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# Welcome!

Please put your name and email in the chat box. If you are sharing a computer with others, please include everyone participating today

We encourage you add your preferred pronouns with your name and image.





# LGBTQ+ and Cancer Care Through the Primary Care Lens Project ECHO: Session 2

*Shared Decision Making*

**7.22.2022**





# Today's Agenda

- 
- 01** Housekeeping, Agenda Preview, & Introductions  
(5 minutes)

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  - 02** Didactic Presentation: (15 minutes)

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  - 03** Didactic Q/A (5 minutes)

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  - 04** Case Presentation (5 minutes)

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  - 05** Case Presentation Recommendations & Discussion  
(20 minutes)

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  - 06** Post-Session Poll & Wrap Up (5 minutes)

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The American Cancer Society is proud to present this ECHO series

in part through funding support provided by Merck & Co., Inc.



# Session 1



Each ECHO session will be recorded and *will* be posted to a publicly-facing website



You will be muted with your video turned off when you join the call.  
Use the buttons in the *black* menu bar to unmute your line and to turn on your video.  
**If you do not wish to have your image recorded, please turn OFF the video option.**



Today's materials will be made available on our ACS ECHO website



Please type your name and email in the chat box



This ECHO session takes place on the Zoom platform.  
To review Zoom's privacy policy, please visit [zoom.us/privacy](https://zoom.us/privacy)



Remember: Do NOT share any personal information about any patient



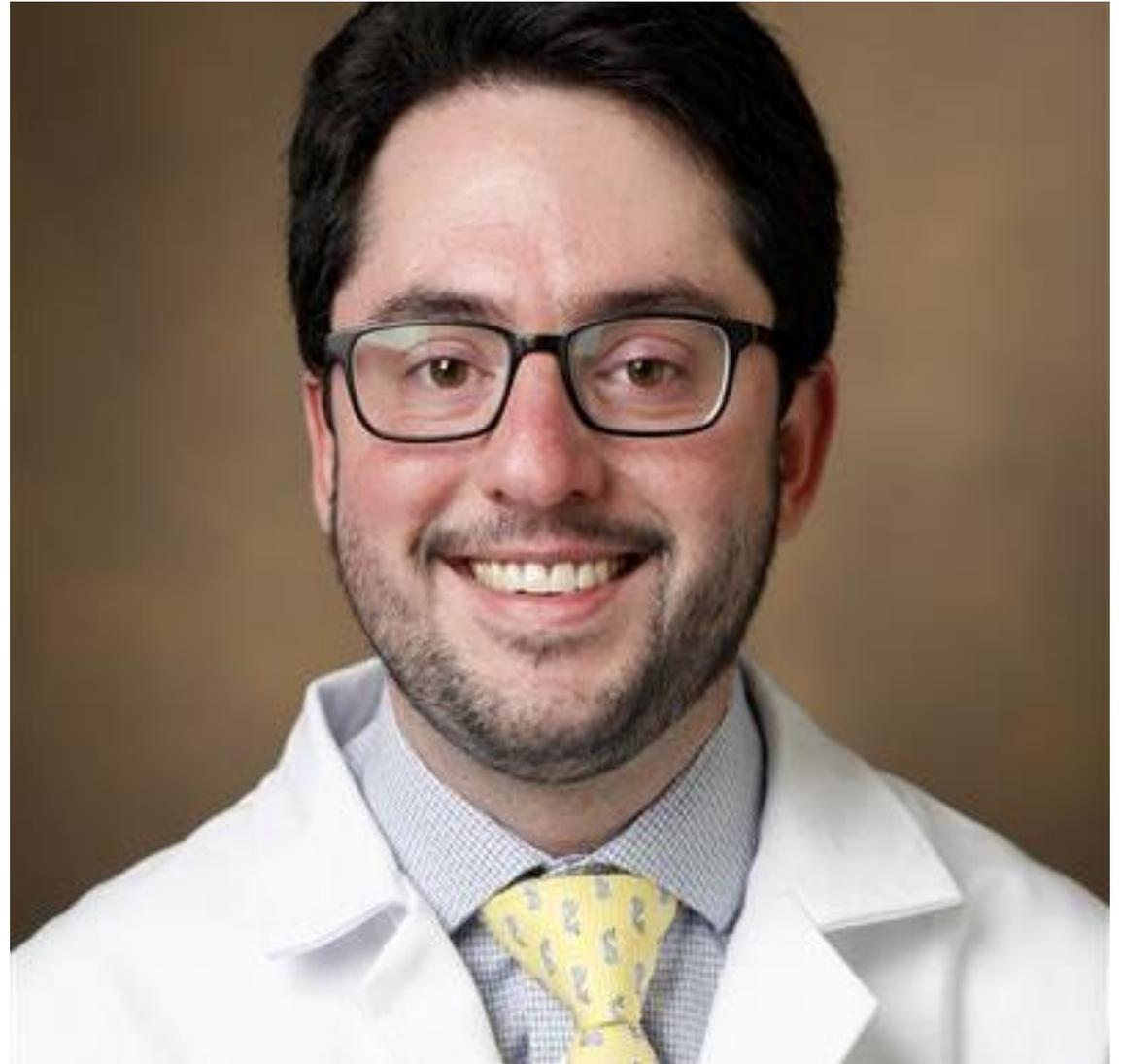
Questions about Zoom? Type them in the chat box



# Welcome to our Facilitator for today!

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**Steven Allon, MD (he/his)**  
**Vanderbilt University Medical Center**  
**Assistant Professor of Medicine**  
**Division of General Internal Medicine**  
**and**  
**Public Health**



## WELCOME TO OUR SPOKE SITES!

- Domino's Farm Family Medicine – Michigan 🙌
- Indiana University Health 👍
- Memorial Hospital & Health Center- Indiana ❤️
- University of Louisville Family Medicine 😂
- Internal Medicine Faculty, Residents and Staff at Vanderbilt Primary Care 🎉

# Didactic Presentation

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**Charles Kamen PhD, MPH**

**Associate Professor in the Department of  
Surgery, Division of Cancer Control, at the  
University of Rochester**



# Shared Decision Making with LGBTQ+ Patients

Charles Kamen, PhD, MPH

he/him his

*Associate Professor of Surgery, University of Rochester  
Assistant Director of Community Engagement, Wilmot Cancer Institute  
Chair of Health Equity Research, URCC NCORP Research Base*

# Objectives

- Define shared decision making
- Describe issues relevant to shared decision making with LGBTQ+ patients along the cancer continuum
  - Involving informal caregivers and families of choice
  - Decoupling gender and anatomy
  - Offering affirming options
- Discuss steps to LGBTQ+ friendly shared decision making

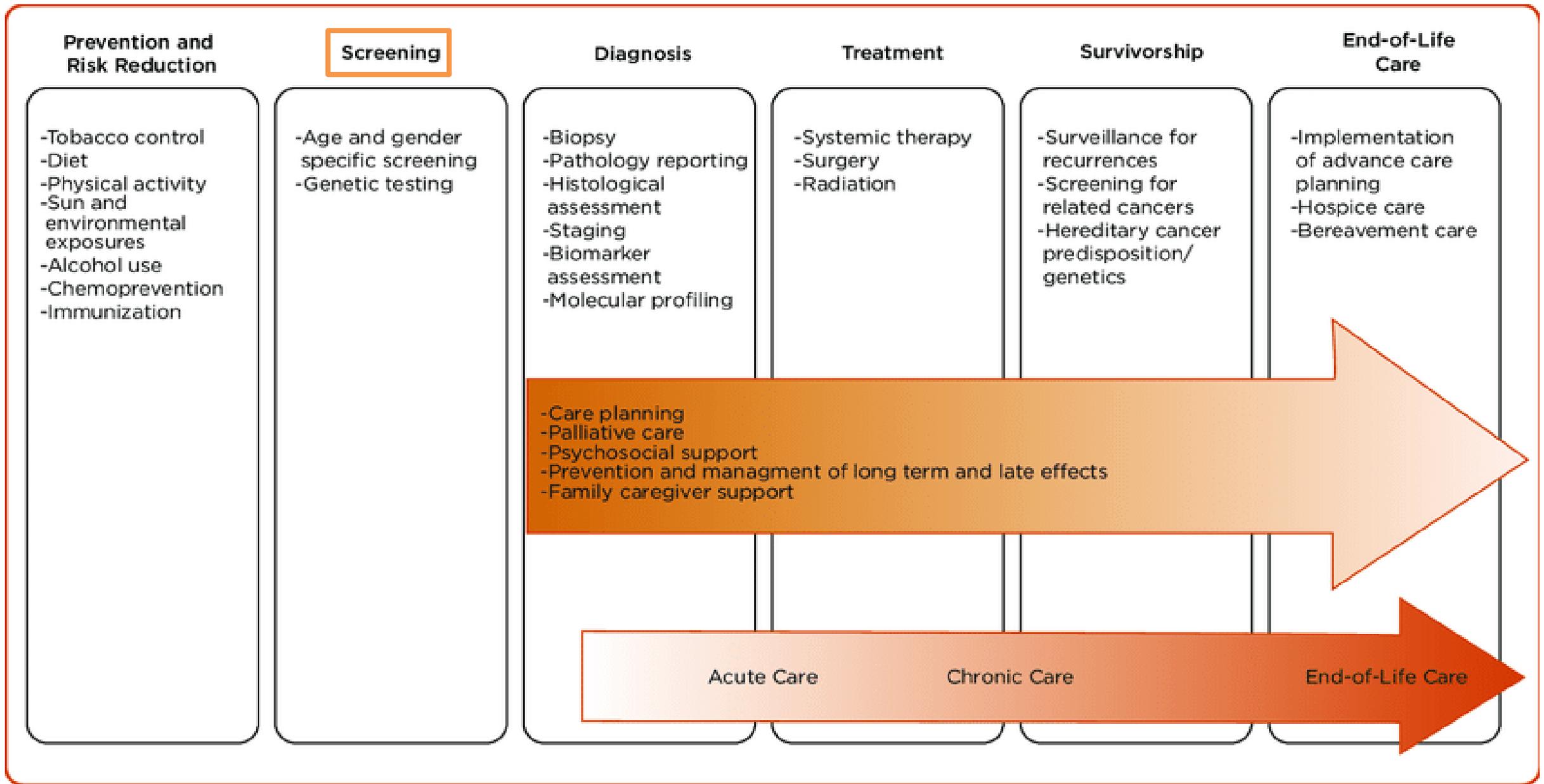
# What is shared decision making?

- a process in which clinicians and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values
- helps providers and patients agree on a health care plan
- facilitates patient follow-through with health care plans

# When do we use shared decision making?

- when there is more than one reasonable option
- when no one option has a clear advantage
- when the possible benefits and harms of each option affect patients differently

SDM is particularly relevant along the cancer continuum!



# Cancer screening among LGBTQ+ patients

- 71% of 2,728 respondents completed guideline-based screening
- Of the 29% of respondents who had not:
  - 40% did not know about screening
  - 35% were not told about screening by a healthcare provider
  - 11% did not see a healthcare provider
  - 9% could not afford a healthcare provider

## **Cancer screening and minority stress**

“Although my doctor knew all about me, each encounter with new people—with blood draws, ultrasound, breast x-ray, etc.—had the basic anxiety of the procedure and layered on to that, the possibility of homophobia and having to watch out for myself.”

(Cis white lesbian, breast cancer)

# Create safe spaces for LGBTQ+ patients

- Train everyone in cultural humility
- Use visible signs of inclusiveness
  - Non-discrimination policy
  - Pronoun badges
  - Single-occupancy bathrooms
  - Rainbows!
- Ask SOGI questions of all patients



## **Involve LGBTQ+ patients' caregivers**

“Since my biological family refuses to have any contact with me, it is essential to my health and survival that they understand that my partner IS MY FAMILY and when they treat him as such my outcomes are much better.”

*(Gay man, prostate cancer)*

# Acknowledge LGBTQ+ caregivers' diversity

- Compared to H/C patients, LGBTQ+ patients are:
  - less likely to rely on biological family or marital partners, and more likely to rely on friends, ex-partners as caregivers
  - half as likely to be married or partnered
  - four times less likely to have children
  - more than twice as likely to report consensual non-monogamy
  - twice as likely to live alone
- Ask: “Who do we have with us today?”

## **Decouple gender and anatomy**

“Expect the unexpected. For example, don't get upset when you go to put in a Foley [catheter] and find the person is pre-op.”

(Bisexual transgender woman)

# Consider gendered cancer care spaces



WOMEN'S CANCER CARE CENTER  
Gynecologic Oncology and Pelvic Surgery  
THE PATHWAY TO SUCCESS...



Ask your doctor if  
it's time for your  
**Mammogram**  
and schedule an appointment today.



**PROSTATE CANCER  
RESEARCH INSTITUTE**  
Helping Men Research Their Options

# Use an organ inventory to guide decision making

**WHICH OF THESE ORGANS DO YOU HAVE NOW?**

- BREASTS
- CERVIX
- OVARIES
- UTERUS
- VAGINA/FRONT HOLE
- PENIS
- PROSTATE
- TESTES

**PLEASE INDICATE ANY ORGANS THAT WERE SURGICALLY ENHANCED OR CONSTRUCTED:**

- BREASTS
- CERVIX
- OVARIES
- UTERUS
- VAGINA/ FRONT HOLE
- PENIS
- PROSTATE
- TESTES

**PLEASE INDICATE ANY ORGANS THAT WERE PRESENT AT BIRTH THAT ARE NO LONGER PRESENT:**

- BREASTS
- CERVIX
- OVARIES
- UTERUS
- VAGINA/ FRONT HOLE
- PENIS
- PROSTATE
- TESTES

# Remain humble when data are lacking

- Is there increased cancer risk from exogenous hormone use?
- Should a trans man on testosterone have a different screening timeline?
- How much risk does surgical removal of organs offset?
- Should screening for HPV-related cancers be based on a patient's sexual activity?

## Offer affirming options for care

“I was given a total, bilateral mastectomy with male chest reconstruction as a part of my treatment. This was definitely a silver lining and if you can avail your patient of something positive...be sure to make every effort to do so.”

(White heterosexual transgender man)

# Referrals

- Look within your institution for LGBTQ+ affirming options
- Consider starting a list of LGBTQ+ affirming providers
  - ...but make sure they are actually LGBTQ+ affirming first
- Look within your community for resources

# Consider trauma-informed care

“My provider assumed the dilator is merely uncomfortable...not all lesbian women have had their body cavities opened and painfully examined”

- Guided by safety, choice, collaboration, trustworthiness and empowerment
- Shared decision making is a first step!

# Steps for shared decision making

1. Invite the patient to participate
2. Present options
3. Provide information on benefits and risks
4. Assist patients in evaluating options based on their goals and concerns
5. Facilitate deliberation and decision making
6. Assist patients to follow through on the decision

# Steps for LGBTQ+ shared decision making

1. Invite the patient to participate **and include diverse caregivers**
2. Present options **including affirming options where possible**
3. Provide information on benefits and risks **acknowledging lack of data**
4. Assist patients in evaluating options based on their goals and concerns
5. Facilitate deliberation and decision making **with a trauma-informed lens**
6. Assist patients to follow through on the decision **and refer as needed**

**THANK YOU!**

# Case Presentation

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Julie Prussack, MD  
*she/her*



## Family Medicine at Domino's Farms in Ann Arbor, Michigan

- 1 of 6 Family Medicine Clinics at UM
- Caring for LGBTQ+ patients within primary care since its opening in 2006
- Also home to Japanese Health Program, Integrative Health Program, and Sports Medicine Clinic
- 20 physicians (mostly part time), 15 MAs, 1 NP, 1 pharmacist, fellows, RNs, LPNs, clerical, etc.
- Newly centralized clerical call center and nurse call center
- Using Epic since 2012 with biggest updates in SOGI data and displays in 2016-2017

# Family Medicine at Domino's Farms in Ann Arbor, Michigan

## Our ECHO Team:



Nicole Dietrich, MA  
*she/her*

Bethany Rowe, RN  
*she/her*



Dina Marzolino, RN  
*she/her*

Heidi Diez, PharmD  
*she/her*



Julie Prussack, MD  
*she/her*

# 47yo male, assigned female at birth

Presents for virtual visit with non-PCP doc in our office for DM/obesity

- Roomed virtually by MA who notes surgical history of hysterectomy

Pronoun / Gender Identity:  
he/him/his / Transgender  
Male / Female-to-Male [4]

Disability Accommodations:  
**None**

Active FYIs: Controlled  
Substance Agreement

Infection: None

Select Cervical Cancer  
Screening plan

A1c over 8%

Select Colorectal Cancer  
Screening plan

More Advisories (8)

Topic	Due Date	Frequency	Date Completed
Current Care Gaps			
Hepatitis C Screening	Overdue - never done	Once	
Cervical Cancer Screening: Pap	Overdue - never done	3 year(s)	
Pneumococcal Combined (2 - PCV)	Overdue since 12/6/2017	<a href="#">Imm Details</a>	12/6/2016 - Pneu...
Colon Cancer Screening: Colonoscopy	Ordered on 3/7/2022	10 year(s)	
BREAST CANCER SCREENING: MAMMOGRAM	Ordered on 3/17/2022	2 year(s)	11/21/2018 - BI...
FOOT EXAM	Overdue since 1/27/2021	1 year(s)	1/27/2020 - HM D...
COVID-19 Vaccine (3 - Booster for Pfizer series)	Overdue since 9/29/2021	<a href="#">Imm Details</a>	4/29/2021 - Pfizer...
DTaP,Tdap,and Td Vaccines (2 - Td or Tdap)	Overdue since 3/1/2022	<a href="#">Imm Details</a>	3/1/2012 - Tetanu...
Dilated Retinal Exam	Due soon on 10/15/2022	1 year(s)	10/15/2021 (Don...

# 47yo male, assigned female at birth

Presents for virtual visit with non-PCP doc in our office for DM/obesity

- Roomed virtually by MA who notes surgical history of hysterectomy
- Asks him if he has history of breast surgery or is due for mammogram
- Patient notes family history of breast cancer (mom at age 42) and knows he needs to get updated mammogram
- Would like mastectomy, but has significant financial and social barriers to care
- MA offers to schedule mammogram, patient declines but takes number to schedule
- MA asks doc to clarify need for Pap and update chart

# Pap smear needed?

**Established care in 2014:** “Per his description, he did have an abnormal pap smear and was told he had cervical cancer prior to the [hysterectomy], however he has not had a pap smear since 2005 and history about this is a little unclear.” – *MD asks RN to ask patient to get op reports.*

*History also includes OSA – gets records, bipolar disorder – establishes with psych. Then, diagnosed with diabetes in 2016.*

**2017 HME:** “Had abnormal Pap and was told he had cervical cancer. Had cone biopsy which showed 1mm of abnormal growth beyond the biopsy site, thus proceeded to surgery. Very little follow up afterwards so doesn't know the final pathology report. No Pap since 2005. We had requested records about this but have not yet received any.”

# Pap smear needed?

**2018:** “outside... records clarify that he had cone biopsy because of severe dysplasia on 11/7/2005 which revealed microinvasive squamous cell carcinoma arising in a background of high-grade intraepithelial dysplasia/CIN 3... they had recommended TAH with BSO for this. The pathology report of the uterus showed healing cone biopsy site but no residual neoplasm identified. I discussed with him that based on this, I believe he needs no further testing, but will try to clarify with one of my oncology colleagues.”

**2019 HME:** “has had hysterectomy which didn't show any residual neoplasm on uterus per outside records. Will try to clarify with Ob/gyn if he needs any additional paps or followup.”

**7/2019 PCP email w/Gyn Onc:** “Our [Soc. Of Gyn. Onc.] guidelines indicate annual Pap testing for cytology but not HPV testing.... However, almost all destined recurrences are in the first 5 years. With his informed consent, I don't think the risk is excessive to stop.”

 Cervical Cancer Screening: Female patients 21-65 years of age should be screened for cervical cancer. This patient has been assigned the default screening plan - select a specific plan.

Add Problem	Do Not Add	No cervical cancer screening: hysterectomy (benign conditions w/ cervix removed)  <a href="#">Edit details</a> (Share with patient)
Add Problem	Do Not Add	No cervical cancer screening: cervix removed with remaining uterus  <a href="#">Edit details</a> (Share with patient)
Add HM Modifier	Do Not Add	Pap & HPV ages30to64 - 5 years
Add HM Modifier	Do Not Add	Pap Smear - 3 year
Add HM Modifier	Do Not Add	Pap Smear - 2 year
Add HM Modifier	Do Not Add	Pap Smear - Annual
Add HM Modifier	Do Not Add	Pap Smear - 6 months
Add HM Modifier	Do Not Add	No cervical cancer screening: medical comorbidities/organ not present
Add HM Modifier	Do Not Add	No cervical cancer screening: hysterectomy ( <u>benign conditions w/ cervix removed</u> )

# Referral to Comprehensive Gender Services

3/7/2022 virtual visit: requests referral for top surgery (no mention of FHx breast cancer)

7/14/2022 Social Work note:

## ASSESSMENT:

Referral from Domino's Farms Family Medicine clinic for financial assistance and community resources. SW spoke with pt who states that a referral was placed to the Comprehensive Gender services in March and he has not been contacted for an appt. Pt also is unsure if his Msupport is still active. Pt has no other SW concerns at this time.

## PLAN/RECOMMENDATION:

- SW contacted Msupport and confirmed pt has active coverage for balances after insurance thru 1/31/23
- SW contacted the Gender Services clinic and they will f/u with pt
- Pt was informed of the above thru pt portal message.
- No further SW intervention planned at this time.
- Please re-consult SW as needed.

**M** MICHIGAN MEDICINE  
UNIVERSITY OF MICHIGAN

Date: \_\_\_\_\_

**ADULT SERVICE INQUIRY FORM**

By returning this completed form, you consent to this information becoming part of your electronic medical record at Michigan Medicine.

Michigan Medicine Medical Record Number: \_\_\_\_\_ *If you don't know your MRN, leave this field blank.*

Legal first name: \_\_\_\_\_ Legal last name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Current legal sex:  F  M *Please make sure that your answer to this question matches your legal sex according to your insurance provider.*

**PLEASE READ THIS SECTION**

If you provide your preferred name, gender identity, and pronouns on this form, we will add this information to your electronic medical record. This information will be available to all health care providers and staff using the Michigan Medicine electronic medical record system. It is your choice whether or not you provide the information in this box, below. If you provide the information:

- Providers, staff, and automated systems (including automated appointment reminders) should use your preferred name when communicating with you.
- Office visit notes from Michigan Medicine providers should include your preferred name and pronouns.
- Clinic staff may use your preferred name when they call you from a waiting room.
- Your gender identity will appear in addition to your legal sex at various places in your chart.
- If you receive care from a non-Michigan Medicine hospital or emergency room that can access Michigan Medicine's electronic medical record, that other health care system may see your preferred name, pronouns, and gender identity.
- If a Michigan Medicine provider refers you to a non-Michigan Medicine facility, your preferred name and gender identity may appear along with your legal name and sex.

You may leave any part of this section blank.

Preferred first name: \_\_\_\_\_ Preferred last name: \_\_\_\_\_

Gender:  Trans woman  Trans man  Genderqueer  Nonbinary  
 Woman  Man  Two spirit  Other: \_\_\_\_\_

Pronouns:  She/her  He/his  They/them  
 Use my name  Other: \_\_\_\_\_

Race/Ethnicity: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Preferred phone number: \_\_\_\_\_ OK to leave message?  Yes  No  
Type: Home  Mobile  Work  Other  \_\_\_\_\_

Alternate phone number: \_\_\_\_\_ OK to leave message?  Yes  No

# Talking points

- MA empowered to have health maintenance conversation with patient (seemingly very positive for this patient, but could this be a potentially negative experience for some patients?)
- Epic has great tools, but how can we keep them up-to-date, especially when record review and specialist input are needed (e.g. cancer survivors)? (++)other competing clinical and social needs)
- How can we make sure to consider family history of cancer when referring for gender-related surgery?
- How can we improve our Gender Services referral process to make it more streamlined, communicative, and patient-centered?

# A Few Reminders



**NEXT ECHO Session: 8/26/2022 @ 12:30 PM ET/1:30 PM CT**



**Next Didactic Presenter:** *Mollie Aleshire* DNP, MSN, APRN, FNP-BC, PPCNP-BC, FNAP

**Topic:** *HPV vaccination and HPV related cancer risk factors*



**Materials and Resources will be made available within one week.**

**All resources will be available on the [ACS ECHO Website](#)**



## **Case Presentations**

**Spokes:** We are still in need of a case presentation for August 26<sup>th</sup>

**Faculty:** All future case presentations will be shared with you at 24-hours in advance.



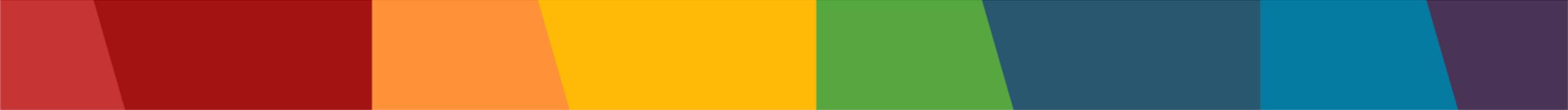
Complete the post-session poll questions



**Questions?** Reach out to your state ACS lead or [Elizabeth.Holtsclaw@cancer.org](mailto:Elizabeth.Holtsclaw@cancer.org)

# LGBTQ+ Cancer ECHO Post-session Survey

[tinyurl.com/echosession2](https://tinyurl.com/echosession2)



THANK YOU!

SEE YOU ON 8/26/2022!