

2023 Learning Collaborative on Hereditary Breast Cancer & Narrative Medicine

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Introduction

Early detection, in conjunction with risk reduction, is essential to reducing cancer mortality rates. With an estimated ten percent of cancer diagnoses linked to a high-risk genetic mutation (\cong 200,000/year in the United States), identifying and counseling those individuals who carry the mutation can save lives. However, millions of Americans are unaware that they have a genetic mutation that increases their risk of developing cancer.

Family physicians are at the heart of the early detection and prevention of cancer. This is particularly true with hereditary cancers. Family physicians and their care teams are uniquely positioned to assess their patients' risk and counsel them through options to evaluate and reduce their risk.

"When we talk about early onset breast cancer, we're really looking at women between the ages of 18 and 45. Many of them are only getting their care from you. If you're not having this conversation with them, nobody is." Dr. Susanna Evans speaking to the FMEC's cohort of faculty and residents.

This is why the Family Medicine Education Consortium (FMEC) created the

2023 Hereditary Breast Cancer/Narrative Medicine Learning Collaborative. According to the CDC's Division of Cancer Prevention and Control, only about 41% of primary care physicians refer women with a high risk for breast cancer for genetic counseling and testing. Our challenge is changing this and asking how we can develop the means to stimulate authentic conversations that lead to action.

Background

The FMEC is committed to engaging residency programs in learning collaboratives to advance quality healthcare and medical education. Not only can collaboratives improve care and teaching, but they meet the Accreditation Council for Graduate Medical Education (ACGME) cross-institutional collaboration requirements, which went into effect July 1, 2023. The guidelines state, "Programs are strongly encouraged to partner with other family medicine residency programs through regional learning collaboratives to share resources to facilitate programs and their family medicine practice's attaining educational and community aims." To help residencies meet this commitment, the FMEC launched the cross-institutional learning collaborative on <u>Hereditary Cancers in Women and Narrative Medicine</u> in early 2023.

Through funding provided by the <u>National Association of Chronic Disease Directors</u> (NACDD) and utilizing tools from CDC's <u>Bring Your Brave campaign</u>, participating family medicine residency programs convened virtually to learn about women's hereditary cancer risk, using videos and stories in training and in clinic, and supporting women to learn about their risk, get testing, and find community supports.

Key Takeaways

Learning Collaborative Reach

On the final project survey, 100% of Resident and 90% of Faculty respondents indicated that they had, or planned to, share the Bring Your Brave resources with patients. Over the course of the Collaborative, participants were encouraged to start using the materials, and as a result have already reached approximately 101 patients using Bring Your Brave Campaign materials or strategies.

In addition, participants have indicated that they have or planned to share the information with colleagues, community support organizations, and other groups outside their programs. Participants reported an immediate potential to reach over 550 individuals with Bring Your Brave information.

Faculty Final Survey Responses

Audience	How many residents did you/do you plan to reach
Fellow Faculty	101
Program Residents	188
Individuals outside your program	24

Residents Final Survey Responses

Audience	How many residents did you/do you plan to reach
Fellow Residents	108
Program Faculty	34
Individuals outside your program	95

Most promising, 100% of Faculty members responded that they would continue to distribute the information to new residents in the future, suggesting that information on hereditary cancer and Bring Your Brave will become institutionalized in these programs' curricula.

Faculty and Residents have, or planned, to share information internally through many strategies, including: Resident business meetings, lectures, shared Google drive, handouts, email, seminar hard copies of information, resource folders, in-person announcements, faculty meetings, learning sessions, and didactics.

Faculty and Residents have, or planned, to share information outside their training programs through newsletters, webinars, and emails.

In addition to participant distribution of Bring Your Brave Resources, FMEC communication efforts included reaching over 3,000 individuals through member-wide communication and online presence. A breakdown of reach is available in <u>Appendix A</u>.

Takeaways at a Glance

- The Bring Your Brave Campaign is a multilevel training and education tool that can be used to empower patients and healthcare providers.
- Successful deployment of the Bring Your Brave Campaign to family medicine practitioners for use with patients should include training in genetic testing to feel comfortable initiating hereditary cancer discussions with patients.
- To assist family medicine practitioners in distributing campaign materials to patients, further development of materials is encouraged, including translations and tools for quick access to the online materials.
- In the final survey, 70% of programs responded that they had identified gaps in their curriculum that they planned to address utilizing the Bring Your Brave material.
- The project proved that review and discussion of the resource materials and exploration of the subject increases the likelihood that physicians will conduct regular hereditary cancer discussions with patients.

"just in this week I had a patient a young patient who was seeing me for something else, but I ended up asking her question about if there are any cancers in her family and she told me that her mom had breast and ovarian cancer and then when I delved deeper into it, it was diagnosed at a younger age and now that is going to, I mean with all this information with me, that is going to prompt me to call her back" - 2023 Learning Collaborative Participant

When asked if participating in the Hereditary Breast Cancer/Narrative Medicine Learning Collaborative increased their likelihood of having hereditary cancer conversations with patients the majority of participants responded yes. Only one participant selected No, indicating they were already having regular hereditary cancer conversations with patients before the Collaborative.

Participants who stated that they believed the likelihood of having hereditary cancer conversations with their patients would increase after learning about Bring Your Brave through the Learning Collaborative were asked why they thought this was the case. They were asked to select all that applied.



Learning Collaborative Implementation – Lessons Learned

What Worked?

- The learning sessions and action period activities increase the participant knowledge base and comfort levels with hereditary cancer risk assessment.
- Increased knowledge and comfort, in addition to increased empathy and broadening perspectives, resulted in participants increasing patient risk assessment conversations.
- The Collaborative highlighted gaps in curricula for Faculty participants, resulting in programs exploring and implementing curricular additions or enhancements around narrative medicine, hereditary cancer, and genomics training.
- Solutions to diverse barriers were identified and will be used to assist future programs and clinics in integrating Bring Your Brave, including the development of a Hereditary Cancer Resource Folder.

What could be improved in future Collaboratives?

- Due to the nature of academic family medicine faculty and residents' schedules, we encountered challenges with providing times appropriate for learning sessions, and participants reported challenges completing action period activities within the requested timeframes. Future Collaborative efforts should ensure consideration of residency program calendars for such major program events, including match day, graduation, and new class intake. Exploration of different educational content delivery and group collaboration opportunities should be explored (e.g., shorter sessions, audio or podcast format, electronic discussion boards).
- Exploration of communication alternatives is suggested to ensure data collection efforts reach residents in a timely manner. Our experience was that today's residents rely less on email communication than older physicians. Possible solutions include adding text messaging or messaging platforms for easy access to communications.
- Although the Collaborative engaged academic centers from different health systems and in diverse communities, project activities were not structured as collaborative across institutions, so experiences between learning sessions generally remained within the faculty/resident teams in each institution.

Learning Collaborative Design, Structure and Process

Leadership

Family Medicine Residency Program Faculty members with an interest in Narrative Medicine and/or Hereditary Breast and Ovarian Cancer were recruited to serve as an Advisory Committee for the Learning Collaborative. Four Advisory Committee members were confirmed for the Collaborative and offered a modest stipend for their participation and leadership.

"I joined the Collaborative as a means to incorporate narrative medicine practices which will better allow my residents to engage their patients in discussion over vital health issues. Taking the long view, I see this Collaborative as setting the tone for greater empathy when caring for and communicating with patients." Dr. Adam Perrin - **Tracey Conti, MD**, Chair, Department of Medicine, University of Pittsburgh School of Medicine and UPMC

- **Philip G. Day, Ph.D**., Assistant Professor and Associate Director of Education, Department of Family Medicine and Community Health, UMass Medical School

- **Susanna Evans, MD**, Associate Professor and Chair, Family, Community, and Preventive Medicine, Temple Health Chestnut Hill, Drexel University College of Medicine

- Adam E. Perrin, MD, Associate Professor of Family Medicine and Faculty Co-Director, Student Affairs, UConn School of Medicine

Participant Recruitment, Responsibilities and Benefits

Beginning in November 2022, FMEC began identifying leadership and recruiting participants for the Learning Collaborative. Recruitment emails were sent to the entire FMEC membership and contacts at the 200+ family medicine residency programs in the FMEC's 14-state region. FMEC Board members and staff also did personal outreach to program faculty based on expectation of their interest. Family Medicine Residency Programs participating in the Collaborative were asked to:

- commit one faculty and two residents to serve as project leads and primary contacts
- ensure project leads or representatives, participate in 5 virtual learning sessions (60-90 minutes each) between January and July 2023
- share information with other residents and faculty at their program, experiment with tools during the "action periods" between learning sessions, and report back to the FMEC and the group
- evaluate and collect data on the inclusion of the CDC's Bring Your Brave campaign materials in training and practice

In addition to helping programs meet the ACGME cross-institutional collaboration requirements, program participation was incentivized through offering either a complimentary Residency Fair booth at an upcoming FMEC Annual Meeting or an FMEC organizational membership or membership upgrade.

Nine residency programs completed the Collaborative, including 11 faculty and 19 residents. Together, they reached an additional 122 faculty and 212 residents, who either learned from or provided feedback on the storytelling materials or benefited from the integration of the materials into their program once the learning portion of the project ended. Participants included residency programs from 6 different states and provided a strong cross-section of family medicine residency programs, representing various program types, community populations, and geographic regions. (Appendix B)

Process

The Advisory Committee and staff designed a series of learning sessions and action period activities to successfully integrate the Bring Your Brave Campaign in Family Medicine for educating patients in clinic and physicians within residency training programs. Participating residency programs were asked to participate in five learning sessions between February and July 2023. Learning sessions served to educate participants on topics and to provide a forum for reporting action period findings and facilitating group discussions.

Participants were also asked to complete action period activities in between learning sessions. These activities were designed to educate participants, encourage group brainstorming and discussion opportunities, and allow for data collection opportunities to inform recommendations for the future.

In addition, participant surveys were conducted throughout the project to evaluate subject knowledge and comfort levels and tracked changes throughout the collaboration.

Learning Objectives

The following learning objectives were created for this project. At the conclusion of the project, faculty and resident participants will be able to;

- Understand the risk and incidence of breast and ovarian cancers in young women
- Identify at least three benefits of using stories, videos, etc. during patient visits
- Be able to introduce discussion and raise awareness about cancer risk with young women during patient visits
- Be familiar with at least two community resources to educate and support young women with regard to hereditary cancers
- Implement a strategy to educate current and future residents about the Bring Your Brave campaign

Learning Sessions & Action Period Activities

The following sessions and action period activities were completed to achieve the Learning Collaborative's objectives.

	Learning Session Topic	Action Period Activity	
1	Introduction: Background on Storytelling in Medicine + Background on Hereditary Cancers in Women	Review and Report Back on Bring Your Brave Campaign Materials and Resources	
2	Bring Your Brave Tools and Resources: Participant Reactions and Sharing	Brainstorm and Report Back on Barriers and Solutions for Utilizing Bring Your Brave in Clinic	
3	Strategies to Integrate into Residency Training	Develop and submit two work plans for utilizing the Bring Your Brave campaign materials in your Residency Training Program.	
4	Strategies to Integrate into Patient Care	Create a draft outline for a Hereditary Cancer Resource Folder for your clinic.	
5	Hereditary Breast Cancer Risk Assessment & Narrative Medicine: Resources from FORCE and What We've Learned through the Collaborative	Contact other departments or specialists in your area's health system or community groups to provide them with information on the Bring Your Brave Campaign.	

Challenges Encountered/Solutions:

The learning session plan above reflects what occurred rather than what was initially planned. After reviewing the first survey and action period responses, the Advisory Committee adapted the plan to better meet the needs of the participants. For instance, the lack of knowledge and low comfort levels around genetic testing and referral was identified as a significant barrier to using the Bring Your Brave materials with patients. Therefore, the project shifted plans and invited a guest speaker, Mylynda B. Massart, MD, PhD of the University of Pittsburgh Medical Center, to give a high-level overview of where genomics intersects with family medicine. Other changes included shuffling the order of planned content based on participant input, and postponing the timing of the final session to avoid busy graduation and orientation periods, which limited time afterward for reporting and data collection.

A complete overview of the learning sessions is available in <u>Appendix C.</u>

Collaborative Group Resources and Communication

A Collaborative Resource Folder was created to provide a central location for action period activity tools, learning session information, and resources. In addition, to allow for group-wide communication and discussions, a Google Group Email was created and shared with participants. Participants were encouraged to share their knowledge, ask questions, and participate in conversations as the group explored various topics during the Learning Collaborative. Routine communication was directed primarily through direct email messages from the project manager to the participants.

Challenges Encountered/Solutions:

Residents' communication styles are changing, and considerations were made to encourage residents to check and respond to email requests from the project manager. Tasking Faculty to assist in prompting residents through text messages was recommended. Future collaboratives should consider alternate communication options.

Program Participation

Challenges Encountered/Solutions:

Residency Program participation in the Collaborative was high. It was anticipated that not all participants would be

able to attend all the live learning sessions. Programs were given a full learning session schedule at the beginning of February 2023 and asked to attempt to have at least one person from each residency program attend each learning session. All five learning sessions had representatives from at least 80% of programs attend. To support participants unable to participate in the live learning sessions, FMEC provided recordings via a shared folder and on the organization's YouTube channel.

"This is an outstanding and highly impactful resource that should be regularly utilized." - 2023 Learning Collaborative Participant

maintain an active involvement, reducing the number of active participants to from 33 to 30 individuals (11 Faculty Members, 19 Residents).
Google Group Email was an underutilized resource by the group. Considerations for future collaborative

Ten programs originally signed on to participate in the Collaborative. However, one program could not

- Google Group Email was an underutilized resource by the group. Considerations for future collaborative projects should include exploration of alternative platforms or discussion forum structures.

"Reviewing this page is extremely impactful. It is a whole different story when patients tell their own stories." - 2023 Learning Collaborative Participant

"These videos were very impactful and something I will share with the residents at our program." - 2023 Learning Collaborative Participant

Evaluation Write-Up and Analysis

Before looking at the logistical aspects of incorporating Bring Your Brave materials into clinic or practice, it was necessary to establish our participants' knowledge base and comfort levels in the following areas:

- Knowledge of Narrative Medicine Principles
- Hereditary Cancer Risk Assessment Options/ Frequency of Discussions with Patients
- Genetic Testing Options/ Results Discussion with Patients

These were tracked throughout the Learning Collaborative with the following outcomes.

Participant Knowledge of Narrative Medicine Principles

In a baseline survey, the majority of participants (70%) reported no formal narrative medicine training, and almost all (96%) reported they had little knowledge/wanted to learn more. In comparison, when asked about their knowledge of narrative medicine principles on the post-collaborative survey, the majority of participants felt their knowledge of narrative medicine principles had increased and the majority still wanted to learn more.





Hereditary Cancer Risk Assessment Options/Frequency of Discussions with Patients

When asked about their comfort level in discussing hereditary cancer risk assessment options with patients in the baseline survey, most participants (79%) reported feeling uncomfortable or neutral. When asked how often they conducted these risk assessments, the majority (54%) responded Rarely or Never.

These changed significantly after participation in the Collaborative, with only 5% of participants reporting in the post collaborative survey that they were uncomfortable discussing hereditary cancer risk assessment options with patients and 89% reporting they now conduct risk assessments sometimes or often.

"Prior to this I didn't really think too much about genetic screening or hereditary cancers when I typically do my well women's exam or male physicals. But now that's something that I've incorporated into my practice to really hone in" - 2023 Learning Collaborative Participant





Genetic Testing Options/Results Discussion with Patients

Prior to the Collaborative, the majority of participants reported that they felt neutral to very uncomfortable when discussing genetic testing options and results with patients.

In contrast, after the collaborative, 95% of participants reported feeling neutral to very comfortable with discussing genetic testing options with patients and 80% of participants reported feeling neutral to very comfortable with discussing genetic testing results with patients.







Participants Bring Your Brave Resources – Impressions

Overall, the faculty and residents have had a positive response to the campaign materials. Reactions have included comments such as "Enlightening, Insightful, Touching, Motivating, and Eye-Opening." In addition, programs have responded that their increased comfort level with the topics and a new appreciation for the importance of hereditary cancer discussions have increased their focus and encouraged proactive behavior when initiating patient conversations.

All the programs believe that the materials will have a positive impact on patient outcomes, either through:

- increasing provider knowledge/comfort with the topic;
- increasing empathy by providing insight into the patient experience and/or
- increasing motivation by learning from other physicians' experiences.

All programs stated that materials could be used with medical staff to increase provider knowledge about hereditary cancer/genetic testing/the importance of family history. Programs saw this material being used by different levels of medical professionals within their practice, not just by the family physicians.

"..(in the Bring Your Brave video,) he notes that he didn't tell anyone in his life about his diagnosis due to stigma. In my mind, I imagine that most patients want to share their diagnosis with people they love to be surrounded with thoughts and prayers, emotional support and physical support, etc. This changed my perception on the way that some patients could be approaching their diagnosis in connection with friends/families." - 2023 Learning Collaborative Participant responding to Kenneth's Family History video

All programs stated they believe the materials provided valuable insight into patient experiences, increased awareness of personal bias/preconceived understanding of the patient experience, or stated they were positively influenced by the videos highlighting a physician's perspective.

During the first action period activity, participants were asked to review resources and report back. In total, participants submitted 164 reviews/comments for items (videos, webpages, workbooks) across three specific resource pages.

- Bring Your Brave Talking About Your Family History of Cancer webpage (total number of hours of videos reviewed– 2 Hours, 25 Minutes)
- StoryCenter Conversations About Hereditary Breast and Ovarian Cancer Save Lives Page, Workbook, and Videos (total number of hours of videos reviewed – 2 Hours, 32 Minutes)
- Kognito Let's Talk: Sharing Info About Your Family Cancer Risk Simulator (total number of hours of simulations reviewed – 5 hours, 43 Minutes)

A summary of all the comments submitted by participants is available in <u>Appendix D</u>.

"I think it is helpful to go through this exercise. As a physician, we spend a lot of time learning how to have difficult discussions with patients, but I do not always explore how they will tell others unless they ask for advice. Having these conversations can be difficult and it would be good to take that next step and offer support to patients since we are often the people preparing our patients to talk with their families." -2023 Learning Collaborative Participant

"I liked seeing those connections between family members and friends. I think that's just such a good thing. The simulations, I actually really liked. I couldn't believe how developed they were, with thought bubbles, and what is this person going to be thinking, or what might you be thinking when someone is saying something. I thought that was really interesting." -2023 Learning Collaborative Participant In response to the resource review activity;

- 100% of respondents indicated they would share videos from the Bring Your Brave campaign.
- 100% of the videos reviewed would be shared by at least one of the Collaborative Participants in the future.
- 94% of participants indicated they learned something new/changed their perspective on at least one of the videos they reviewed.

Our participants thought the majority of the resources would be appropriate to share with both patients and colleagues.

Barriers to using Bring Your Brave resources with patients and potential solutions.

While participants' responses to the materials were positive, and they envisioned recommending the Bring Your Brave resources to patients, we asked them to take a deeper dive into what recommending the materials would look like. To help shape future outreach efforts to family medicine providers, the Collaborative sought to understand the feasibility of its real-world application. To this end, we asked participants to consult with fellow healthcare providers in their clinics to determine barriers to using the Bring Your Brave resources with patients. After identifying barriers, we asked them to brainstorm and suggest possible solutions.

Interviews were conducted with representatives from each program to collect responses. The barriers identified in these interviews were grouped into the following categories:

- Physician Comfort Level (e.g., knowledge-based, emotional)
- Regulatory or Legal Restrictions (e.g., reimbursement issues, EMR integrations)
- Organizational Capacity (e.g., lack of time, lack of human resources)
- Patient Considerations (e.g., language barrier with materials provided, patient readiness to discuss topic)
- Departmental or Community Support Systems (e.g., another department handles this subject matter, lack of additional support programs)
- Logistical Considerations (e.g., lack of patient access to technology, unable to forward materials easily)

Participant solutions to outline barriers are summarized below.

Physician Comfort Level (e.g., knowledge-based, emotional)

Every program interviewed expressed knowledge/education gaps as a barrier to using the Bring Your Brave campaign. Specific issues cited as barriers on which residents and other physicians should receive additional training included:

- Insurance (health) helping patients navigate options for genetic testing;
- Insurance (life) implications of genetic testing results on future policies; and
- Genetic testing general information, what testing options are available, navigating patient burden of knowledge (how one family member's results can impact their families/responsibilities of disclosure).

Regulatory or Legal Restrictions (e.g., reimbursement issues, EMR integrations)

Discussion generally focused on technical challenges in terms of getting actionable information about BYB into patients' hands. A concern from the physicians was that while paper handouts may be easiest to provide without practice systems change, patients would not easily leap from paper to the internet to access Bring Your Brave. When programs considered providing their patients with links to the material, each program saw electronic medical record (EMR) and After Visit Summary integration as the most effective potential option. While some EMR systems are more robust than others, all programs stated that integrating links into After Visit Summaries would be possible within their EMR systems. However, integrating information into EMRs may require administrative approval, compete with other requests, and need technical skills not often readily available at the physician level. Other solutions included:

- Creating a system for follow-up calls with patients identified as high-risk to remind them about the resources and/or
- Electronically sending active links within systems such as "My Chart."

Organizational Capacity (e.g., lack of time, lack of human resources)

"What I'm finding with all of these conversations is yes, this is good for patients, but we don't have the time to sit there and go through them" - 2023 Learning Collaborative Participant Overwhelmingly, finding time to have discussions with patients was the most significant barrier to family physicians utilizing the Bring Your Brave materials. Ideally, the programs would like to provide the appropriate time to discuss the topic with patients. While using other care team members might increase the time available, participants generally saw the conversation surrounding hereditary cancers needing to with the physicians.

Solutions included:

- Adding topic discussion to new patient/annual wellness visits;
- Adding discussion to well-woman exams;
- Scheduling dedicated follow-up appointments for patients identified as high-risk;
- Creating group medical appointments or providing information during established reoccurring group appointments;
- Attaching the videos at the end of already-developed family history surveys (in-office survey on iPad during the waiting period, ending on the video page); and/or
- Utilizing other staff to initiate patient viewing videos in the clinic (e.g., having medical assistants or nursing staff start the conversation through surveys and iPads). Programs acknowledge that this option creates a set of barriers when considering the need for additional staff training/assessment of current workloads.

Patient Considerations (e.g., language barrier with materials provided, patient readiness to discuss topic) All programs saw some, if not all, of their population as open to discussing hereditary cancer. Many programs noted the need for Spanish materials or videos within their practice. One program has a population that is 90% Spanish speaking, so referring their patients to the website is not currently an option. Solutions to this included translating the materials or using captioning.

Departmental or Community Support Systems (e.g., another department handles this subject matter, lack of additional support programs)

All the programs highlighted the desire to better understand the care/testing/support options within their practices to accompany their use of the Bring Your Brave materials. Participants needed more knowledge of available resources, and also cited a lack of resources generally within the healthcare system, particularly for genetic testing and counseling. For example, the majority of programs engaged in the Collaborative do not have a referral program in place for genetic testing services. Another barrier is the time and capacity to be proactive; while most doctors will find resources to help an individual patient in the moment, it is difficult to be prepared in advance with knowledge about options. All programs identified the need for more research on available options, education for clinicians about those options, and then procedure development within their practices to create a roadmap of care and services within their system and community. Solutions included:

- Identifying resources and services and developing tools for referral
- Reaching outside the clinic/health system to identify testing services/genetic counseling services (e.g., one program uses Myriad Genetics, Inc. as their testing service. Patients are provided with a QR code directing them to the appropriate form. Myriad offers genetic counseling for their patients.)

Logistical Considerations (e.g., lack of patient access to technology, unable to forward materials easily)

The programs believe the videos are the correct length for patients. However, at least two programs have stated that the website may be overwhelming or hard to navigate for their population. In addition, programs in rural areas and some lower socioeconomic areas saw reliable at-home internet access as a barrier to using the materials with patients. In addition to adding links or smart phrases in their EMR systems, programs suggested the following options for getting their patients to access the website:

- Creating handouts/business cards/QR codes to direct patients to the resources;
- Providing iPads in waiting rooms or exam rooms during wait periods for patients to watch the videos;
- Creating community connections with groups such as patient support groups or public libraries who could be educated about the resources and prepared to show them to patients after referral; and/or
- Playing videos on TV screens in the waiting rooms.



Flyer with QR Code Created in response to requests from Collaborative

cycle of cancer that runs in families

Conversations about the cancers that run in your

family can be lifesaving. For many, it's not an easy talk to have. Scan the QR code to access material

Participants

Additional Recommendation: Hereditary Cancer Resource Folder

As one of the final action period activities, collaborative participants were asked to take the first steps in incorporating the Bring Your Brave Campaign resources in patient care. To address some of the barriers to using the resources, namely lack of knowledge and process uncertainty, participants were asked to create a draft outline for a Clinic-Specific Hereditary Cancer Resource Folder. We asked participants to include guides, procedures, and resources for healthcare providers to refer to and to identify resources to share with patients.

This exercise proved educational, requiring staff to source and compile folder assets and to determine policies and procedures, including the referral process, to use while navigating patients through their hereditary cancer journey. A Hereditary Cancer Resource Folder Template, with outline and sample documents, was developed for this exercise. The template will be housed on the FMEC website as an open-access tool for use by Family Medicine clinics and is available in <u>Appendix E</u>.

Utilizing Bring Your Brave in Residency Training

More than just reviewing the tools from the CDC's Bring Your Brave campaign, the Collaborative sought to understand how these resources, and the narrative medicine principles behind them, could prepare family medicine residents to navigate hereditary cancer conversations with patients. This includes examining how the videos and resources could be utilized to educate residents about hereditary cancer risk assessments while providing insights into patient experiences and expectations.

During the exploration of the campaign resources, faculty and residents participating in the Collaborative reported a new appreciation for the importance of hereditary cancer discussions with patients, along with an increased comfort level with the topic. In addition, many of the participants were introduced to the powerful role that narrative medicine can play in patient and physician education.

As a direct result of participating in the Learning Collaborative, 70% of participating programs plan to address gaps in their curriculum utilizing the Bring Your Brave resources.

This is an opportunity for your program to identify strategies that can be used by other medical schools and residency training programs to help prepare family medicine residents to navigate hereditary cancer conversations with patients.



During an action period activity, participants were asked to develop and submit two work plans for utilizing the Bring Your Brave campaign materials in their Residency Training Program. This could include not just training on Bring Your Brave but on many additional topics that arose during the Learning Collaborative. They were asked about topics to incorporate, the relation of these materials to existing goals for residency training, and strategies to incorporate them (see lists below).

Topics Identified for Inclusion in Residency Training

- Finding Greater Joy and Purpose in Daily Practice of Family Medicine
- Preventative Medicine Practices/Cancer Screening
- Breast Cancer in Women Younger Than 45
- Medical Genetics and Genomics
- Genetic Counseling
- Survivorship
- End of Life Care
- Narrative Medicine
- Preventative Medicines
- Patient Advocacy
- Physician Empathy and Wellbeing
- Medical Humanities
- Enhancing Empathy

Options Identified for Enhancing or Shaping Curriculum

- Curriculum Integration Faculty Curriculum Lead or Task Force Evaluation
- Faculty Meetings Presentation to Faculty to increase topic awareness
- Resident Meetings Presentation to Faculty to increase topic awareness
- Resident As Teacher Seminars
- Faculty- Resident Research and Scholarly Activity
- Grand Rounds
- QI Project
- Newsletters/Faculty & Resident Message Boards/Emails
- Guest Lectures/Workshops/Seminars
- Promotion of Internally Recorded Webinar (self-learning module)
- Promotion of Externally Record Webinar (self-learning module)
- Project Creation of Curriculum for Submission to Family Medicine Residency Curriculum Resource or MedEdPORTA





Contributions to Skills and Competencies using Bring Your Brave Resources

Participants identified several uses for the Bring Your Brave resources in training that could directly address some of the skills and competencies being developed in resident physicians. Materials could be applied and useful in the following areas:

- Developing Resident Perspective and Empathy through:
 - Exposure to patient experiences: before, during, and after hereditary cancer discussions, genetic testing, and results, conversations with families
 - Exposure to fellow healthcare provider experiences
 - Developing Resident Skills and Confidence Building through:
 - Utilizing simulators and videos to provide learning experiences
- Expanding Residents' Knowledge Base Topics, including:
 - Identifying high-risk patients
 - Risk Assessment Screening for hereditary breast and ovarian cancer (HBOC) and understanding risk factors for hereditary breast and ovarian cancer (HBOC)
 - Risk Reduction- Preventive options for individuals diagnosed with BRCA1 or BRCA2 mutations
 - Genetic Testing Options/ Referral

Summary of Integration Proposals Submitted by Participants

- 14 Work Plans for curriculum integration were submitted
- 57% highlight topics not currently addressed within the residency program
- 71% of topics selected would be a new for faculty leads

Topic Selected	# Of Times Selected
End of Life Care	1
Hereditary breast cancer / breast cancer in women younger than 45	1
Preventive Medicine Practices/Cancer Screening	1
Narrative medicine	5
Genetic Counseling/ Medical genetics	6

Options for Integration	# of Times Selected
Faculty Meetings – Presentation to Faculty to increase topic awareness	1
Newsletters/ Faculty & Resident Message Boards/ Emails	1
Curriculum Integration – Faculty Curriculum Lead or Task Force Evaluation	2
QI Project	2
Resident Meetings - Presentation to Faculty to increase topic awareness	2
Guest Lectures/ Workshops/ Seminars	3
Resident As Teacher Seminars	3

Putting it All Together

The Bring Your Brave Campaign is a versatile tool with several possible applications. This Learning Collaborative focused on the Campaign's impact on the training and skill development of family medicine doctors by incorporating campaign materials in residency training programs.

While this project was not designed to evaluate patient outcomes, the ultimate goal of this work is, in essence, to lower cancer mortality rates and save lives. Research has shown that cancer early detection and risk reduction efforts are key, and increasing the identification of individuals who have genetic mutations that increase their risk of developing cancer in their lifetime can significantly impact these outcomes. Since it is estimated that only 41.1% of primary care physicians refer high-risk women to genetic counseling, increasing the likelihood of referral and testing is one step in achieving a lower cancer mortality rate.

To increase the likelihood of family medicine practitioners routinely incorporating hereditary cancer discussions with their patients, we discovered there first must be a demystification of the genetic testing and counseling process. To begin this process, family medicine residency programs can incorporate the review and discussion of the Bring Your Brave resources with residents. This can be achieved in one-off seminars or fully incorporating a Family Medicine Genomics coursework option within training.

In addition, residency programs would benefit from utilizing the Bring Your Brave Campaign as a case study of narrative medicine principles. This serves as an opportunity to educate residents on narrative medicine techniques for their own use, while simultaneously providing information and skill development around hereditary cancer risk assessment.

While we have identified several topic areas where the Bring Your Brave resources can enhance residency curriculum, the most significant is hereditary cancer. Utilizing the Campaign to develop physician communication skills, increase empathy for patients' experiences, challenge biases, and deepen subject matter knowledge.

When these education components are offered and explored, Faculty and Residents showed a significant increase in comfort levels around hereditary cancer conversations with patients. In addition, exploring the Bring Your Brave campaign highlights and reinforces the critical role that family medicine physicians play in risk assessment and reduction for their patients. The combination of higher comfort levels and awareness of the role that family physicians play on the front line of hereditary cancer diagnostics has proven to increase the desire and the actuality of faculty and residents increasing the frequency of their risk assessment conversations in practice.

Appendix A: Learning Collaborative Communications and Reach Summary

Webpage	Hits (Sept 2022- Aug 2023)	
https://www.fmec.net/breast-and-ovarian-cancer	2,164	

YouTube	Views (From February 2023)
FMEC Learning Collaborative Learning Session 1 - 02.09.2023	33
FMEC Learning Collaborative Learning Session 2 - 03.08.2023	68
FMEC Learning Collaborative Learning Session 3 - 04.13.2023	15
FMEC Learning Collaborative Learning Session 4 - 05.17.2023	43
<u>FMEC Webinar Hereditary Breast Cancer Risk Assessment and Narrative</u> <u>Medicine – 07.31.2023</u>	9

Email	Distribution (Opens)	Clicks	
July 28 - FMEC webinar: Hereditary Breast Cancer Risk Assessment & Narrative Medicine	4,237 (937 = 23%)	20	
July 24 - FMEC webinar: Hereditary Breast Cancer Risk Assessment & Narrative Medicine	4642 (2521 = 57%)	23	
June 23 - "FMEC-Insights from our Hereditary Breast Cancer/Narrative Medicine Collaborative"	4962 (2,761 = 58%)	29	
March 29 – "FMEC-Insights from our Hereditary Breast Cancer/Narrative Medicine Collaborative"	4056 (1,083 = 27%)	30	
July 19 - FMEC in Focus Newsletter	4642 (2,617 = 59.2%)	Bring Your Brave – 8 Breast and Ovarian cancer - 8	
February 17 – FMEC in Focus Newsletter	4,224 (1111 = 27.2%)	Bring Your Brave – 3 National Association of Chronic Disease Directors - 0	

Email	Distribution (Opens)	Clicks
January 18 - FMEC in Focus Newsletter	4,135 (1,160, 29%)	Bring Your Brave – 0 National Association of Chronic Disease Directors - 2
December 16 - FMEC in Focus Newsletter	4,405 (1,180, 28%)	News Release – 2 <u>Bring Your Brave</u> – 2 <u>National Association of Chronic Disease</u> <u>Directors</u> - 2

Appendix B: Participating Family Medicine Residency Programs Information

- Geisinger Health System Family Medicine Residency Program Lewistown
- Greater Lawrence Family Medicine Residency Program
- LewisGale Medical Center
- Mercy St. Elizabeth Youngstown Family Medicine Residency
- Middlesex Health Family Medicine Residency Program
- Penn Medicine Lancaster General Health
- <u>Temple Family Medicine Residency Program</u>
- UConn Family Medicine Residency Program
- <u>United Health Services/Wilson Family Medicine Residency Program</u>

Name of Family Residency Program	City/Town	State/ Province	ZIP/ Postal Code	Please describe the type of residency program associated with your department.	What is the approximate size of the community in which your department is located?	Program geographic region
Geisinger Lewistown Rural FM Residency	Lewistown	PA	17044	Community- based, medical school affiliated	30,000 to 75,000	Rural
Family Medicine Residency at St. Elizabeth Youngstown Hospital	Youngstown	ОН	44504	Community- based, medical school affiliated	150,001 to 500,000	Urban, inner city
Temple University Hospital Family Medicine Residency Program	Philadelphia	PA	19140	Medical school- based	Less than 30,000	Urban, inner city
UConn Family Medicine Residency Program	Hartford	СТ	06105	Community- based, medical school affiliated	75,001 to 150,000	Urban, inner city
UHS Wilson Family Medicine Residency	Johnson City	NY	13790	Community- based, non- affiliated	Less than 30,000	Small city or town
Middlesex Health Family Medicine Residency	Middletown	ст	06457	Community- based, medical school affiliated	30,000 to 75,000	Small city or town
Penn Medicine, Lancaster General Health Family Medicine Residency Program	Lancaster	РА	17602	Community- based, medical school affiliated	30,000 to 75,000	Urban, not inner city
LewisGale Medical Center Family Medicine Residency Program	Salem	VA	24153	Medical school- based	Less than 30,000	Suburban
Greater Lawrence Family Medicine Residency Program	Lawrence	MA	01841	Community- based, non- affiliated	75,001 to 150,000	Urban, inner city

Session	Date	Торіс	Overview	Moderators/Speakers	Action Period Activity
1	02/09/2023	Introduction: Background on Storytelling in Medicine + Background on Hereditary Cancers in Women	Welcome and Learning Collaborative Overview/Goals followed by presentation on narrative medicine background/benefits. The session will include a presentation on hereditary cancer background and on overview of the Bring Your Brave campaign, followed by an overview of the Action Period assignment and Q&A session.	Scott Allen, MS Philip Day, PhD Susanna Evans, MD, FAAFP Anya Karavanov, PhD	Learn about Bring Your Brave. Activity One- Participants will review the Bring Your Brave - Talking About Your Family History of Cancer - Overview Page and provide impressions. Participants will select at least three videos for review. Activity Two- Participants will review the StoryCenter - Conversations About Hereditary Breast and Ovarian Cancer Save Lives Page, Workbook, and Videos to provide impressions. Participants will select at least one story from the Workbook and watch the corresponding video. Provide feedback on the video and workbook discussion questions. Participants will select at least one Healthcare Provider story from the page and provide their impressions. Activity Three- Participants will review the Kognito - Let's Talk: Sharing Info About Your Family Cancer Risk and provide impressions.

Session	Date	Торіс	Overview	Moderators/Speakers	Action Period Activity
2	03/08/2023	Bring Your Brave Tools and Resources: Participant Reactions and Sharing	Welcome and Discussion on Learning Session One Pre-Survey Results – Discussion on the responses from the Learning Session 1 pre- survey, with a focus on where participant discomfort with the topics stems from. The session will continue with an overview report on the results from the Action Period One Activities, followed by a moderated group discussion on participant impressions from Action Period One Activities. The session will conclude with an overview of the Learning Session 2 Action Period Activity and Q&A session.	Scott Allen, MS Philip Day, PhD Tracey Conti, MD	Barriers and Solutions for Utilizing Bring Your Brave in Clinic. Consider using the Bring Your Brave materials with patients. Identify any barriers to use and identify potential solutions. Talk to your colleagues and identify issues that may limit using the Bring Your Brave materials. Once you have identified barriers, brainstorm solutions. Select at least one representative from your Residency Program to report back during a 30-minute interview.
3	04/13/2023	Strategies to Integrate into Residency Training	This session will focus on how to train current and future residents about the issues raised during the project. The session structure will involve Advisory Committee members discussing how they do/would teach related content in their programs and will include an open discussion about how these issues are currently taught within participant programs. The session will also solicit ideas from participants on what additions to programming could be made available to prepare residents to utilize the Bring Your Brave materials to improve their understanding of the topics and to translate this into their practice.	Scott Allen, MS Adam Perrin, MD, FAAFP	Develop two work plans for utilizing the Bring Your Brave campaign materials in your Residency Training Program. Consider how you could use the Bring Your Brave campaign to enhance your current Residency Training Program. As a group, identify topics and integration options for using the Bring Your Brave campaign materials within your residency training program. Pick two topics/issues/skills and complete separate simple work plans for each on how you might integrate education opportunities into your program if you could enhance the curriculum, add lectures or projects, etc.

Session	Date	Торіс	Overview	Moderators/Speakers	Action Period Activity
4	05/17/2023	Strategies to Integrate into Patient Care	This session will focus topics such as identifying patients for discussion about hereditary cancers, available screening tools and how to use them in practice, and referral for genetic testing or other supports. Session will conclude with an overview of integrating genetics into family medicine.	Scott Allen, MS Susanna Evans, MD, FAAFP Mylynda Massart, MD, PhD	Create a Clinic Resource Folder- As a group, draft an outline for a Practice Resources Folder for your clinics. The resource folder should include guides and resources for the medical team and patients. For example, for the residency program/clinic, identifying provider fact sheets and education materials, compiling a referral/resource list for providers to support patients, and identifying your options utilizing the Bring Your Brave materials. For patients, identify at least three local support resources available to patients (community group, social service agency, church program), and identify options for providing patients access to the Bring Your Brave campaign (e.g., printed materials, forwarded links).

Session	Date	Торіс	Overview	Moderators/Speakers	Action Period Activity
5	07/31/2023	Hereditary Breast Cancer Risk Assessment & Narrative Medicine: Resources from FORCE and What We've Learned through the Collaborative	 This session will a discussion on FMEC's collaborative insights, including a need for increased genetic testing training for family medicine practitioners, ways of applying narrative medicine practices, and how you can utilize the Bring Your Brave Campaign tools: In clinic with patients beginning or during their hereditary cancer journey For healthcare provider skill and competency development As a curriculum tool in family medicine residency programs In addition, special guest Dr. Piri Welcsh, VP of Education at FORCE (Facing Our Risk of Cancer Empowered), who will provide insights on supporting patients through their hereditary cancer journey. 	Scott Allen, MS Tracey Conti, MD Philip Day, PhD Susanna Evans, MD, FAAFP Adam Perrin, MD, FAAFP Piri Welcsh, PhD	Help Spread the Word About the Bring Your Brave Campaign Contact other departments or specialists in your health system, or community groups in your area, to provide them with information on the Bring Your Brave Campaign. Become an ambassador for these important resources. This will also help your program to build or strengthen a network of partners in your area for you to call on. We have provided you with an email template that you or your administrator can forward to individuals or groups you believe would benefit from having the Bring Your Brave materials in their toolbox.

Summary of All Comments Submitted Review of Bring Your Brave - Talking About Your Family History of Cancer

Title	Bring Your Brave - Talking About Your Family History of Cancer - Overview Page		
Comments	Comments		
	Easy to navigate. I can see patients finding this easy to peruse and find what they are looking for or quickly glance at clip titles to see what they want to hear more about.		
These videos were very impactful and something I will share with the residents at our program.			
I really liked that the initial text was concise with a big list of videos and patient stories. Both of the first videos are of men. Maybe have one of the initial videos be a woman since women are the most affected by breast cancer. There is a perception among patients that "male" health issues receive more attention but conversely there is a misconception that breast cancer only affects women. I think having both a male and female story as the first 2 would be important.			
	maybe I was on the wrong page, but there wasn't much information on this page other than the videos which are very great. I think the page is a good place to house all of the videos with information		
Was a little hard to get to but then I red	lized their was a link in this document. I liked that calculator		
Reviewing this page is extremely impac	tful. It is a whole different story when patients tell their own stories.		
How important open ended questions of situations compared to any yes/no q	re because it allows you to discover more about the patient and their understandings uestions		
Comprehensive, good material for patie	ents and their families. Easy to navigate, important information conveyed.		
Title	Kenneth's Family History of Breast Cancer: Finding Strength Through Connection		
	Comments		
The content resonated with me due to my FH of cancer in a grandparent and in a parent. However, what did not resonate with me was the patient's approach to connecting with others. He notes that he didn't tell anyone in his life about his diagnosis due to stigma. In my mind, I imagine that most patients want to share their diagnosis with people they love to be surrounded with thoughts and prayers, emotinal support and physical support, etc. This changed my perception on the way that some patients could be approaching their diagnosis in connection with friends/families. My approach to patient care might change because now I might be more likely to ASK a patient with hereditary cancer (or any cancer) if they are sharing this with their families/friends and what their support system looks like. I'm not sure this video was high yield for residency training, but would be worthwhile in general to broaden the medical professional's perspective on how a patient might be dealing with the diagnosis, and how they may be without much support (be choice or possibly not by choice). Additionally, I do think that this video helped to demonstrate that BRCA genes are an issue in men as well as women. Currently USPSTF mentions "women" only in their recommendation, which is problematic.			
It is good to hear from a male patient's perspective regarding herediatry breast cancer as it is not well talked about and patients aren't usually educated about it. It shows the importance of assessing for family history of medical conditions and raises awareness on breast cancer in male patients. Would be education for both patients and providers.			
I love this story. When we think of the 'typical' breast cancer story, Kenneth's is an outlier. We often don't think of men having breast cancer let alone a young healthy man. It brings attention to an often underlooked populatino of breast cancer patients. Very powerfully told story in a relatable, palatable way. I think the pictures of him and clips of him with his family were more			

powerful than the cuts to a surgical room and lab pipettes. The picture near the end of him at a breast cancer walk in a pink shirt and ending with him saying "That's strength" was beautiful!

I did not recognize the stigma that may be associated with male breast ca

This video resonates with me in regards to patients I have seen in the clinic presenting with very rare forms of cancer be it rare per gender or just pathophysiology. I believe the narration of this experience is powerful as it helps patients in this situation feel connected and not alone. They are able to see that others have passed through this, although not an easy journey but they will scale through.

I appreciated his story. Interesting perspective to hear from a man with breast cancer as this is not common.

It does a good job of humanizing breast cancer, especially in those for whom it is not very common

This video gets rid of the misconception that only women can get breast cancer. It gives a very powerful message.

I was not aware that men can get mammograms

Key reminder that men can also get breast cancer. I have a close male friend who survived advanced breast cancer. His description of his experience is harrowing and he is very grateful for having highly knowledgeable and caring oncology team.

Title

Dr. Alter on Asking the Next Question

Comments

the delivery of this information is very impactful, especially in using the patient/family story. I think I am struck by this because the video is asking us as clinicians to be sure to ask the next question, and that even if someone says "no family hx of cancer" on the sheet, it is our job to ask further questions to ensure that is true. Especially when many of my patient's only speak spanish and I have to make sure the questions are also not being lost in translation through our conversations.

Good to hear perspective from an Oncologist regarding cancer risk assessments. The example he gave is powerful in that it shows the weight of getting thorough family history not only to identify risk factors for patient, but also the families of the patient and for generations to come. It highlightes the responsibility we have as providers to work with patients to assess risk factors and provide appropriate guidance to patients and their families who may be at risk.

An incredibly powerful patient case shared by Dr. Alter where digging deeper into their family history of cancer led to massive ripple effects and potentially saved numerous lives in one family. Encourages me as a primary care doctor in training to always take a few extra moments in my visit with a patient to ask these important questions.

Was excellent reminder that patients initially may not recall/remember family members with cancer

The approach to history taking matters. Asking questions in simple and clear terms while avoiding complex medical terms or ambiguous words is helpful in obtaining family history. Breaking down medical terminologies while narrating examples help the patients understand the importance of these questions and testing better.

This resonated with me because we do not always ask for extended family history of breast cancer. We focus so much on 1st generation family members and this may cause us to miss so much. I think this is a very important message for residency training.

Good at giving ideas on how to educate family on breast cancer screening

Including more provider videos will also make a powerful impact on the viewer.

Thorough family history taking and expanding on what they tell you

I already practice cimilar	rf to thonhucician in tho u	idoo hut think man	w others may herefit
i uneuuy pructice siiniiui	rf to thephysician in the v	ίαεο σαι ιππκ παπ	y others muy benefit.

Title

Don's Family History of Breast Cancer: Taking Responsibility

Comments

Don's story shows the importance of obtaining appropirate family history and screening for herediatary mutations based of risk factors as well as discussing with patients about risks and benefits of management options that are available. It reminds us the reponsibility we have for our patients to get appropriate screening and follow up.

A different perspective from a voice often unheard (men) and explores the stigma around the diagnosis.

Don has a unique perspective to share his story as a surgeon as well as a patient. He is very passionate to talk about the genetic link between cancers and sharing that risk and undersatnding with his family. He even shared he had a hesitancy to find out if he carried BRCA gene, however once he knew, he was immediately proactive. I think this story is especially meaningful to share with everyone in healthcare.

I liked the idea of sharing the experience from a medical professional, but I did not find Don easy to feel a connection with.I liked that he talked about his putting off testing longer than he knoew he should have given his family history. I think that is very relatable. But I would have liked to see some more vulnerability in the why of putting it off (the fear, the "I don't have to deal with it if I don't know") that patients tend to wrestle with. Maybe because I am a female, but his discussion came across as not just his story but a bit of a paternalistic, one-size fits all. I also didn't like the way he described the heritability as "spreading it" to your kids. This was his journey and is as valid as anyone elses and he is brave for sharing, but I didn't connect well with it. Maybe others including some high-achieving men may find Don's story resonates with them.

Consider that some people may be afraid of getting dx or in denial

This makes me view obtaining family history very pertinent and therefore has given me a different approach to patient care even during regular visits. As a family physician, it is essential to obtain patient family history in order to be able to educate them timely to get tested. I understand that some patients might refuse the information due to fear, but I belive through narrative medicine, it makes the approach lighter and their response to the approach better.

Don's story appealed to me as a physician. He aknowledged that breast cancer in men was uncommon but that testing was important despite this. I will use these two exampled in my practice because I do not usually forcus very much on history of breast cancer when speaking to men. I will look into this further in the future .

It emphasizes how a lot of times men will die of breast cancer because they don't think it's possible for them to get it. It would be a good thing to show patients to explain the importance of genetic testing, especially in men who might be BRCA positive.

Title	Allison's Family History of Breast Cancer: Trusting Your Doctor				
Comments					
together that both she and her sister ha planning next steps. I think it is greatly as it influences how I discuss breast can	lary as it reminds me of a friend's family story. She found out while we were in college ad BRCA gene, which had also led to their mother's early death. The heaviness of beneficial to have physician's hearing patient's stories such as Allison's or my friend's, acer risk. I love that Allison found a doctor she trusted who was able to walk her through at perspective to learn from while in residency training.				
This video speaks to the importance of a strong patient-provider relationship and how trust between the two can transform a scary, vulnerable situation into an empowering one. I hope to be that physician each and every day with my patients and this reminder motivates me that much more to continue being there for my patients and connecting them to specialists with these similar qualities.					

because in the current climate, I think ti	eo use of almost scrapbook-style photographs. This is an interesting video as well here is a lot of distrust for the medical field.		
I appreciated this video because it show patient's perspective about what they f	is how important those first meetings with patients are after diagnosis. It gives the ind helpful from their providers.		
Important to find a knowledgeable, con	npetent and empathetic doctor to manage your care and help you navigate the system		
Title	Title Erika's Family History of Breast Cancer: Facing Your Risk at a Young Age		
	Comments		
	ge is power. The power to change the outcome. By getting tested and finding out she make a decision that will ultimately save her life.		
knowing they can find support as Erika	Il for younger patients to recognize their risk and to face those challenges head on and did. She felt isolated and so sought to change her own story by sharing and finding each other. I find this impactful to hear about her change from fear to bravery.		
many people don't think of a young, sin partner or adult children to care for the	owerful about Erika's story; the first being the point she made herself which was that agle woman going through this experience. Not everyone wiill have a supportive em; even more so when it is a young person. I think it is inspirational that she used her eing that example that was lacking for her.		
Trained to screen and consider genetic	predispositions early on but many can benefit from the material.		
Teaches the importance of early identif factors you possess, the earlier you sho	ication and that fact that breast cancer can strike at a very young age. The more risk uld initiate the screening process.		
Title	Shira on Pointing Patients in the Right Direction		
	Comments		
	very moving. This video highlights our roles as clinicians to be sure we don't overlook o offer our patients all the available resources like speaking with a genetic counselor to		
discuss options.			
all of their annual visits. However, I do be very complicated with multiple medi responsibility to know all about their pa	ob as a family medicine doctor/PCP to discuss my patients' family histories with them a not think that this is prioritized by all providers in my FQHC where our patients tend to cal issues. This video would be helpful to remind primary care clinicians of their ntients' medical and family histories in order to provide them evidence-based . I do think that this video might be useful to show to residents in training.		
I personally have realized that it is my jo all of their annual visits. However, I do be very complicated with multiple medi responsibility to know all about their pa recommendations on genetic screening	not think that this is prioritized by all providers in my FQHC where our patients tend to cal issues. This video would be helpful to remind primary care clinicians of their rtients' medical and family histories in order to provide them evidence-based		
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I personally have realized that it is my je all of their annual visits. However, I do be very complicated with multiple medi responsibility to know all about their pa recommendations on genetic screening Not a lot of genetic counselors in rural o Effective reminder that we have the too	not think that this is prioritized by all providers in my FQHC where our patients tend to ical issues. This video would be helpful to remind primary care clinicians of their ntients' medical and family histories in order to provide them evidence-based . I do think that this video might be useful to show to residents in training. areas; challenges associated with ordering and interpreting tests on our own ols to identify those at risk and to act before cancer strikes		

The video goes a long way in communicating the acceptance of diagnosis and taking the necessary steps for prevention.			
How important support is- and being able to talk about what different types of support may look like for them and guiding them and encouraging them to talk about it with someone they trust			
Title	Title Lauren's Family History of Breast Cancer: Breaking the Cycle		
	Comments		
The message that this patient was BRCA negative and now is left without answers about where the familial pattern of breast cancers is coming from would certainly leave questions for other patients (and clinicians). I feel that this video wasn't as helpful as the others in convincing patients to consider genetic screening/testing. It might also deter some clinicians from offering testing if their patient doesnt want more ambiguity. The video WAS helpful in ellucidating an issue that we do not have a good answer for yet. Maybe if you included information about other genes associated with breast cancer (and was this patient tested for them or not?), as well as VUSs and how most testing companies are committed to following up with patients with VUS. Additionally, you could include in this video that although Lauren was negative for BRCA, which is reassuring, her increased risk of breast cancer based on family history alone would qualify her for increased surveillance for her entire life			
Title	Ricki's Family History of Breast Cancer: Being Black with Breast Cancer		
	Comments		
women don't want to talk about health	"She didn't think about cancer in our family until I got sick." This quote to me is so important. Interesting perspective on why women don't want to talk about health and how this perspective is different based on racial and social background. Important emphasis on difference in incidence particularly for health care providers as well.		
I did not know that black women had tv	vice the rate of breast cancer as whites under age 35		
Yes, my patient population is majority a	frican american and female. Important to push them to find out there family history.		
Title	Eli's Family History of Breast Cancer: Taking Control		
	Comments		
	Recognizing that in many families, people do not discuss cancer hx. This video highlights how different cultural backgrounds can influence how a patient and their family discuss their history and cancer risk.		
I frequently hear from patients that "my family does not talk about their health" because it is "private". I thought it was especially interesting that she was discouraged from obtaining her prophylactic mastectomy when she did discuss it with her family. I think that this difficult decision and the perception of going against family traditions/recommendations or "faith" could be very valuable to patients facing a similar situation. I did wonder why she decided to see a genetic counsel/get tested. I assume she had a family history of breast cancer. Maybe this could be put into the video description.			
Title	Lexie's Family History of Breast Cancer: Learning from the Past		
	Comments		
Reminder of how a simple question abo	ut FH may be very difficult for some patients		
Title	Arnaldo and Vanessa's Family History: Facing Breast Cancer Together		
Comments			

can fe	This was a great video that addressed the misconception that men cannot get breast cancer, but also the guilt that a parent can feel passing on the genetic risk to children. This was a powerful story of friendship and support in a family that transcended the traditional parent/child role.			
Title	Dana	Dana's Family History of Breast Cancer: Having the Conversation		
	Comments			
How i	How important having these conversations are- though tough			
	Title	Hannah's Family History of Breast Cancer: Feeling Lucky		
		Comments		
The th	The theme "feeling lucky" really resonated with me. This video makes me thing about the importance of screening.			
	Title Tallulah's Family History of Breast Cancer: Facing the Elephant in the Room			
	Comments			
	The delivery of Tallulah's story was most impactful and highlighted the importance of addressing the elephant in the room; that conversations hold power.			
MUST	MUST DISCUSS and physicians must initiate the disucssion.			
	Title	Ashley's Family History of Breast Cancer: Finding the Courage		
	Comments			
n/a (v	n/a (was not viewed by any project participants)			

Summary of All Comments Submitted

Review the StoryCenter - Conversations About Hereditary Breast and Ovarian Cancer Save Lives Page, Workbook, and Videos

StoryCenter - Conversations About Hereditary Breast and Ovarian Cancer Save Lives WEBPAGE
Title

https://www.storycenter.org/case-studies//conversations-about-hereditary-breast-and-ovarian-cancer-save-lives

Comments

Good resource to include patient and provider perspectives on family history and cancer risk. Reviewing this page makes in clear that these types of personal stories can make others feel the drive to talk to their own families about their history, because it makes me want to do this better with my own.

The overall idea is good, but it would be helpful if the videos each had a longer description so you knew what you were going to be hearing about. I had to go to the workbook to understand what I would be watching in the many videos listed, which took an extra step.

Videos are short and helpful for patients to learn from each senario

I love that there are so many different stories and individuals sharing their experiences. There are so many pieces of the stores that are powerful and can connect with different patients. They are the perfect duration for the videos and the graphics draw you in and keep you engaged.

Great resources. I just wonder how patient's find this if not their provider showing it to them.

This is an outstanding and highly impactful resource that should be regularly utilized.

Title StoryCenter - Conversations About Hereditary Breast and Ovarian Cancer Save Lives- WORKBOOK

Comments

The discussion questions might be helpful for a moderator in a learning environment. The questions helped push me to remember the many facets of discussion and emotional responses that might come up with this content.

helpful discussions to have in group settings to see how a situation can affect patients in several ways, and what we need to understand before helping them, and anticpating the questions that may arise.

Again great resources. How is this workbook being distrubuted?

Reading through such material makes me think- Well I have never given a thought to this! I am sure it will be the same for patients.

Really gets to the core of the issues through relatable case studies/stories and thought-provoking discussion questions. Narrative Medicine model at work. Inspires reflection.

STORYCENTER SURVIVOR AND FAMILY STORIES

Title J	Just for Fun - by Leslie Sidell			
	Comments			
Explains different senarios that can change the outcome of the way one views something and the next steps				
Brings up	very important question of insurance coverage now and in future			
	Interesting persepctive that it was not recommended for testing in mother and patient had it done anyway. This is not an option for everyone , as presumably that initial genetic testing was paid for out of pocket.			
	s video inspire ppl at low risk to do brca testing? There really needs to be more about the implicaitons of this-ie e, life insurance, etc.			
Title	Let's Talk About It - by Caitlin Meyer Krause			
	Comments			
Encourag	Encourages family discussion, and her honest reaction to getting a dreadful phone call of bad news is very realatable			
Considerations with fertility, timing, etc				
Title	Sisters Stories' - by April Bell			
	Comments			

This video gives a good perspective on the importance of educating /encouraging patients to have conversations about hereditary cancers in their family and genetic testing if needed as it has the potential to save their lives and the lives of their families for generations to come.

Shows different outcomes within the same family and How much speaking about it can alter its outcomes/ treatment

this video really spoke to me because I have two sisters that are very important to me. My family historically has been very closed off about speaking about their medical problems and do not like to talk about screening because they believe it is bad luck to discuss things like this. The discussion questions were thought provoking. I think this could be a really meaningful thing to review in a group visit.

All stories provide great perspective on why people do or don't get tested. Would be great to direct patients to these because they humanize these diagnoses

Importance of finding a communitt and talking about cancer diagnosis. I think it is important to be up front about going through testing especially if multiple siblings passed away, there is likely to be a genetic component that is unknown to the family. She may feel guilty or even that it may be a false negative. I would like my health care provider to sit down and have an honest conversation with me and remind me that though unfortunate it is ok to have this guilty feeling though nothing of it is her fault. Treatment may have been delayed. I feel like its important to start these conversations and form a community for support.

Beautifully animated story that is devastatingly sad. Relates a difficult lesson, screams for early action. Factors in health disparities. Heavy emphasis on communication between family members being vital.

Title I Talk About It - by Debra Austin

Comments

I think (as suggested in the workbook) that this is a great story to open up a discussion about systemic racism in medicine and the challenge of trust with a traditionally marginalized population. It is so interesting that she seems to have discouraged her niece from prophylactic procedures depite her BRCA mutation (seems to imply more mistrust of the system). It also brings up challenges with the delicate balance of advocating for ones self/family vs. going againt EBM. I wonder how her family hear her story; one of an inspiring, strong, survivor but also a good reason to not trust the medical profession? I wonder how that will affect how her family choose their care and develop the health plan that is right for them. The mistrust can both help and hurt. It is such an important discussion of how to we rebuild that trust and address systemic racism both personally, locally, and nationally.

As physicians, we should be proactive with screening exams and tests. Hearing and narrating these stories to fellow physicians help them understand the need for proactive screening and obtaining pertinent history. We come to understand that we should not water down patient's concerns as little as they may seem.

Its important to understand culture. As a black woman myself I am hyper aware of the issues that prevent conversations but I do believe many others may benefit from the material.

Title	It's Time to Have the Conversation - by Deborah Binder		
	Comments		
"Stomac	h cancer" = female cancer in 40's, 50s		
Title	I Thought I Was Safe - by Cheri Taylor		
	Comments		
	/ was impactful because it made me think about if I was the clinician for this patient. It is a good reminder that people cisions for reasons we may never know why because we aren't them. This patient shared that the fear of the surgeries		

was worse to her than the fear of getting ovarian or breast cancer again. So she chose to do survelliance and was diagnosed with late stage ovarian cancer. As clinicians we can never judge a patient for their decisions. It is our job to ask more questions to see why they made the decision so that we can best support them throughout.

This story from Cheri is important to hear from the perspective of a patient who did not feel she understood all of her risks particularly about ovarian cancer. It tells us physicians that we need to explain better and also ensure the patient can make wel

The sentiment shared by this patient is so important to be aware of as a PCP. That just because I may not agree on a patient's decision, my judgment has no place in the patient encounter and that a thoughtless question can have massive repercussions in a

I do appreciate the insight that preventive surgery is often scarier than recurrence because it is so different from how I would view things. The graphics of the stories threw me off and took me out of the narrative a bit - which is a shame because I thin

Title Do Not Wait - by Felicia Johnson

Comments

I'm not sure this added much to the clinician/provider education except that maybe it is an example that clinicians need to take family histories and advocate for their patients to get testing/screening. Maybe if the positive FH had been addressed by Felicia's PCP, she wouldn't have ended up with metastatic breast cancer later in life. I do think that it speaks to the patient who might be waiting around thinking that they should consider screening/testing due to their family history. As far as the Discussion Questions - I think that Felicia's family members could have talked with her about the patterns she was seeing in their family, instead of being quiet about them. If a parent/loved one is undergoing cancer treatment, it is important to ensure that the children can visit their parents regularly and spend time with them when they are healthy (and not sick from chemo). Additionally, a memory book/videos to watch when their parent is away getting treatment might be helpful. Without the ability to get genetic testing in older generations, these patients were left with an unknown and grey area and were not able to share specifics with their family members. Although older generations are likely more hesitant to obtain genetic testing of their own (due to privacy concerns mostly), I do think that in general they are probably happy that the generations to come have access to knowledge that could help prolong their lives.

Title Lucky - by Carla Jimenez

Comments

Comments

This story and the workbook prompts for discussion being up excellent discussion points and provides another path; what happens if my testing is negative in the setting of cancer at a young age and a strong family history?

Title Waves - by Christina Hibbert

beautiful, inspiring, poetic

······································			
Title	Safety - by Sherri Orenberg-Ruggieri		
Comments	0		
Title	Surrender - by Vilma Haas		
Comments	0		
Title	Beginning Conversations - by Shana Beigelman		

STORYCENTER HEALTHCARE PROVIDER STORIES

	Comments
cancer gen	his video shared the perspective of a doctor who suffered from an era that we did not have genetic testing for es. I think this message is strong for both clinicians and patients. I did think that the speaker was very monotone Id have been more engaging to have a video of her talking at some point, as well as a more dynamic voice.
Being supp	ortive for patients to help guide them with the decicison they make, and to help them make a informed desicion.
Reminder o	f how rewarding this can be and how a lot of us have personal reasons for what we do
l appreciat	ed that this showed the perspective of being a physician but also how it related to her personal experiences.
Title	Family Discussions - by Joyce Turner
	Comments
	lpful perspective and story to share about navigating the particular challenges and potential stress or even harms ning aware of results of genetic testing. It also emphasizes the importance of allowing each individual to make the
Very Powe	ful message about awareness and acceptance of hereditary cancers and genetic screening.
Gorgeously big way.	rendered video that gently reveals a difficult story and many challenging questions. Promotes self-advocacy in a
Title	Best Laid Plans - by Martina Murphy
	Comments
and their c	s a good reminder that we too as clinicians are human, and that it is okay to feel emotions for our patients' lives ircumstances. I enjoyed this video it gets at the idea of discovering what is important to our patients in their lives g them turn those into goals and priorities through the course of illness and disease.
	paints a picture about the challenges of diagnosis and management of hereditary ovarian cancer. It highlights the e of providing appropriate support and presence for patients as they are going through difficult journey.
Very touch	ing
through ea have come	e the role of physicians as patients go through the hardest times of their lives after cancer diagnosis. How they wal ch step with them and be strong for them. How they show up for them while trying not to absorb the emotions. I to realize that these situations are also tough on the caregivers. Narrating these experiences help physicians the care of patients diagnosed with cancer understand that they are not alone, they are seen and their emotions
Good remii	nder that your patient's goal may be different from your own

Comments

We come to our patient encounters as a whole person, who may have personal experience with the diagnoses we are about to share with our patient. That role is so unique and its power is important to remember as I continue residency and start practicing on my own.

Strong opening with the pause after "resist." The drawings of the woman went well with the narrative. It sounded like a story slam with the delivery of the words and the music which I appreciated.

Title Appointments Kept - by Elizabeth Stark

Comments

It is easy to assume that patients know cancer isn't their fault, but yet many patients still feel that way; paricularly if they defered screening they knew was important (CRC, mammogram) or smoked. There is a persaive feeling of "not wanting to be a burden". This was a great video because she experienced the challenges from all 3 points of view- the medical provider, the family, and the patient.

Reminder that all genetic cancer links not discovered; difficulties with consent/children, etc

not sure who would benefit from this video, more of a provider perspective, possibly helpful for patients

Having conversations with family members about how important it is to show up to appointments for preventative measures. Also to have providers reach out to try and guage why patient may keep missing appointments and if there was anything they can do to help so they can come to the appointments.

Although I try to investigate I do not always do an extensive job trying to understand ones barriers to treatment, appointments, etc.

Summary of All Comments Submitted

Review the Kognito - Let's Talk: Sharing Info About Your Family Cancer Risk

Title	Family Risk Linda	
Comments		
	ople who may be afraid of talking to their family because the guide can help you brainstorm what to say next and make r about what you want to say.	
informative. It of their family	at first, however I found the many different options to choose from made this more interesting to use as well as is very well put together. In my experience, many younger patients (and especially teenagers) are completely unaware history. I appreciate that this was addressed as well as how to bring it up to children or teenagers in the first place. It emphasize patient autonomy in making decisions, and this did a great job of point that out.	
	ep, nonjudgmental guide about how to discuss cancer risk with family members can be so helpful. It's easy to assume know how to have these conversations and that is not always the case. Having a resource to quide them through these	

and it would be good to take that next step and offer support to patients since we are often the people preparing our patients to talk with their families.

I liked the options of predicting how the family may react - doubt, denial, etc and why they react that way (ie fear vs don't talk about health). But I am not sure if this mode of starting that thinking process is better than a video or paper talking about it. Of course, everyone processes differently so some may really appreciate this modality. It was easy to navigate.

I realized I was not as good as I thought at having these discussions. The feedback after choosing certain responses was eye opening and helped me see that there are better ways to bring up these discussions.

It really does a great job of showing you how to start these difficult conversations and could be helpful for providers and patients alike

Be positive and direct, ask how they are feeling,

This particular simulation could be a great tool for patients. Allowing them to truly think through genetic testing and how it affects the whole family, not just themselves.

Would not recommend. Relatively clunky, graphics not great. Info better acquired through resources reviewed in Activity 1 & 2.

Title Talk with Sydney

Comments

I like this activity because its good practice with having these conversations that likely seem scary before you do it. The app also gives you feedback on how you met each domain and tips to improve.

I wish one of them was an older family member to talk to, however it still was beneficial to go through the concepts twice. The conversations felt similar to each other. I did like the feedback given and that you could choose different answers and see the response.

Being able to practice the discussion with such a well-made and thoughtful simulation will be so helpful for patients who may be unsure or scared of having these conversations with their family.

Obviously the choices are limited so are not necessarily the phrasing/approach I would take, but it could still give patients the opportunity to practice and hopefully increase their comfort going into a conversation. It would be nice to have other sims like sharing with a partner or adult sibling.

It was hlepful to think of phrasing but as the simulation went on it felt a bit redundant to me. I do think I could use this as a guide to helping patients start these conversations with me having done the simulation and then discussing it with them in real-time in the office.

I recognize the importance of early information and knowledge building confidence. With early information, you are able to take charge of the outcome of the story, make early informed decisions and avoid the consequences of late outcomes. I also learnt that it is important to express mutuality and inclusion through narrations. It allows the person you are narrating to understand that their feelings are not strange and that youhave felt the same way or most people feel the same way when they hear these kind of news for the first time. It is essential to show support as that makes the recipient feel safe and more vulnerable.

A lot of good information in this and some real responses from Sydney. I am impressed by how knowledgable Linda is. I thought this was very informative but I thought this simulation was trying to push for a lot of the conversation to happen in this first discussion. This is such a big discussion and I think bringing up the information and setting the stage for future discussion is helpful, I eventually got there but it was not an option as soon as I wanted it to be.

This simulation is long and detailed. The virtual coach and thought bubbles along with choices of next part of conversation may be too much for some patients. As a physician was also hard to keep my attention.

Title	Talk with Aaron	
Comments		
The simulation does a good job of teaching both providers and patients about initiation of conversation regarding hereditary cancers. It shows good communication methods and encourages patients to think about having similar conversations with their own families.		
This one was more direct and easier to go through I think. It was still beneficial to review how to share this information. This conversation also felt somewhat more genuine than the one with Sydney .		
Title	Reflect	
Comments		
I liked receiving the feedback even if some of them were intentional to see where the conversation went.		
Found the tool to be very helpful and learned some pointers that I hope to bring into my patient visits when discussing genetic cancer risk. I will be sure to share this simulation with patients looking for resources on how to have these conversations.		
Did bring up some interesting points		
Title	Resources	
Comments		
it can be helpful to provide patients with materials to take home to further review things you discussed in the office. I think the "Sharing Info About Family Cancer Risk" is helpful because it outlines that there are many ways to share info with one's family and gives the patient options and resources.		
Hereditary Risk information was helpful to me - but I wonder if it is at a higher level than the general patient population? Maybe some diagrams/illustrations would help. Love the email/letter templates. Increasing visibility of Direct to Consumer test information might be helpful.		
Excellent resources especially online or over the phone resources I didn't know existed.		
Yes- explored		
A lot of good resources.		

Appendix E: Template for Clinic Hereditary Cancer Resource Folder

Please use this template to create a resource folder for your clinic. Folders can be electronic, and/or hard copy for easy access.

The resource folder should include guides and resources for the medical team and patients.

For the residency program/clinic:

- identify provider fact sheets and education materials
- compile a referral/resource list for providers to support patients
- identify your options utilizing the Bring Your Brave materials
- provide option for news and latest research/resources to be shared

For patients:

- identify options for providing patients access to the Bring Your Brave campaign (e.g., printed materials, forwarded links)
- identify at least three local support resources available to patients (community group, social service agency, church program)

Hereditary Cancer Resource Folder- Sample Documents & Outline

Resources for Patients

- Bring Your Brave Flyer for Patients With QR Code
- Talking with your family about hereditary breast and ovarian cancer
- Letter to family members patients who have tested positive for the BRAC1 or BRAC2 gene
- ** INSERT Clinic-Specific Research and Document Contact Information for Local Cancer Support Options for Patients. Maintain copies of material for distribution to patients

Resources for the Medical Team

Resources Available from the Bring Your Brave Campaign

- Assessing Risk in Young Patients
- Strategies for Managing Risk
- Early Onset Breast Cancer Provider Risk Assessment Tools
- Understanding Early Onset Breast Cancer Continuing Education Courses
 - Part I: Risk Factors
 - Part II: Engaging with Patients at Risk

Fact sheets for healthcare providers

- Understanding risk factors for hereditary breast and ovarian cancer
- <u>Screening for hereditary breast and ovarian cancer</u>
- Preventive options for individuals diagnosed with BRCA1 or BRCA2 mutations
- Caring for Young Women Who Are at High Risk for Early-Onset Breast Cancer
- <u>Caring for Young Women Who Are at High Risk for Early-Onset Breast Cancer- A Summary of Screening</u> <u>Counseling, and Testing Guidelines- 1</u>
- <u>Caring for Young Women Who Are at High Risk for Early-Onset Breast Cancer- A Summary of Screening</u> <u>Counseling, and Testing Guidelines - 2</u>
- Preventive options for individuals diagnosed with BRCA1 or BRCA2 mutations

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Risk Assessment/Screening Tools for Physicians

- Bring Your Brave Assessing Risk in Young Patients Webpage
- Guidelines in Oncology Genetic-Familial High-Risk Assessment- Breast Ovarian Pancreatic
- The Breast Cancer Risk Assessment Tool Gail Model (NIH)
- Georgia CORE's Breast & Ovarian Cancer Genetics Referral Screening Tool
- <u>AAFP Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer:</u> <u>Recommendation Statement</u>

Genetic Testing Resources

- Genetic Information Nondiscrimination Act
- Direct-to-Consumer Genetic Testing FAQ Healthcare Professionals

- National Society of Genetic Counselors (NSGC) Find a Genetic Counselor
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Genetic/Familial High-Risk Assessment

Infographics

- Bring Your Brave Campaign Take Action to Lower Your Breast and Ovarian Cancer Risk Infographic African American
- Bring Your Brave Campaign Take Action to Lower Your Breast and Ovarian Cancer Risk Infographic Jewish
- Bring Your Brave Campaign Take Action to Lower Your Breast and Ovarian Cancer Risk Infographic
- -

** **INSERT** – Clinic-Specific – Research and Document Contact Information for Local Genetic Test / Counselling Resources, Breast Cancer Specialists/ Departments, and/or Procedures for Referral

** **INSERT** – Clinic Specific – Research and Document Contact Information for Local Cancer Support Options for healthcare providers use (collaboration, education opportunities, networking)

News/ Research

** Provide options for viewing news and latest research/resources. E.g.,

- NPR Testing your genes for cancer risk is way cheaper now and it could save your life
- Primary care physician referral practices regarding BRCA1/2 genetic counseling in a major health system. Linfield DT, Rothberg MB, Pfoh ER, Noss R, Cassard L, Powers JC, Lipold L, Martinez KA. Breast Cancer Res Treat. 2022 Sep;195(2):153-160. doi: 10.1007/s10549-022-06523-5. Epub 2022 Jul 16. PMID: 35842521