansion of genetics testing and the current strain on the genetics services workforce, Primary Care Providers (PCPs) will have to play a growing role in the management of of patients with genetics needs. However, PCPs do not have the knowledge or support to take on this role. This study used semi-structured interviews with 12 PCPs in the Pacific Northwest region of the United States to gather information on the types of resources PCPs believe would best support them in this role. PCPs in this study reported needing organized and prioritized information, accessible, easy-to-use screening tools, supplementary support from specialists, and, finally, accessible and understandable patient-facing resources. These findings can inform the development of an expanded suite of genetic screening-related resources for PCPs.

Introduction

The current expansion in genetic technology has placed a strain on the medical genetics work force. Job vacancies indicate that there are not sufficient medical school graduates choosing genetics as a specialty to meet demand (Maiese et al., 2019). Indeed, wait times over 3 months for a nonemergency appointment with a medical geneticist have increased by 19% since 2003 (Maiese et al, 2019). The genetic counselor workforce is similarly stretched, further limiting access to genetics services in many cases (Stoll et al., 2018). Until this workforce gap is closed, primary care awareness and support will be critical in ensuring timely diagnoses and care. Genetics specialists will increasingly need to rely on primary care providers (PCPs) to evaluate patients for heritable disease risk, order tests, and counsel patients (Carroll et al., 2019).

Decades ago, PCP's reported believing that their role in genetic medicine was solely to take family histories and refer patients on to genetic specialists (Watson et al., 1999). Currently, PCPs still report high involvement in these aspects of genetic medicine, while others view evaluating the usefulness of genetic tests and discussing the risks, benefits, and limitations of tests as part of their expanding role in genetic medicine (Carroll et al., 2019).

However, PCPs often do not have adequate knowledge or support to act in these roles. Several studies spanning the last two decades have demonstrated a lack of knowledge, confidence, and resources amongst PCPs in regard to genetic medicine (Greendale and Pyeritz, 2001; Baars et al., 2005; Chambers et al., 2015). In a 2019 study, PCPs reported low confidence even in skills they practice often, such as taking a family history (Carroll et al., 2019). It is clear that a holistic approach must be taken to bridge this gap; improvements should be made in

education, health systems, and physician resources. Previous studies have recommended integration of genetics results into electronic health records (EHR) as a form of clinical decision support and system level change (Manolio et al., 2013; David et al., 2015). A recent survey study identified medical databases, Google (and related search engines), and local specialists as resources PCPs currently use for genetics information and identified genetics clinics' contact information, testing guidelines, and contact with a geneticist via phone or email as desirable resources (Carroll et al., 2019).

Preparing PCPs for genetic medicine must begin with an assessment of their unique needs. Resources must be developed within the context of PCPs' clinical workflow and priorities. While other studies have suggested a variety of potential resources to assist PCPs, little is known about what resources PCPs value and desire. This study utilizes qualitative interviews with 12 primary care physicians in the Pacific Northwest region of the United States to gather rich data about resources PCPs currently value for information on genetic cancer screening of patients, what improvements they wish to see, and what new resources they wish to see in the future.

Methods

This study was conducted as a secondary qualitative analysis of previously collected conducted and transcribed semi-structured interviews, as described below. The secondary analysis was conducted from February to April 2020.

Participant Recruitment

Twelve interviews were conducted with clinicians whose main responsibilities were primary care and/or family medicine. Colleague recommendations and snowball sampling were used to identify participants and ensure that the pool of participants extended beyond the study team's professional networks. All participants were located in the Pacific Northwest region of the United States.

Table 1: Participant Characteristics

Gender		
	Male	4
	Female	8
Race/Ethnicity		
	White	9
	Black	0
	Asian/Pacific Islander	3
Medical Specialty		
	Family Medicine	10
	Internal Medicine	1
	Primary Care	1
Years in Practice		
	1-5	5
	6-10	2
	11+	5
Practice Setting		
	Academic	8
	Community	4

Data Collection

Interviews were conducted by phone from September 2017 to March 2018 using a semi-structured interview guide that explored the roles PCPs play in genetic medicine, as well as the resources PCPs had and needed for genetic medicine, through two different patient-centered scenarios (Appendix A). These scenarios presented participants with a patient presenting with family history of cancer, and questions focused on how the participant would respond to each scenario (Appendix A). Interviews lasted roughly 30 minutes, were conducted by one interviewer and audio recorded. Later, the interviews were transcribed, de-identified, and checked for accuracy. This study was approved by the University of Washington Institutional Review Board and all participants provided informed consent.

Secondary Data Analysis

A codebook was developed based on interview guide questions related to tools and resources as well as the coder's (MM's) impression of the data upon first read (Appendix B). The codebook was reviewed and revised by the coder and a second qualitative researcher (DMK), who was involved in initial data collection. The coder then manually coded transcripts in Microsoft Word (as opposed to using qualitative analysis software) using the highlight and comment functions to perform directed content analysis (Hsieh & Shannon, 2005) focusing on language and themes related to resources and tools. As a coding check, the second qualitative researcher compiled a list of major themes independent of the coder's coding (Ryan et al., 2003). Together, they then reviewed the coding against that thematic framing, revising codes

and major themes as needed through a series of consensus discussions to clarify coding and resolve any discordant interpretations.

Results

In this study, we conducted semi-structured interviews with 12 primary care providers (PCPs) with the aim of identifying perceived needs with regard to resources for screening and assisting patients seeking information about a possible hereditary cancer predisposition.

Throughout these interviews, we heard PCPs describe features of their clinical responsibilities and workflow that motivated their desire for specific resources. First, we outline some of the pressures and needs expressed by respondents. Next, the kinds of resources PCPs suggested would be helpful are organized in four major themes: 1. Organized and prioritized information, 2. Accessible, easy-to-use screening tools, 3. Supplementary support from specialists, and, finally, 4. Accessible and understandable patient-facing resources.

While we have parsed out four separate themes, it is worth noting that these themes overlap with one another. For example, our first theme, “Organized and prioritized information,” overlaps with our second theme, “Accessible, easy-to-use screening tools” as the technology mentioned in theme two can aid in providing information that is organized and prioritized. Accordingly, theme two also overlaps with theme four, as this technology can also aid in making patient-facing resources more readily available.

Busy PCPs Need Help

The clinicians interviewed for this study framed their need for certain resources within the context of their busy workflow and limited time with patients. Many expressed a preference

for timely, quick-use resources, such as databases, in response to pressure on them to see patients as quickly as possible.

> *"…because there's more and more pressure on us to see people in a very… expeditious way, I don't have the time that I would prefer to be able to look up some of this information. So…it's easier for me now just to go to UpToDate or go to-to DynaMed and-and get a guideline, and then tell the patient what the guideline is, and move on to the next person, 'cause that's what's expected of me." (P2, Family Medicine)*

The pressure to see patients quickly results in PCPs having a limited time to spend with individual patients. This makes resources that can be consumed quickly all the more valuable. As one participant stated:

> *"Just thinking about primary care providers in a busy—sort of, like, busy schedules and limited time to talk to patients and being able to have tools that, like, quickly sort of spit out an answer rather than having to go to, like, a book or, like, a resource where I would have to spend 10 to 20 minutes to read through to actually find the answer." (P9, Family Medicine)*

Many characteristics of resources can contribute to their ability to be consumed quickly. One participant, for example, voiced a desire for information within resources to be neatly summarized for rapid reading.

"…I think mostly availability and like the rapidity—like, how fast I can get through the information that's presented to me. So, the more it's like summarized in bullet points [laughter], the better it—that is, just because my clinic visits are 30 minutes for new patients and 15 minutes for established patients." (P7, Family Medicine)

Organized and Prioritized Information

Content Organized for Easy Search/Access

PCPs in this study expressed a need for resources that contained organized content so that they could easily and quickly find what they are looking for, saving valuable time. This includes improving searchability of databases. As one participant noted:

"Sometimes I just can't get the right catchword to come up that makes sense…it'll go down a different rabbit hole, and I don't have time to look at it" (P2, Family Medicine)

Participants also described a desire for a centralized and comprehensive resource that might be accessible in the same way as other clinical resources.

"I would imagine people out in practice would really benefit from something that's online that they can simply look up information by inputting a specific disease and getting that kind of information, like I was saying, that it would be great to have at UpToDate." (P10, Family Medicine)

Prioritized Information

In addition to wanting better organized information, participants talked about being overwhelmed with the amount of information presented to them. They expressed a desire for prioritizing or highlighting information that is especially relevant.

> *"Um, I think there's so many resources out there that it's kinda overwhelming, so knowing which ones the oncologists would prefer us to use would be helpful." (P4, Family Medicine)*

PCPs also reported having to sift through clinically irrelevant information to get to information that is valuable to them and their patient.

> *"Well, if you just look up—say you look up…cervical cancer guidelines…there's more than one. There's, like, three or four different institutions that have their own guidelines…so if you've never searched something like that before, it gets very confusing. And then they give you all the logic and reason behind why they set up the guideline, before they ever actually give you the guideline." (P2, Family Medicine)*

PCPs expressed frustration with information presented in lengthy paragraphs, with clinically relevant information scattered throughout.

> *"…I feel like…there's no specific—like, the information is dispersed… over… paragraphs…usually…most commonly asked questions aren't like, oh, there's like a list. Like,*

this is your risk of passing it on…it's usually like a long paragraph and you have to sift through a lot of information….if there was just like a good, distinct summary."(P7, Family Medicine)

Accessible Easy-to-Use Screening Tools

Discoverability

All participants in the study voiced frustrations with not being able to find the information they needed and the need for more easily discoverable resources. Several participants expressed a desire to use the EHR as a means of clinical decision support and to aid them in finding appropriate information.

"I think our EPIC has some platform but I think if your EPIC was able to—if you're able to put family history of colon cancer age 45 that it would pop up something that would link you to screening or not screening tools, EHR prompting." (P3, Family Medicine)

Ease of Use

Because of their limited time with patients, participants desired efficient, easy to use tools. PCPs reported wanting tools that allow them to decide if a patient is recommended for screening.

"And really, I think what's helpful for just the primary care physician is just to have…step-by-step, okay…almost like a-a chart…the patient comes in, they're this age. And then they have a…relative with this type of cancer, and it's a first degree relative, and…what are the next

steps?...how it…goes down in like—not like a pyramid, but…just an algorithm…which would make it just really, really easy to-to figure out who—we only have, you know, 15 and 20-minute appointments sometimes, and so it just needs to be really efficient and really direct in terms of-of what we should be doing next." (P8, Family Medicine)

Some PCPs believed mobile apps used in other areas of care were effective, and recommended an analogous genetics screening app, which could also function as a "calculator" or algorithm in which the app could tell PCPs if a patient should be screened.

"I guess one thing that might help for genetic screening in particular is—and I use these types of resources for other types of things like preventative healthcare—is, like, an app that—I don't know if there is an app—where I could type in patient demographics and history or family history and then it could spit out…this patient—or consider whatever type of genetic screening for this patient at this juncture…maybe that's a resource that could be helpful." (P9, Family Medicine)

"Yeah…this might already exist, I'm not sure, maybe I just don't know about it. So for certain like preventative medicine screens, or like really good apps, um, like the CDC vaccine schedule has a good app, and the like TB risk score has an app. And AHRQ…has an app… I'm not sure if genetic screening or genetic cancer and stuff has an app or not." (P12, Family Medicine)

Supplementary Support From Specialists

Most of the participants in this study voiced the need to be able to communicate as needed with specialists. Some voiced concerns about wasting a geneticist's time, and were quick to suggest synchronous or asynchronous communication, depending on the urgency of the situation.

> *"It's always nice to talk to somebody on the phone but I don't know that having a geneticist sitting by the phone waiting for phone calls is a good use of their time is what I mean. If it were something like if there was a number or a e-mail address or something where you could make a phone call or you could say, gee, I got this problem that I'm not sure what to do with it, what would your advice be, that would be fantastic." (P5, Family Medicine)*

> *"I think being able to have, like, a hotline or…I don't know if it's a hotline, but, like, some sort of resource that primary care physicians could easily access if there were questions would be nice." (P9, Family Medicine)*

Accessible and Understandable Patient-Facing Resources

In addition to describing the need for practice resources and specialist support, the PCPs that were interviewed also described wanting to have better accessible and understandable patient-facing resources such as information sheets and related educational supports.

Discoverable

The same issues of accessibility that our participants faced when searching for their own resources also arose when searching for patient facing resources.

> *"I always like having easy-to-access embedded in the medical records, reliable patient education information that's written at a good level for the patient." (P6, Primary Care)*

Understandable

Participants reported that their patient-facing resources needed to be written at a low reading level to accommodate patients.

> *"…They definitely need to be at a very low reading level, like, third-grade reading level, maybe…they could have links to go find more complex stuff, but I find the more complicated, it's harder for patients." (P4, Family Medicine)*

PCPs in this study recognized that the use of pictures and images within patient-facing resources could aid in patient understanding,

> *"…Sometimes videos—I've used videos before to provide patient education…if they're available…a…pictograph kind of card, maybe, if there was something sort of simple as far as…being able to walk a patient through a process or testing or something like that… something with minimal amount of words—" (P9, Family Medicine)*

Participants felt that patient-centered resources should be accessible both to themselves and their patients. They recognized the importance of free resources, as well as resources written in a variety of languages.

> *"..I think as long—if they [patient resources] are as patient-friendly and patient-centered as possible. Different languages…I think they may even already have those. I just haven't looked it up myself….those are always best…and then short, like one page, and then freely available that I can just print out for them." (P11, Internal Medicine)*

> *"We have a lot of Russian speaking patients. We have a lot of patients who speak Arabic or Tamil or other languages. So I think...availability of resources in different languages is really important." (P12, Family Medicine)*

Tiered

However, participants pointed out that some patients have advanced health literacy and low reading level resources are not valuable to this group. PCPs recommended the use of tiered (both basic and advanced) patient-facing materials to accommodate all patients. One clinician in our study even stated that they can read and benefit from the advanced materials:

> *"But…the other thing is that sometimes the…I do appreciate when patient education materials are basic and advanced. So I often will immediately go to the advanced patient education materials, so that I can read those more accurately." (P2, Family Medicine)*

Discussion

PCPs have busy workflows and report feeling unprepared to assist patients with questions pertaining to genetics. In this study, PCPs describe the challenges they face in delivering quality advice around genetic screening, as well as resources they desire to help bridge these gaps. PCPs described a need for 1. Organized and prioritized information, 2. Accessible, easy-to-use screening tools, 3. Supplementary support from specialists, and, finally, 4. Accessible and understandable patient-facing resources.

A common theme throughout our interviews with PCPs was that PCPs desired information that was presented in a more organized and prioritized manner. Many spoke to the frustration of having to read through paragraphs of information within online databases when looking for a specific piece of information or guideline. This sentiment is echoed when PCP's search for information regarding pharmacogenetics (Heale et al., 2017). While several genetic variant databases are available to PCPs to decipher the significance of a specific variants/conditions (Prawira et al., 2017; Dumur, 2014), there is no singular, comprehensive source of this information (Haga, 2019). Furthermore, these databases only contain information that is clinically useful *after* a patient has had a genetic test, while PCPs report counseling patients about genetic risk and benefits of screening before a test is ordered (Carroll et al., 2019). A 2016 review found long term exposure to genetics could result in improved genetics care amongst PCPs, while short course interventions could not (Paneque et al., 2016). However, given PCPs' time constraints, long term educational courses could be difficult to for clinicians to access. Some suggest that the ability to access information at the point of patient

care is an important part of improving PCPs' genetics knowledge (Trinidad et al., 2008; Institute of Medicine, 2015). Improving online sources of information to include a summary of clinical applications and improving search filters could improve PCP's ability to access information at point of care.

PCPs in this study suggested using EHR prompts or mobile applications (apps) to improve the accessibility of relevant information. EHR prompting has been suggested before as a means to decrease the workflow burden on PCPs by assisting in clinical decision support (David et al., 2015). For example, if a clinician input a strong family history of colon cancer into a patient's chart in the EHR, they would receive an alert recommending screening if the patient met the age criteria. However, in practice, over 49% of clinical decision support alerts are overridden (van der Sjls et al., 2006), which could hinder the effectiveness of such an intervention. It is generally accepted that this practice stems from "alert fatigue," or a desensitization to alerts after being exposed to a large number of such (Ancker et al., 2017) As a clinician's likelihood of accepting alerts decreases as the overall number of alerts increases (Ancker et al., 2017), care should be taken to ensure that EHRs prioritize alerts that are strongly related to clinical outcome.

During the course of the interview, a few of our participants brought up using mobile apps in other areas of care they provide, and a desire to have an analogous app to assist them with decision making with genetic screening. For example, one participant mentioned the CDC vaccine schedule app. This app contains standard vaccination schedules for children and adults, as well as a catch-up schedule for children and adolescents. The information within the app is also color coded for ease of use, and vaccine names are hyperlinked to dose information to

support physicians in their decision making (CDC, 2020). A similar app for genetics would help physicians sort through the overwhelming amount of genetic screening information, perhaps helping PCPs to identify which patients are the best candidates for genetic testing and providing hyperlinked information about appropriate tests and labs.

Participants in this study consistently emphasized a need to be able to communicate with specialists about patients with genetics needs. The suggestions we heard included synchronous and asynchronous communication with specialists, depending on the urgency of the situation. Some participants suggested a hotline to consult with specialists. This idea has been put into practice with a variety of specialties (but not medical genetics) in the RACE (Rapid Access to Consultative Expertise) program in Vancouver, BC with great success. An evaluation of the RACE program found that 60% of PCP calls prevented patients from visiting a specialist and 32% of calls prevented referrals to hospital emergency department (Wilson et al., 2016). A similar program providing PCPs with real-time access to medical geneticists or genetic counselors could yield similar results, as access to a genetics specialist has been positively associated with use of genetic testing for disease diagnosis or susceptibility (Haga et al., 2013), and could circumvent the need for referral to a genetics specialist.

Another theme that appeared in this analysis was the need for improvement in patient-facing resources. Given the diversity of patients' reading levels, health literacy, and language, it can be challenging to create patient facing materials that cater to all patients' needs. The clinicians interviewed in this study suggested the use of patient-facing materials written at low reading levels as well as those that use pictures to explain health-related concepts. Multiple professional organizations recommend using materials written at low reading levels to ensure

materials are accessible to all patients (Hersch et al., 2015). Additionally, prior work shows that the use of pictures can be an effective tool to communicate with patients thatenhances patient attention, recall, and comprehension (Houts et al., 2005). Physicians are encouraged to use evidence based visual aids, models, photonovelas, and videos to enhance patient understanding and optimize care (Hersch et al., 2015). However, some participants in our study stated that a subset of their patients had high health literacy and did not benefit from the standard patient-facing materials. For such patients, it is possible that more advanced materials will be required to address the needs of this patient group. Additionally, as stated by one of our participants, these advanced materials can also be helpful to clinicians to pinpoint information directly related to patients' wellbeing.

Limitations

This study was limited by its convenience sample, regionality, setting, and small sample size. This study utilized snowball sampling to recruit participants, which could bias the nature of the views we identified. All PCPs interviewed in this study practice in the Pacific Northwest region of the United States. Providers in other regions or countries may face different challenges and have different needs in regard to resources for genetic screening. Additionally, the participants in this study were largely based in academic medical settings, which occluded a thorough comparison of the needs of academic and community- based clinicians.

Conclusion

PCPs will need to play a growing role in genetic medicine to fill current gaps in the medical genetics workforce. In order to meet the needs of busy PCPs and equip them with the tools needed to meet this challenge, PCPs will need improved genetics screening resources. These resources must address organized and prioritized information, accessible, easy-to-use screening tools, supplementary support from specialists, and, finally, accessible and understandable patient-facing resources.

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Appendix

A. Interview Guide

Views about Whole-Exome Sequencing in the Clinic: Part of the NEXT Medicine Study

INTERVIEW GUIDE

Primary Care Views of Genetic Cancer Predisposition Management

INTRODUCTION [3 mins]

Thank you for agreeing to speak with me today.

My name is _____ and this interview is part of the "New Exome Technology in Medicine" or the NEXT Medicine Study led by Dr. Gail Jarvik at the University of Washington. We're investigating the role primary care providers might play in managing patients at risk for a genetic cancer predisposition, including helping at-risk patients communicate with family members.

Before we begin, I just want to review a few ground rules:

- Your participation in this discussion is voluntary.
- You can decline to answer any question, and you're free to stop at any time.
- If it's ok with you, I will audio-record this conversation so that we have a reliable record of your comments. The audio-recording will be used to make a transcript of the conversation, and we will remove your name and any other personal identifiers from the transcript.

I have us down for 30 minutes. Is that still okay for you?

Any questions before we begin? Please remember that there are no right or wrong answers to any of the questions we'll be talking about. We really want to hear your honest opinions, to the degree that feels comfortable to you.

TURN ON AUDIORECORDER

State that you are now recording. [Use the date in file name when you name the file.]

SECTION 1: DEMOGRAPHICS & WARM UP [5 MIN]

We'll begin with a few demographics.

- What is your gender?
  - □ Male
  - □ Female
  - □ Other

- What is your age? _____

- What is your race/ethnicity? (allow multiple responses)
  - □ American Indian or Alaska Native
  - □ Asian
  - □ Black or African American
  - □ Native Hawaiian or Other Pacific Islander
  - □ White
  - □ Other

- Are you Hispanic or Latino?
  - □ Yes
  - □ No

- What is your specialty? _____
- Including residency, how many years have you been in practice? _____
- How would you describe your familiarity with genetics?

- Have you ever ordered a genetic test for a patient?
  (If participant requests an example, use BRCA or pre-natal genetic testing)
  □ No
  □ Yes
  (If yes) For what? _____

Now I'd like to ask you a few questions about your healthcare role.

1. **What is your current job title or position?**
2. **Could you tell me –briefly – what that means? What are some of your key responsibilities?**
3. **How would you describe your practice setting? Consider its location, size, type of patients, care of families, or any other feature your clinic may be known for.**

SECTION 2: SCENARIOS [20 MIN]

Thank you for that information. I'd now like to present you with the details of two different hypothetical patients. After I tell you about the patient and their concerns I'll ask you a series of questions about actions or advice you might recommend.

Patient #1

Say you have a 40-year-old female patient who makes an appointment with you to discuss her concerns about a family history of cancer. At the appointment, you learn that her father was diagnosed with colorectal cancer at age 45 and that she has a 60-year-old aunt (her father's sister) who is currently being treated for endometrial cancer. She, her mother, and two younger siblings have no history of cancer.

4. **How do you imagine you would approach the patient's concerns? Can you step me through what your conversation with her might look like?**
5. **What additional information, if any, would you request from the patient?**
6. **What would you be likely to recommend by way of next steps?**
7. **Considering that biological family members might also be at risk in this scenario, what responsibilities, if any, would you consider yourself to have towards them?**
    a. **(If the participant indicates responsibilities, then ask: What resources would help you fulfil those responsibilities?)**
8. **Are there external resources that you would find helpful in caring for this patient?**
9. **If yes, what would make those resources more helpful to you? (e.g., making access to them easier, improving presentation of material, etc.)**
10. **Would you provide materials to your patient? If so, what might make those materials more helpful to your patients? (e.g., updating presentation, improving readability, improving accessibility, offering culturally appropriate versions, etc.)**
11. **Does this hypothetical scenario feel familiar to you (i.e. like a patient you may have encountered previously)? Why or why not?**
12. **In general, what do you think primary care has to offer in this situation?**

Patient #2

Now let's imagine instead that you have a 55-year-old male patient who has recently undergone treatment for colorectal cancer. At the time he was diagnosed, tumor pathology was consistent with a possible genetic predisposition to colorectal cancer. The oncologist made a note of this in the medical record and informed the patient, but due to preoccupation with his cancer treatment nothing further has done. In preparing for a routine check-up, you notice the oncologist's note and decide to ask your patient about it.

NOTE: If the participant requires additional specificity, state that the pathology was consistent with a possible genetic predisposition to Lynch Syndrome.

13. **Are there any external resources you would expect to review <u>before</u> meeting with the patient?**
14. **If yes, what would make those resources more helpful to you? (e.g., making access to them easier, improving presentation of material, etc.)**
15. **How do you imagine you would approach the tumor pathology finding at the appointment? Can you step me through what your conversation with the patient might look like?**
16. **What additional information, if any, would you request from the patient?**
17. **What would you be likely to recommend by way of next steps?**
18. **Would you provide materials to your patient? If so, what might make those materials more helpful to your patients? (e.g., updating presentation, improving readability, improving accessibility, offering culturally appropriate versions, etc.)**
19. **Considering that biological family members might also be at risk in this scenario, what responsibilities, if any, would you consider yourself to have towards them?**
    a. **(If the participant indicates responsibilities, then ask: What resources would help you fulfil those responsibilities?**
20. **Does this hypothetical scenario feel familiar to you (i.e. like a patient you may have encountered previously)? Why or why not?**
21. **In general, what do you think primary care has to offer in this situation?**

WRAP UP [5 MIN]

22. **Do you have any final thoughts to share about these scenarios or the management of patients with similar concerns?**
23. **Is there anyone else you recommend we speak with for this study?**

Thank you very much for your time and for sharing your thoughts with me. I have just a couple more housekeeping items before I let you go.

FINAL HOUSEKEEPING – NON-UW ONLY [1 MIN]

We would like to offer you a $50 Amazon gift code as a thank you for speaking to us. May I please have your email address so we can send you this card? We will redact this information from the interview transcript.

- Add email address to the Interview tracking sheet on OneDrive

We'd like to re-contact you after we analyze all the interviews to have you review and comment on a brief summary of our findings. May we re-contact you for that? We would provide an additional $50 Amazon gift code as a thank you for your time and insights.

B. Codebook

Code	Definition	Example
Busy PCPs Need Help		
Timeliness	participant expresses a desire to have a resource that can be found and/or used quickly	*"I think it's really just making it so that they're [RESOURCES] quickly accessible"*
Busy workflow	participant states or alludes to a busy work day and/or limited time with patients	*"Um, because there's more and more pressure on us to see people in a very, uh, expeditious way, I don't have the time that I would prefer to be able to look up some of this information."*
Organized and Prioritized Information		
Conciseness	participant expresses a desire for information in resources to be concise	*"They're pretty darn useful if you keep 'em simple. The more simple and easy to—to find and not have to search, the easier. I feel like I look at least 3—3 to 10 things up in a single day, and the harder it is to find stuff or the harder it is to—to look at that—*

		to get what you're needing in that sort of situation, like, the more difficult it is, so keeping it simple, um, is nice."
Prioritizing Important Information	participant states a desire for resources to prioritize important information to avoid information overload	*"Well, if you just look up—say you look up…cervical cancer guidelines…there's more than one. There's, like, three or four different institutions that have their own guidelines…"*
Accessible Easy-to-Use Screening Tools		
Risk/screening "calculator"	participant states a desire for a way to calculate risk and appropriateness of screening of patients	*"And really, I think what's helpful for just the primary care physician is just to have…step-by-step, okay…almost like a-a chart…the patient comes in, they're this age. And then they have a…relative with this type of cancer, and it's a first degree*

		relative, and…what are the next steps?...how it…goes down in like—not like a pyramid, but…just an algorithm…which would make it just really, really easy to-to figure out who…"
Screening app	participant states desire for a mobile app that could help screen patients	*"I guess one thing that might help for genetic screening in particular is—and I use these types of resources for other types of things like preventative healthcare—is, like, an app that—I don't know if there is an app—where I could type in patient demographics and history or family history and then it could spit out, like, um, this patient—or consider whatever type of genetic screening for this patient at this juncture."*

Information built into EHR	participant expresses desire for resources to be built into the electronic health record as a form of clinical decision support	*"I think if your Epic was able to—if you're able to put family history of colon cancer age 45 that it would pop up something that would link you to screening or not screening tools, EHR prompting."*
Online database	participant describes the use of electronic databases as resources (e.g. – DynaMed, UpToDate)	*"I usually start with UpToDate."*
Discoverability	participant describes difficulties searching for resources	*"Um, searching is difficult sometimes. So, yeah. The presentation of the material would be, um, mmm, um—could be better."*
Accessibility	participant describes a need for resources that do not have barriers to access or use	*"And it's freely available, and it's only, like, six questions."*

Unsure of where to look for resources	participant acknowledges that resources likely exist, but is unsure of where to look	*"I'm sure there are resources out there, I just don't know what they are."*
Supplementary Support from Specialists		
Specialist consult	participant states desire to be able to consult with a specialist when necessary	*"I think my first step in this scenario would probably be to contact the treating oncologist and open a dialogue there."*
Specialist hotline	participant states or alludes to a hotline or some method of contact to specialists where synchronous or asynchronous communication could occur, depending on the case	*"Uh, yeah. If there was a-a-a, uh, easily accessible hotline or a place where you could raise a question and get an answer, um, or present a case. Uh, it wouldn't have to be, um—it wouldn't have to be—it co—it could be time delayed."*
Accessible and Understandable Patient-facing Resources		
Accessible to low reading levels	participant states desire for patient-facing resources to be	*"Um, they definitely need to be at a very low reading level, like, third-grade reading level…"*

	written at low reading levels so that they are accessible to all	
Tiered levels of resources to accommodate different knowledge levels	participant acknowledges that some patients' knowledge is more advanced than patient-facing materials, and there is a need for varied levels of patient materials	*"But…the other thing is that sometimes the…I do appreciate when patient education materials are basic and advanced.*
Multilingual resources	participant states need for patient-facing resources that are written in a variety of languages to accommodate diverse patient groups	*"I see people in-in my clinic, you know, speak English, Arabic, Spanish, Russian, you know, um, the ability to-to just change out the language, that's—you know, and print it off in different languages would be very helpful too.*