Current issues in advocacy and public policy
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Legislative and oversight challenges to the hereditary breast and ovarian cancer community. Challenges facing members of the hereditary breast, ovarian and related cancer community are many. This community faces significantly elevated lifetime cancer risks, diagnoses at younger ages and treatment-related long-term quality of life issues (early menopause, infertility, osteoporosis and cardiac disease), more aggressive disease, increased risk of multiple diagnoses, having multiple family members affected, and a lack of understanding of guidelines or policies on management. This high-risk population also tends to have higher out-of-pocket health care costs from earlier, more intensive cancer screening and preventive services, risk-reducing surgeries, and/or treatment. High-risk individuals often suffer associated loss of income, childcare costs, and other expenses related to hereditary cancer or its prevention/treatment.

The Affordable Care Act and the United States Preventive Services Task Force

The Affordable Care Act (ACA) established some patient protections and required access to health insurance for all Americans. This legislation eliminated pre-existing conditions as a barrier to coverage. It abolished annual and lifetime caps on what insurance companies pay out. It also capped out-of-pocket healthcare expenditures for the individual. It provides coverage for specific screening and preventative services without copay or deductible. It covers young adults on their parents’ plan up to the age of 26. The ACA also requires insurance coverage for any routine care costs or complications experienced while an individual is enrolled in a clinical trial.

The United States Preventive Services Task Force (USPSTF) establishes preventative guidelines for individuals of “average risk” for diseases. Under the ACA, services receiving a grade A or B from the Task Force must be covered by most health insurers with no out-of-pocket costs to the consumer. The Task Force does have guidelines on risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women. If specific criteria are met based on risk assessment models most insurers must cover BRCA counseling and genetic testing with no out-of-pocket cost.

The USPSTF does not address the following:
- Screening and prevention options other than chemoprevention for certain high-risk women.
- Cancer survivors in treatment.
- Genetic counseling and testing for Lynch Syndrome and other hereditary cancer syndromes through either single gene or multi-gene panels.
- Secondary genetic testing for women who previously tested negative.
- Genetic testing for men.

Because the Task Force does not address these, some health plans use that as justification to exclude or deny coverage of services. (FORCE can help with appeals for denial of coverage.) Denials that are upheld can result in high-risk individuals being deprived of the opportunity to receive genetic counseling with a certified genetic counselor and being unable to access genetic testing and important risk information. This may put them at risk of financial toxicity (financial problems an individual encounters due to health care expenses), foregoing the standard care for prevention or treatment due to financial constraints, need for more treatment due to more advanced cancer at diagnosis, and an impact on relatives who may also be at risk.

Regarding breast cancer screening for average risk women, the USPSTF recently recommended that mammograms not begin until age 50. However, waiting that long could lead to cancers being missed, more treatment, and deaths. Through FORCE’s advocacy efforts, the Protecting Access to Lifesaving Screenings (PALS) Act was passed in 2015, establishing a moratorium on the USPSTF recommendation and keeping the previous guideline of beginning mammograms at age 40. As a result, women ages 40-49 continue to have access to annual mammogram screenings at no cost. The moratorium is set to expire on January 1, 2020 but it will likely be extended.

**Breast density**

Notification laws in certain states in the U.S. require that women who undergo mammography be informed if they have dense breasts, and the potential risks posed by breast density. Only 4 states have laws requiring insurance coverage for the additional imaging that is recommended for women with dense breasts. However, other states are working to pass laws that will ensure health insurance coverage for the additional imaging.

**3D mammograms**

Recent laws expand the legal definition of breast cancer screening to guarantee 100% health insurance coverage for 3D mammograms in addition to standard mammograms under the ACA. Medicare covers 3D mammograms, and FORCE is working to ensure that Medicaid also provides coverage.

**Oral chemotherapy**

Currently, most states have laws in place to ensure coverage of anti-cancer regimens, regardless of how they are administered. However, a national law is needed to ensure that patients don’t pay exorbitant costs for treatments not administered by IV. Legislative efforts are ongoing to ensure that patients have equal access and insurance coverage to all approved anti-cancer regimens.
**PSA testing for prostate cancer**

USPSTF guidelines gave a “C” grade to the use of prostate specific antigen (PSA) testing, which means that health insurance companies are not required to cover it. However, the Task Force modified its recommendation to clarify that BRCA-positive men should not be precluded from PSA testing and the vast majority of health insurers cover this.

**Medicare and Medicaid coverage**

Medicare does not guarantee coverage for preventive medicine; however, it currently covers BRCA genetic testing for men with breast cancer and women with breast or ovarian cancer who meet certain criteria. These is no nationwide Medicare policy in place because the program is operated by 10 different contractors who oversee specific regions. These contractors can create their own region-specific coverage policies called local coverage determinations, as long they do not conflict with Medicare’s national policies. As a result, BRCA testing for people who have pancreatic cancer and multigene panel testing are only covered in some regions. Medicare does not cover genetic counseling with a certified genetic counselor, counseling and testing for people who have not had cancer, or prophylactic surgeries for unaffected carriers (although some individuals have been able to get coverage).

Each state determines its own policies and coverage for low-income Medicaid services, including coverage of BRCA genetic testing, counseling, screening, and risk management services. FORCE is working to determine the policy and coverage of each state. Current information indicates about 75% of states cover the cost of BRCA genetic testing and counseling, but whether the costs of risk management and risk-reducing strategies are covered is unclear.

**Future legislative goals for the high-risk community**

In the future, continued legislative efforts will aim to preserve access to mammograms for women ages 40-49 with no out-of-pocket cost, and to make the 7.5% medical expense deduction permanent. FORCE is participating in efforts to pass state and federal legislation to ensure equal access to anti-cancer treatments, regardless of how they are administered. Legislation that facilitates Medicare coverage of screening and preventive services for previvors will be introduced. Collaborative efforts will also work toward requiring insurance coverage of fertility treatments for previvors and survivors.