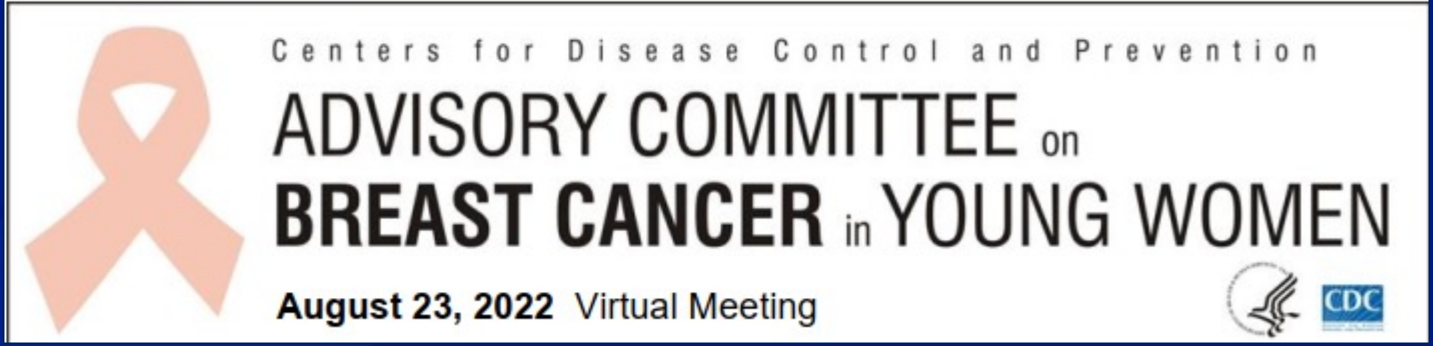

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

August 23, 2022 Virtual Meeting

Cristina M Checka MD

Associate Professor of Breast Surgical Oncology

MD Anderson Cancer Center, Houston TX

Overview

- Review statistics and epidemiology
- Specific needs faced by young patients
- Overview of patient journey
- Review minutes and workgroup recommendations from last meeting, Nov 2020

- Consider:
  - Workgroup membership and leadership
  - Plans for meetings in 2023

Review Article about Breast Cancer in Young Women

AYA ONCOLOGY: REVIEW

WILEY Pediatric Blood & Cancer SIOP aspho the american society of pediatric hematology/oncology

Breast cancer in adolescents and young adults

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Abstract

Breast cancer is the most common cancer of adolescents and young adult (AYA) women aged 15 to 39 years, accounting for 5.6% of all invasive breast cancer in women. In comparison with older women, AYAs are more likely to have familial cancer predisposition genes, larger breast tumors, unfavorable biological characteristics, distant metastatic disease at diagnosis, and adverse outcome. Endocrine therapy and some chemotherapy recommendations differ between young and older women. AYAs require coordinated multidisciplinary care, treatment regimens that minimize late effects such as premature menopause and osteoporosis, and proactive management of psychological and sexual health during and after cancer treatment.

KEYWORDS
age, breast, neoplasm, pregnancy, young adult

Breast Cancer In Young Women

- Defined as in situ and invasive disease occurring in patients **younger than 45 years** [1]
- 11% of breast cancer diagnoses occur in women <45 yrs, representing about **26,500 annual cases** [1]
  - AYA ages 15-39 account for 5.6% of all invasive disease [2]
  - Uptick in incidence after age 40 yrs reflects asymptomatic disease **detected by screening protocols**

1. Center for Disease Control and Prevention Statistics
2. Johnson et al, Breast Cancer in Adolescents and Young Adults, 2018

Epidemiology

- Compared to older women, young patients tend to present with **more advanced disease**, including more cases of de novo stage IV disease [1]
  - Likely reflects unscreened age group
  - The subset of patients with known high risk (family history or genetic status) undergoing high-risk surveillance tends to present with earlier-stage disease

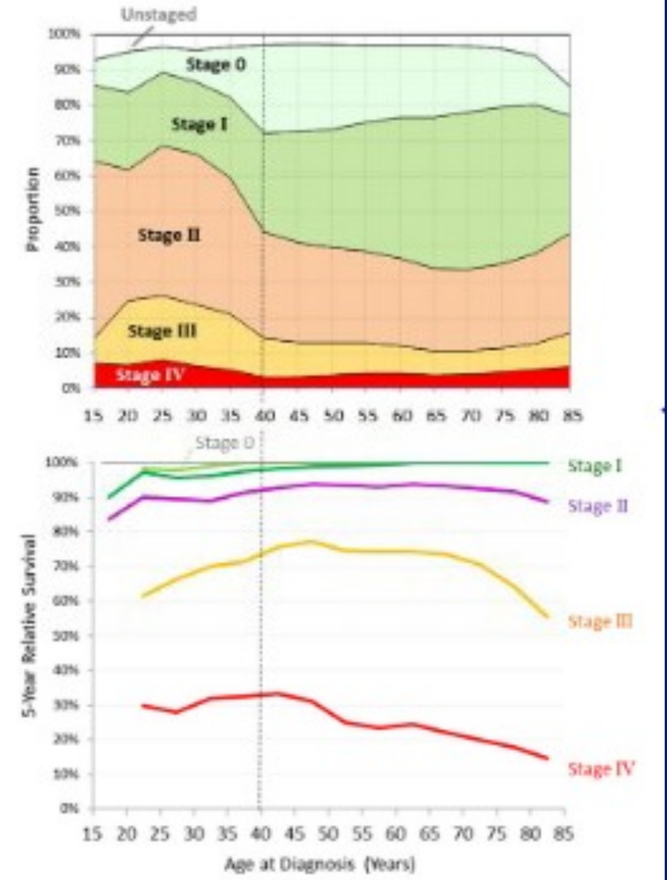


FIGURE 4 Incidence (upper panel) and 5-year relative survival (lower panel) of women with invasive breast cancer, SEER18, 2000–2014, by breast adjusted AJCC6 stage

1. Johnson et al, Breast cancer in adolescents and young adults, 2018

Race and Outcomes

- Black women <35 yrs have a higher incidence of invasive breast cancer and a 3x higher mortality, compared to young white women [1]

- Advanced stage disease is more common in young patients who are Black, Hispanic, Native American, and in all patients with a lower SES [2]

1. Johnson et al, Breast cancer in adolescents and young women, 2018.
2. SEER Database

Risk Factors for Breast Cancer in Young Women

- **Family history of cancer**, particularly early-onset disease
  - Knowledge of personal risk is important
  - Family pedigree is key

- **Hormonal**: earlier menarche, later age >30 yrs at FFTB, post-partum milieu is a risk for PABC[1]

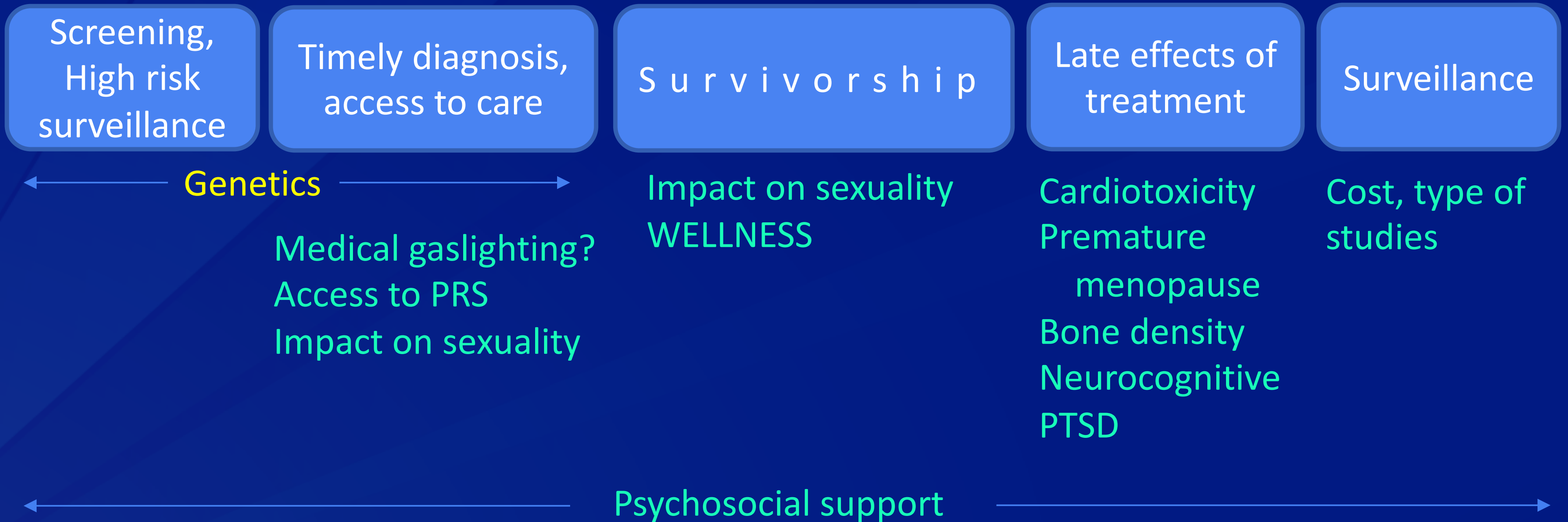
- **Lifestyle and other personal risk factors**:
  - Mantle XRT, EtOH use[2], substantial risk associated with increase in BMI after age 18 (2-fold increased risk for ER-*negative* breast cancer), physical inactivity, diet high in red meats/fast food

1. Johnson et al, Breast cancer in adolescents and young adults, 2018
2. Allen et al, Moderate Alcohol Intake and Cancer Incidence in Women, 2009

Issues for Young Women with Breast Cancer

- Fertility preservation, including access/cost/options
- Premature menopause
- Post-surgical reconstruction (including access/cost/options)
- Body image
- Sexual health
  - WHO: state of physical, emotional, mental and social well-being in relation to sexuality; not merely the absence of disease or dysfunction
- Psychosocial support of mental health
- Surveillance
- Late effects of treatment
- Survivorship

Multimodal Treatment Journey



Screening, High risk surveillance

Timely diagnosis, access to care

Survivorship

Late effects of treatment

Surveillance

Genetics

Medical gaslighting?
Access to PRS
Impact on sexuality

Impact on sexuality
WELLNESS

Cardiotoxicity
Premature menopause
Bone density
Neurocognitive
PTSD

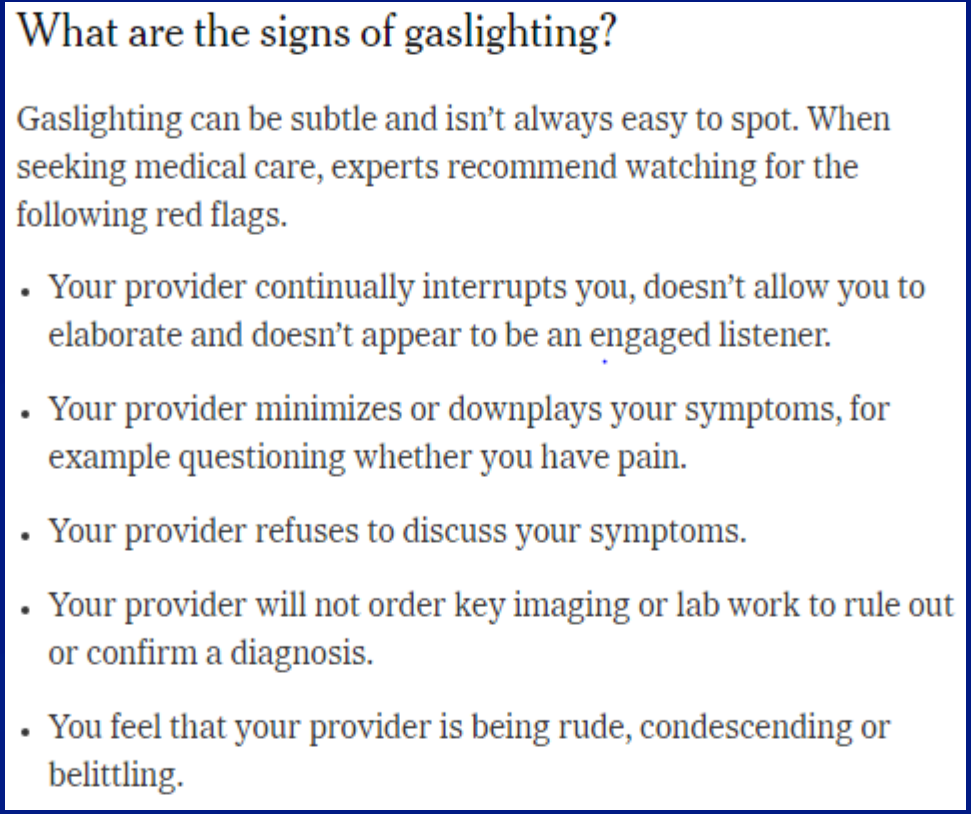
Cost, type of studies

Psychosocial support

Medical Gaslighting

Feeling Dismissed? How to Spot 'Medical Gaslighting' and What to Do About It.

The experience of having one's concerns dismissed by a medical provider, often referred to as medical gaslighting, can happen to anyone. A recent New York Times article on the topic received



What are the signs of gaslighting?

Gaslighting can be subtle and isn't always easy to spot. When seeking medical care, experts recommend watching for the following red flags.

- Your provider continually interrupts you, doesn't allow you to elaborate and doesn't appear to be an engaged listener.
- Your provider minimizes or downplays your symptoms, for example questioning whether you have pain.
- Your provider refuses to discuss your symptoms.
- Your provider will not order key imaging or lab work to rule out or confirm a diagnosis.
- You feel that your provider is being rude, condescending or belittling.

"I was told I was too young to have cancer."

"I had to advocate for myself to have a breast biopsy."

NYT Health, July 29, 2022

Current ACBCYW Workgroups

- Mental/ Behavioral Health Workgroup
- Provider Workgroup
- Sexual Health and Fertility Workgroup
- Genetics and Genomics Workgroup

Review of Last Committee Meeting, Nov 2020

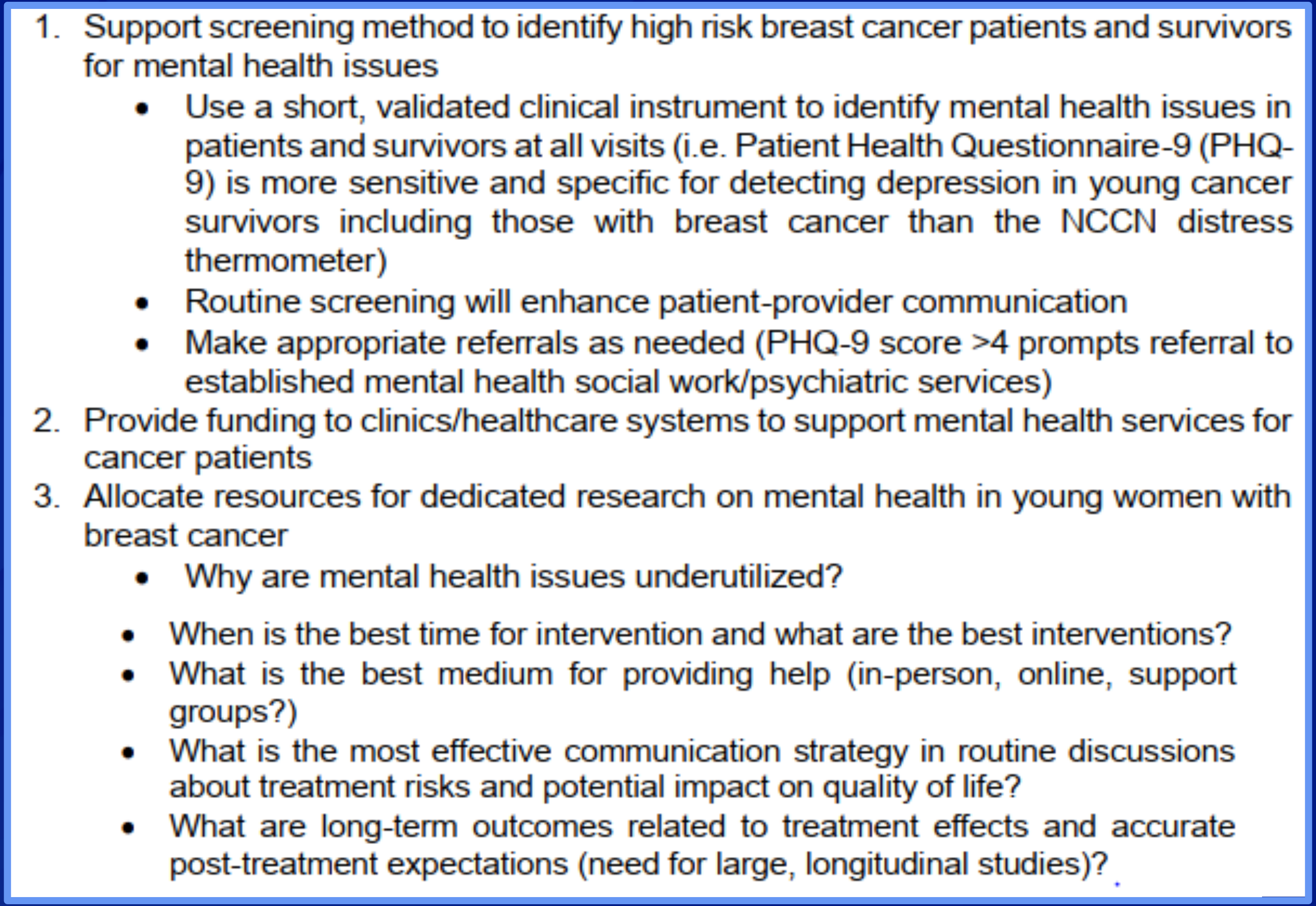
- **CDC Updates:**
  - Bring Your Brave Campaign, launched 2015
  - CME course co-sponsored with ACOG, “Early Onset Breast Cancer Education Program,” June 2020
  - Co-sponsored podcast with NSGC (Natl Soc Gen Counselors)

- **Barriers to Care Presentation (FORCE)**
  - Previous work centered on *BRCA* carriers now expanded to other high risk patients due to family history and/or other gene mutations
  - Multigene panel testing has become the SOC, done for $250 or less
  - USPSTF recommendations do not address all high risk patient needs and carriers who rely on these for coverage decisions may exclude some
  - Equity lens: nominal cost vs exacerbating cost

Mental/Behavioral Health Workgroup

- Work centered on :
  - 1. Extensive literature review
  - 2. primary interviews with patients/SMEs
- Major concerns persist even years after active treatment including fear of recurrence, depression, anxiety/stress, and SI, PTSD
- Gaps identified re effective uptake of services

Mental Health Workgroup Recommendations



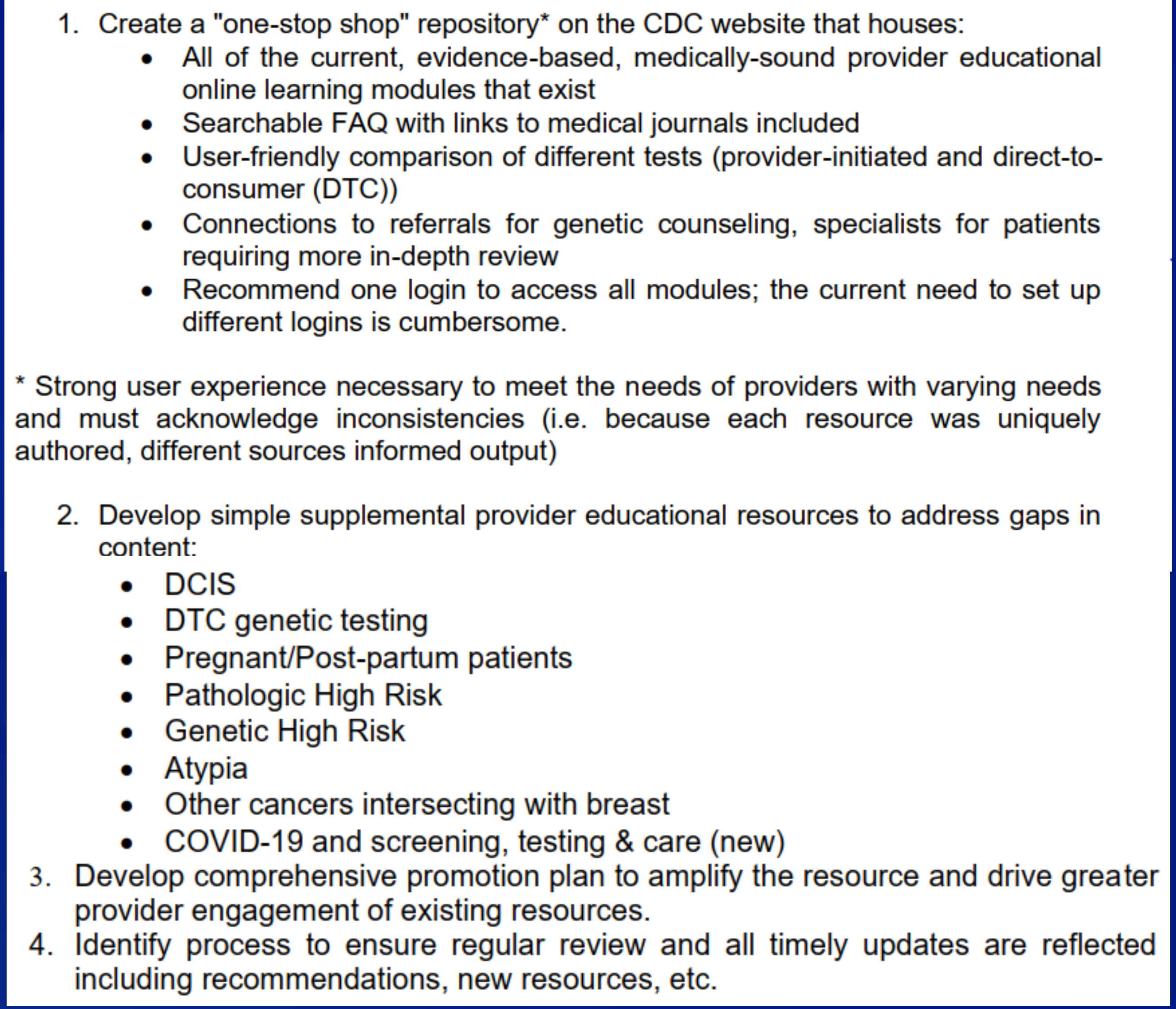
1. Support screening method to identify high risk breast cancer patients and survivors for mental health issues
    - Use a short, validated clinical instrument to identify mental health issues in patients and survivors at all visits (i.e. Patient Health Questionnaire-9 (PHQ-9) is more sensitive and specific for detecting depression in young cancer survivors including those with breast cancer than the NCCN distress thermometer)
    - Routine screening will enhance patient-provider communication
    - Make appropriate referrals as needed (PHQ-9 score >4 prompts referral to established mental health social work/psychiatric services)
2. Provide funding to clinics/healthcare systems to support mental health services for cancer patients
3. Allocate resources for dedicated research on mental health in young women with breast cancer
    - Why are mental health issues underutilized?

    - When is the best time for intervention and what are the best interventions?
    - What is the best medium for providing help (in-person, online, support groups?)
    - What is the most effective communication strategy in routine discussions about treatment risks and potential impact on quality of life?
    - What are long-term outcomes related to treatment effects and accurate post-treatment expectations (need for large, longitudinal studies)?

Provider Workgroup

- Work centered on (early) impact on COVID-19 on rate of diagnoses, delayed presentation, decreased screening
    - *These effects and outcomes are still being examined in 2022*

Provider Workgroup Recommendations



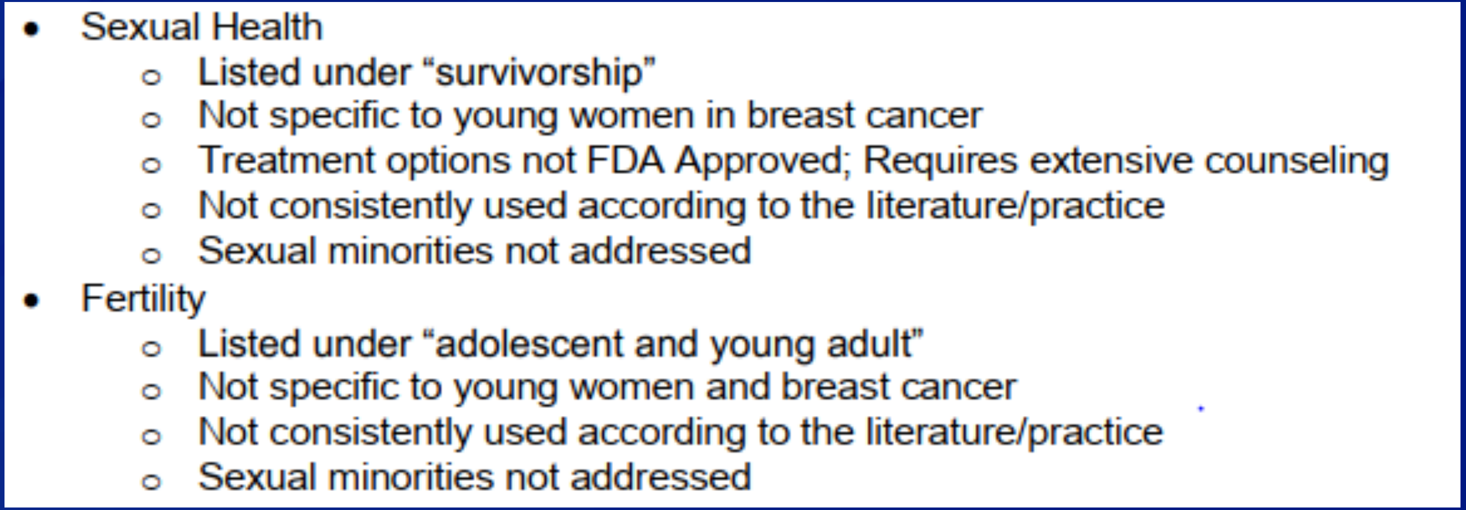
1. Create a "one-stop shop" repository* on the CDC website that houses:
    - All of the current, evidence-based, medically-sound provider educational online learning modules that exist
    - Searchable FAQ with links to medical journals included
    - User-friendly comparison of different tests (provider-initiated and direct-to-consumer (DTC))
    - Connections to referrals for genetic counseling, specialists for patients requiring more in-depth review
    - Recommend one login to access all modules; the current need to set up different logins is cumbersome.

* Strong user experience necessary to meet the needs of providers with varying needs and must acknowledge inconsistencies (i.e. because each resource was uniquely authored, different sources informed output)

2. Develop simple supplemental provider educational resources to address gaps in content:
    - DCIS
    - DTC genetic testing
    - Pregnant/Post-partum patients
    - Pathologic High Risk
    - Genetic High Risk
    - Atypia
    - Other cancers intersecting with breast
    - COVID-19 and screening, testing & care (new)
3. Develop comprehensive promotion plan to amplify the resource and drive greater provider engagement of existing resources.
4. Identify process to ensure regular review and all timely updates are reflected including recommendations, new resources, etc.

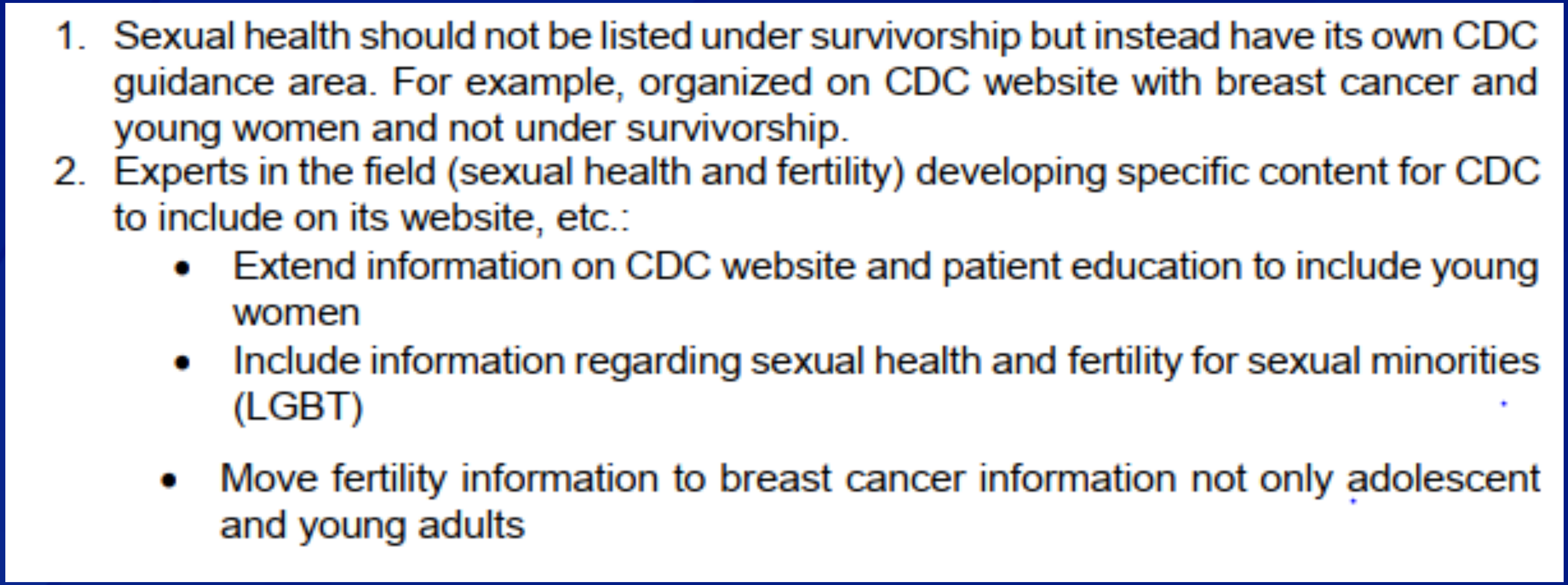
Sexual Health & Fertility Workgroup

- Two problems when the group was first formed:
  - 1. Lack of consistent acknowledgement/assessment/interventions offered for **sexual health concerns** in young women w breast cancer
  - 2. Lack of consistent acknowledgement/assessment/interventions offered for **fertility concerns** in young women w breast cancer
- NCCN guidelines = insufficient (Feb 2020) and lacked advice that would address the nuances of needs in young women



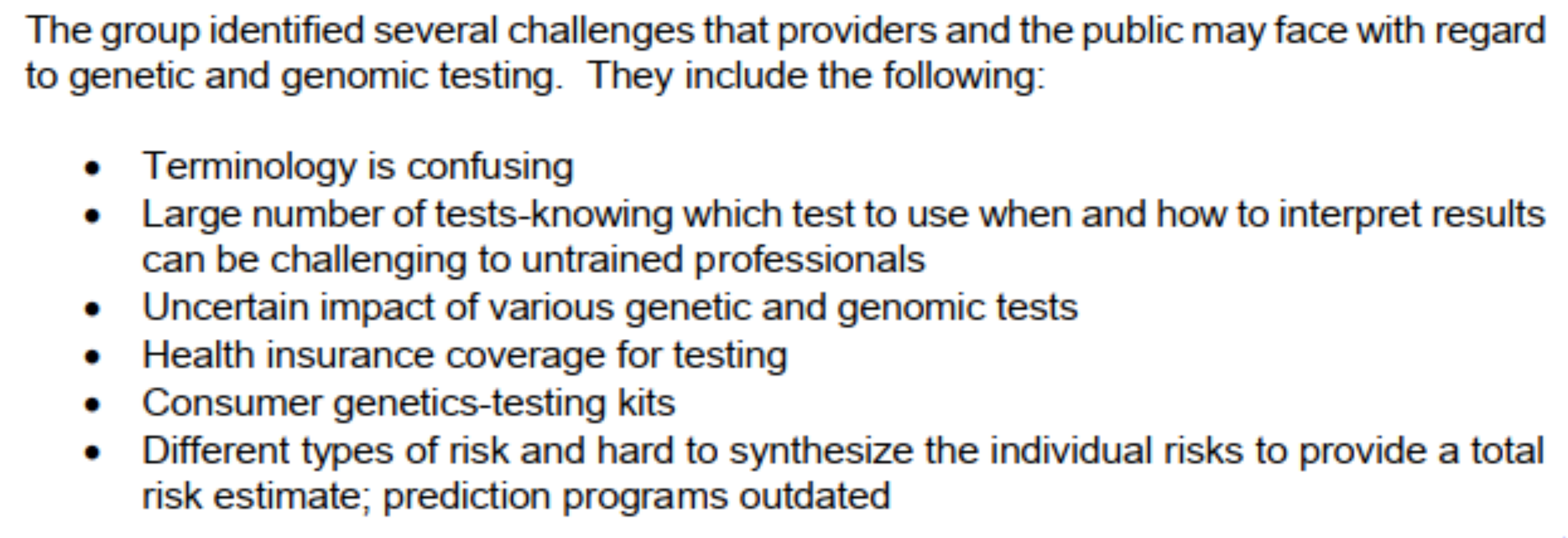
- Sexual Health
  - Listed under "survivorship"
  - Not specific to young women in breast cancer
  - Treatment options not FDA Approved; Requires extensive counseling
  - Not consistently used according to the literature/practice
  - Sexual minorities not addressed
- Fertility
  - Listed under "adolescent and young adult"
  - Not specific to young women and breast cancer
  - Not consistently used according to the literature/practice
  - Sexual minorities not addressed

Sexual Health & Fertility Workgroup Recommendations



1. Sexual health should not be listed under survivorship but instead have its own CDC guidance area. For example, organized on CDC website with breast cancer and young women and not under survivorship.
2. Experts in the field (sexual health and fertility) developing specific content for CDC to include on its website, etc.:
   - Extend information on CDC website and patient education to include young women
   - Include information regarding sexual health and fertility for sexual minorities (LGBT)
   - Move fertility information to breast cancer information not only adolescent and young adults

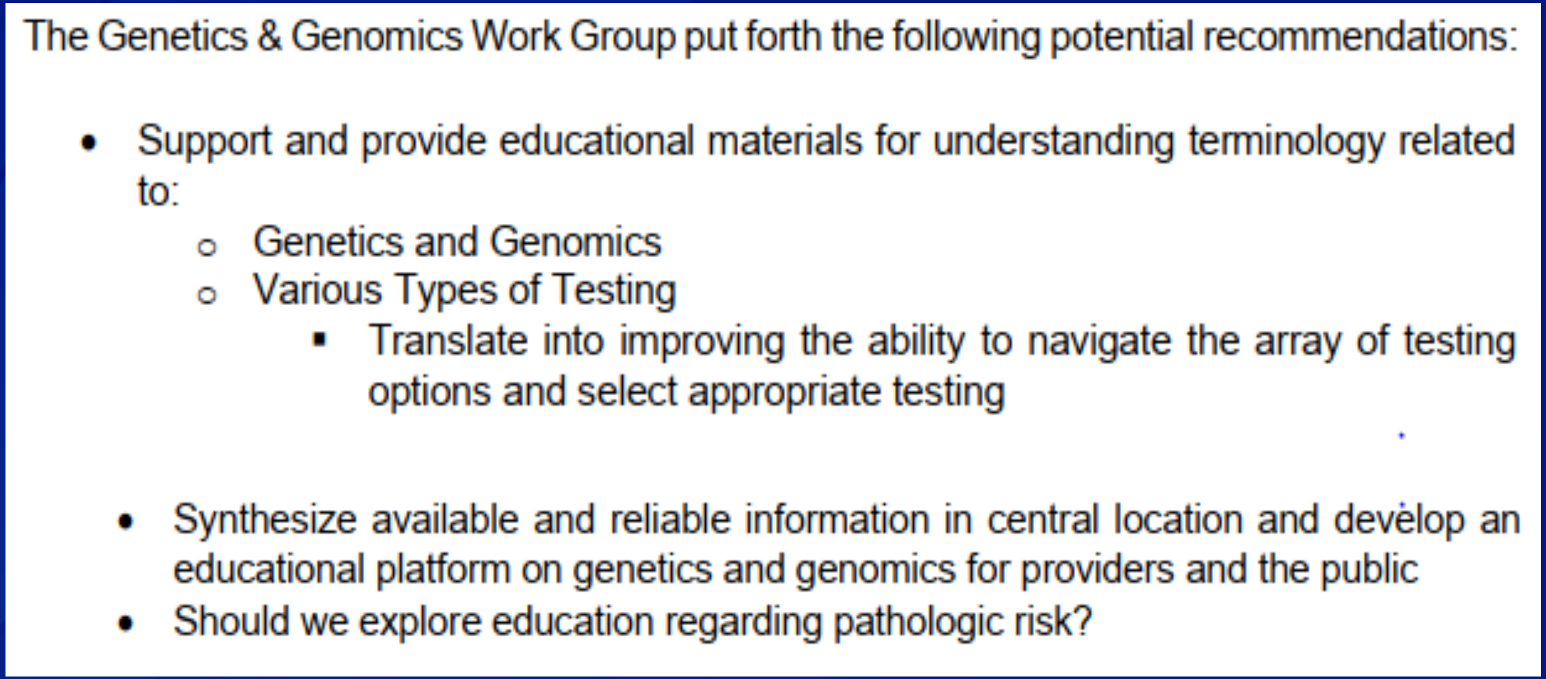
Genetics & Genomics Workgroup



The group identified several challenges that providers and the public may face with regard to genetic and genomic testing. They include the following:

- Terminology is confusing
- Large number of tests-knowing which test to use when and how to interpret results can be challenging to untrained professionals
- Uncertain impact of various genetic and genomic tests
- Health insurance coverage for testing
- Consumer genetics-testing kits
- Different types of risk and hard to synthesize the individual risks to provide a total risk estimate; prediction programs outdated

Genetics & Genomics Workgroup Recommendations



The Genetics & Genomics Work Group put forth the following potential recommendations:

- Support and provide educational materials for understanding terminology related to:
  - Genetics and Genomics
  - Various Types of Testing
    - Translate into improving the ability to navigate the array of testing options and select appropriate testing

- Synthesize available and reliable information in central location and develop an educational platform on genetics and genomics for providers and the public
- Should we explore education regarding pathologic risk?

Conclusions

- **Thank you for welcoming me to the group**
- There is much work yet to be done and our predecessors in the four workgroups have given us meaningful avenues to pursue and continue

- As we consider the upcoming Open Discussion, please be thinking about:
  - Committee membership (and leadership)
  - Cadence of workgroup meetings
  - Consider adding 3rd meeting to 2023 calendar

- Review attached article for our post-lunch visiting guest speaker