Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

Genetics/Genomics Work Group

Notes from meeting: February 21, 2023

GOALS

- Improve collaboration and documentation towards assessment and recommendations related to genetic and genomic testing in young women with breast cancer
- Offer recommendations to improve value and service for the ACBCYW

PREVIOUS RECOMMENDATIONS

- Support and provide educational materials for understanding terminology related to:
  - Genetics and Genomics
  - Various Types of Testing
- Synthesize reliable information regarding genetics and genomics in a central educational platform.
- Explore education regarding pathologic risk factors.
- CDC to join the Consistent Testing Terminology Working Group to stay apprised of and participate in ongoing discussions to develop specific language around "genetics" and "genomics.”

FOR DISCUSSION

- What topics should we focus on?
- Who is the target audience?
- What interventions/strategies should we consider?
- Who else should we look for input from?

TOPICS

- Understanding of genetic testing and (genomic) biomarker testing
  - Terminology
  - Gaps in patient understanding of testing and results
  - Gaps in provider understanding of testing and results
- Providing guidance on tests being marketed directly to patients or to providers outside of guidelines
  - Not-yet-validated/limited utility multi-cancer screening blood tests
  - Direct-to-consumer genetic testing/pharmacogenetic testing, etc
- Access to care
  - Genetic counseling and testing
  - Access to guideline-recommended risk management/care

UNDERSTANDING GENETIC AND GENOMIC (TUMOR BIOMARKER) TESTING

- Gaps in patient understanding of tests and results
  - Examples – tumor type, prognostic testing vs. genetic testing
    - Person whose mother had breast cancer asking for genetic testing for HER2
  - Gaps in provider understanding/time to explain meaning of testing and results
- Patient education suggestions
  - Patients still need the basics – tumor types, what is genetic testing, how is it different from tumor testing?
- Provider education suggestions
  - Focus on navigators/more time to explain to patients

MARKETING OF TESTS WITH LIMITED DATA OR CLINICAL UTILITY

- Gaps in patient understanding of testing and results
  - Example – tumor types vs. genetic testing
    - Person whose mother had breast cancer asking how she can get genetic testing for HER2
    - People using 50-cancer screening blood test instead of guideline-recommended screening like breast MRI
- Gaps in provider understanding/time to explain meaning of testing and results
  - Example, provider at comprehensive cancer center saying that everyone should have the 50-cancer screening blood test
- Updated landscape scan on issues with people using ancestry/DTC testing for hereditary cancer risk
  - Is it still an issue? Is it causing ongoing harm to patients?
  - Do we need more input from patients/providers/other stakeholders on this issue?
- Education suggestions
  - Consider table / infographics with different types of tests, state of validation, guideline recommended and whom
  - Education materials for patients and providers on current standard-of-care guidelines
  - Opportunity to collaborate with Provider Work Group

ACCESS TO CARE

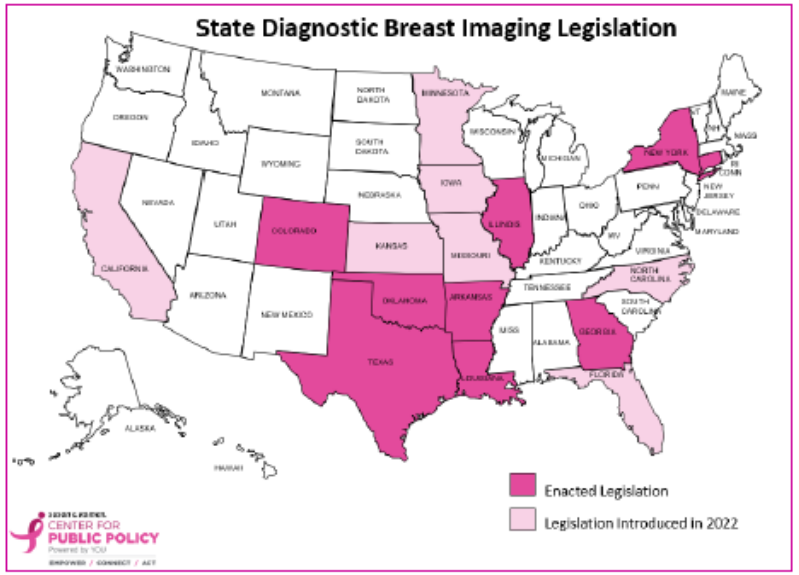
- Access to genetic counseling and testing
  - Many options for low cost genetic counseling and testing
- Access to guideline-recommended risk-management
  - Large out-of-pocket for high-risk women recommended to undergo breast MRI
  - State-by-state policy efforts – helps people in states that pass laws but creates state-to-state disparities

Breast Screening Coverage

- State efforts to eliminate cost of high-risk breast screenings and diagnostic imaging
- NY, AR, TX, CT, GA, OK & MD passed laws - cover breast MRIs/ultrasounds at 100%
- Current efforts in AZ, CA, FL, IA, KS, ME, MN, MS, MO, NV, NM, NC, VA, WA & WI
- State by state approach compounds disparities
- Impact of new ACA ruling?
- CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP) – which states provide assistance for MRI for high-risk people?

Previous Efforts			
State	**Introduced**	**Legislative Status**	**Status**
New York	2017	Passed the House and Senate	Signed by Governor in 2017
Colorado	2019	Passed the House and Senate	Signed by Governor in 2019
Illinois	2019	Passed the House and Senate	Signed by Governor in 2019
Louisiana	2019	Passed the House and Senate	Signed by Governor in 2019
Arkansas	2021	Passed the House and Senate	Signed by Governor in 2021
Texas	2021	Passed the House and Senate	Signed by Governor in 2021

2022 Efforts			
California	2022	Passed the House and Senate	
Connecticut	2022	Passed the House and Senate	Signed by Governor
Florida	2022	Did not move forward this session	
Georgia	2022	Passed the House and Senate	Signed by Governor
Iowa	2022	Did not move forward this session	
Kansas	2022	Did not move forward this session	
Massachusetts	2022	Did not move forward this session	
Minnesota	2022	Did not move forward this session	
Missouri	2022	Did not move forward this session	
North Carolina	2022	Did not move forward this session	
Oklahoma	2022	Passed the House and Senate	Signed by Governor



ACCESS TO CARE

- Suggestions:
  - National scan to measure scope of the issue
    - Lots of documentation on disparities in genetic counseling and testing
    - Very little data on who is getting guideline-recommended screening and how much they are paying
  - Are there opportunities to expand CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to cover more high-risk patients, especially in states without laws about coverage?
  - Create more awareness of CDC NBCCEDP program and new state-level laws about no out-of-pocket costs for screening MRI for high-risk individuals (overlay maps to look at geographic areas with largest disparities?)

NEXT STEPS

- Prioritize issues (we can’t boil the ocean)
- Input from additional stakeholders if needed/available
- Convene at least one more meeting
- Solidify recommendations for Fall CDC meeting