



Published in final edited form as:

J Cancer Policy. 2021 June ; 28: 100275. doi:10.1016/j.jcpo.2021.100275.

Cancer genetic testing in marginalized groups during an era of evolving healthcare reform

Stephen M. Modell^{a,*}, Caitlin G. Allen^b, Amy Ponte^c, Gail Marcus^d

^aEpidemiology, University of Michigan School of Public Health, M5409 SPH II, 1415 Washington Hts., Ann Arbor, MI, 48109, United States

^bBehavioral, Social and Health Education Sciences, Rollins School of Public Health, Emory University, 1518 Clifton Rd., Atlanta, GA, 30322, United States

^cGenedu Health Solutions, 47 Petigru Dr., Beaufort, SC, 29902, United States

^dGenetics and Newborn Screening Unit, North Carolina Department of Health and Human Services, C/O CDSA of the Cape Fear, 3311 Burnt Mill Dr., Wilmington, NC, 28403, United States

Abstract

Background: The Affordable Care Act and subsequent reforms pose tradeoffs for racial-ethnic, rural, and sex-related groups in the United States experiencing disparities in *BRCA1/2* genetic counseling and testing and colorectal cancer screening, calling for policy changes.

Methods: A working group of the American Public Health Association Genomics Forum Policy Committee engaged in monthly meetings to examine ongoing literature and identify policy alternatives in the coverage of cancer genetic services for marginalized groups. 589 items were collected; 408 examined. Efforts continued from February 2015 through September 2020.

Results: African Americans and Latinos have shown 7–8 % drops in uninsured rates since the Exchanges opened. The ACA has increased *BRCA1/2* test availability while several disparities remain, including by sex. Rural testing and screening utilization rates have improved. Medicaid expansion and the inclusion of Medicare in the ACA have resulted in mixed improvements in colorectal cancer screening rates in marginalized groups.

Conclusion: Cancer genetic testing and screening to date have only partially benefited from healthcare reforms. Sensitivity to cost concerns and further monitoring of emerging data are needed. A reduction in disparities depends on the availability of private insurance, Medicaid and Medicare to the marginalized. Attention to value-based design and the way cancer benefits are translated into actual testing and screening are crucial.

This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

*Corresponding author: Research and Dissemination Activities Director, Center for Public Health and Community Genomics, University of Michigan School of Public Health, M5049 SPH II, 1415 Washington Hts., Ann Arbor, MI, 48109-2029, United States. mod@umich.edu (S.M. Modell).

Author contributions

Principal author, devised tables: SM. Wrote portions of paper, made section modifications: CA. Frequent reviewer, contributed portions of paper: GM. Finalized structuring and wording of various drafts: AP. All authors were engaged in paper review and literature search and selection.

Declaration of Competing Interest

No competing financial interests exist.

Policy Summary: The findings suggest the need for further benefits-related health agency interpretation of and amendments to the ACA, continued Medicaid and innovative Medicare expansion, and incorporation of cancer services values-based considerations at several levels, aimed at reducing group disparities.

Keywords

Health care reform; Breast cancer; Colorectal cancer; Early detection of cancer; Genetic testing; African Americans; Hispanic Americans; Rural population; Sex

1. Introduction: healthcare reform and marginalized groups

Healthcare reform over the last decade has been a major part of the United States effort to make preventive health services available to a larger proportion of the population, often focusing on racial-ethnic and lower socio-economic groups. Prior to the Affordable Care Act, about 79 million persons – more than one in four Americans – either lacked health insurance or were underinsured based on income [1]. Approximately two of every five Latinos and one in every five African Americans, compared to 1.5 out of every ten whites, went uninsured [2].

The Patient Protection and Affordable Care Act of 2010, P.L. 111–148 (ACA), aimed at reducing disparities by making primary health care services available through guaranteed coverage and protecting consumers from unfair insurance practices [3]. Changes to the U. S. health care system began as early as 90 days after enactment; states were required to open Health Benefit Exchanges by January 1, 2014. The ACA originally contained premium tax credits for those earning 100–400 % of the federal poverty level (FPL), cost-sharing reduction subsidies to reduce copayments and deductibles, and governmental cost-sharing subsidy payments to insurers (halted in 2017). Such changes had been shown workable in other countries. The Swiss healthcare system incorporated personal eligibility conditions for federal subsidies while carriers were permitted to differentiate plans and associated premiums according to deductible levels [4].

In data from 2012 through 2015, premiums remained level and out-of-pocket spending decreased in low-income (139–250 % of the FPL) and very low-income (≤ 138 % FPL) Americans, and the number of uninsured Americans diminished to 29 million people [5]. Uninsured rates in Latinos dropped to one in five; one in ten in African Americans [6]. The uninsured rate dropped from 16.1 % before the ACA's passage to 7.9 % in 2017 [7]. Administrative changes then shifted the rate in 2018 to 8.5 %. More than 20 million Americans have obtained health insurance who would not otherwise own it. Within this figure, 14.7 million individuals enrolled into Medicaid and the Child Health Insurance Program, a result of Medicaid expansion granting eligibility to people with incomes up to 138 % of the poverty level [8,9].

Cancer, the leading cause of death worldwide and the second leading cause of death in the United States, is a target for the ACA's preventive health services [10]. African American and Latina women nonetheless suffer increased mortality from breast cancer at every stage compared to white women [11]. Rural Appalachians are noted to have higher (by 15–36

%) cancer mortality rates than their urban non-Appalachian peers [12]. “Marginalization” is a process in which a socially defined group is accorded secondary or lesser status, and its members’ needs or desires ignored. In the healthcare setting, marginalization implies being excluded from access to needed healthcare services [13]. This paper describes a series of marginalized groups who are not covered or lack adequate coverage for cancer genetic services under the ACA – African Americans and Latinos [14,15], women and men in specific contexts described below, and rural populations – groups of concern to professionals in public health and genetics [16,17]. It will review the impact of the ACA and subsequent reforms on these groups with respect to cancer genetic testing, examining: (1) the private insurance market; (2) public insurance - Medicaid and Medicare; and (3) essential health benefits. We describe both policy changes that have been made and empirical findings in testing and screening.

2. Methods

2.1. Recruitment and conduct

Following development of a policy statement advancing cancer genomics in public health, the Policy Committee of the American Public Health Association Genomics Forum formed a working group of 5 members from state-level and academic public health, genetic counseling, and health services to address cancer genetic testing services and marginalized groups, and the impact of healthcare reform. Community-based organizational members periodically joined in discussions. Members all had at least a master’s degree in their respective field; each had an additional professional certification such as genetic counseling, epidemiology, or health education. The full working group engaged in monthly conference calls and literature review from February 2015 through March 2017; four members continued through September 2020.

2.2. Policy analysis

The group chose three main categories (seven sub-categories) of literature to collect: policy-oriented (e.g., genetics and reform); group-oriented (e.g., women’s health); and condition-oriented (hereditary breast and ovarian cancer (HBOC) and hereditary nonpolyposis colorectal cancer – Lynch syndrome) [18,19]. Newborn screening, though part of the ACA, was excluded due to lack of relevance to cancer genetic services. Literature inspected was purposefully chosen to enable policy analysis, rather than produce a literature review. Inspection was based on fit within the chosen categories, applicability to ongoing policy measures, and pertinence to the cancer and marginalized groups central theme. In all, 589 pieces of literature – 39 policy documents; 172 policy reports or briefs; 238 journal articles; and 140 news articles – were collected; 408 were examined.

3. Results

3.1. Private insurance

3.1.1. Removal of the individual mandate and extension of short-term insurance—With the change of administration, alternate “Repeal and Replace” legislation emerged from the U.S. Congress in the first quarter of 2017. In October 2017 President

Trump issued an executive order reinstating a twelve-month enrollment period on short-term health insurance, with renewal up to 36 months [20]. A colonoscopy for those shown to be at risk for colorectal cancer (CRC) usually ranges between U.S. \$2,010 and \$3,764, with an average of \$3,081 according to Blue Cross Blue Shield of North Carolina [21]. Polyp removal can cost an additional \$548. Molecular screening for Lynch syndrome, an inherited, high-risk form of CRC, can cost upwards of \$1,200 [17]. With short-term coverage these costs would essentially end up being paid out-of-pocket, reflecting why the measure did not provide additional security for many.

The Tax Cuts and Jobs Act of 2017 repealed the ACA's individual mandate [22]. The Kaiser Family Foundation reports that the average premium increase in 2019 due to the individual mandate penalty repeal and expansion of more loosely regulated plans was 6% (range 0–16%) [23]. One offsetting measure pursued by the U.S. Department of Health and Human Services to hinder premium increases was to allow out-of-pocket (deductible and copay) maximums to increase yearly [24]. Consequently, deductibles are estimated as increasing 4% between 2019 and 2020 for Bronze plans, held by families with less expendable income [25].

The median household income in the U.S. in 2018 was \$41,361 for African Americans; \$51,450 for Latinos; and \$70,642 for whites [26]. Genetic testing and follow-up can be expensive for individuals without coverage and low-income families only able to afford insurance with high deductibles. In one study, the average figure for *BRCA* genetic counseling and mutation testing was \$341 (range: \$249 (Color) to \$3,100 (Myriad Genetics) [19]; paid without cost-sharing so long as the individual has insurance on a state Exchange); \$8,144 for risk-reducing salpingo-oophorectomy; and \$12,596 for prophylactic mastectomy [27].

3.1.2. Racial-ethnic disparities and insurance coverage—Evidence suggests that testing cost and ability to pay have and continue to play a significant part in cancer genetic testing disparities. Prior to the ACA, a Harvard/MGH Center on Genomics review of national claims data (2004–2007) for 15 million commercially insured new breast cancer cases showed that whites were almost twice as likely as Latinos and three times as likely as African Americans to have received *BRCA1/2* breast-ovarian and *MLH1/MSH2* colorectal cancer genetic testing [28]. A hospital-based case-control study at University of Pennsylvania of 408 women with a family history of breast or ovarian cancer found, after adjustment for socioeconomic factors, that African American women were much less likely (O.R. = 0.28, 95 % C.I. 0.09–0.89) to undergo counseling for *BRCA1/2* genetic testing than white women [29]. The research team subsequently showed income and cost to be major factors in the women's decision whether to test [30]. Investigative teams examining HBOC and Lynch syndrome genetic counseling and testing inequities in Latina women in the New York City [31], Tampa Bay [32], and Dallas [33] areas reported difficulties with cost and coverage to be major barriers [34].

Utilization studies from the period preceding the opening of the state Exchanges evinced continuing disparities [35,36]. A University of South Florida / Florida Department of Public Health study of 1,622 women with medical record-verified invasive breast cancer (2009–

2012) revealed African Americans were 16.6 times less likely than whites to have discussed the possibility of genetic testing with a healthcare provider and 5.6 times less likely to have had genetic testing; Spanish-speaking Latina women were 2 times less likely than whites to have discussed genetic testing, though differences in testing were no longer significant. The investigators observed, “The presence of private insurance had a direct impact on both genetic testing discussion and receipt of testing” [35].

Bhandari and Li, utilizing Medical Expenditure Panel Survey data from 2009 and 2011–2014, did not observe a statistically significant increase in CRC screening in 2014 compared to 2009 among African Americans and Latinos holding private insurance [37]. Similar group-specific data for *BRCA* testing does not yet exist for the period following the opening of the Exchanges. One study suggestive of possible post-ACA trends looked at *BRCA1/2* test ordering (not policy as a whole) cancellation rates (2012–2014) following the introduction of a medical geneticist / genetic counselor authorization requirement to a national insurance plan [38,39]. It found that cancellation rates increased for all ancestries, but were more pronounced for African American and Latina subscribers. These findings suggest that attention to the way ACA counseling and coverage requirements are handled is important [39,40].

Fogleman et al., in a post-ACA survey of perceived barriers to genetic testing (*BRCA* testing as the example) in three Kentucky rural communities, found “no genetic counselor nearby” to be a major barrier in only 15 % of residents surveyed, while cost was a major barrier in 27 % of participants [41]. Nevertheless, that study and one performed by the Centers for Disease Control and Prevention described *BRCA* testing as increasing among non-Metropolitan, rural women with employer-sponsored insurance, likely due to a reduction in cost barriers to testing [41,42]. This trend is suggestive of increasing equity given that one in five rural Americans is a person of color, and in some rural areas, the proportion is greater than 50 % [43].

3.2. Public insurance

Medicaid and Medicare are important options for the marginalized. In an analysis of a nationally representative sample of 1,724 men and women, African Americans were more likely to have Medicare (odds ratio O.R. = 1.68) and Medicaid (O.R. = 2.51) and less likely to have private insurance (O.R. = 0.55) than their white counterparts. Latinos were less likely to have private insurance (O.R. = 0.49) or more likely to have no insurance at all (O.R. = 0.60) than non-Hispanic whites [44].

3.2.1. Medicaid—Coverage options in those eligible for Medicaid start when an individual has an annual income of \$12,490 or less, and a family with up to four members has a combined annual income of \$25,750 or less [45]. So far, 39 states including the District of Columbia have elected to expand Medicaid. As of 2017, the percentage decrease in uninsured rates for African Americans was 9% in expansion states compared to 7% in non-expansion states; for Latinos, 12 % and 8 %, respectively. A coverage gap exists for individuals with incomes above traditional Medicaid eligibility limits, particularly in states that did not expand their Medicaid programs (41 % FPL), but below the lower limit for

insurance Marketplace premium tax credits (100 % FPL). Uninsured African Americans are more likely than whites to fall in this coverage gap [46]. Nationally, 51 % of uninsured adults in the coverage gap are minority (28 % African American; 23 % Latino) [47].

A survey by the advocacy organization FORCE (Facing Our Risk of Cancer Empowered) indicates that *BRCA* predictive testing is currently covered by Medicaid in all but three states, up from 32 states in 2013 [19,48]. A study by Zerhouni et al. of 2012 through 2016 Behavioral Risk Factor Surveillance System data found a significant increase in CRC screening rates (from 56.7%–67.6%) for African Americans in early expansion states, those that adopted Medicaid expansion before 2014, compared to a statistically nonsignificant increase (from 57.7%–61.4%) for those in nonexpansion states [49].

Data on the impact of Medicaid expansion on Latino cancer screening is less clear-cut. Zerhouni et al. found that unlike African Americans, Latinos did not show a statistically significant increase in CRC screening in expansion states, suggesting additional access obstacles [49]. On the other hand, Latino Medicaid enrollees in Oregon, where Medicaid expansion was enacted in 2013, displayed relatively high CRC screening rates (screening risk ratio 1.16 compared to whites) for the 2010–2014 period [50]. Possible contributors were a statewide public health campaign to promote CRC screening and the use of community health workers. A Phoenix, AZ-based safety-net hospital utilizing specialist training in financial assistance guidelines and principles of cultural tailoring was able to achieve *BRCA1/2* genetic counseling and testing rates of 78 % in its at risk Latino clinical population, half of whom were non-English speaking [51].

In terms of rural populations, a study examining 2011–2016 Kentucky Cancer Registry data found that CRC screening for Medicaid patients rose 250 % after ACA implementation. A higher increase in screening was noted for Appalachian (+44 %) than non-Appalachian individuals (+22 %). The former also displayed an increase in the proportion of early stage CRC (stage I/II) detected [52].

3.2.2. Medicare—Screening colonoscopies are fully covered as part of the Medicare initial preventive physical examination included in the ACA (Table 1) [53].

More frequent colonoscopies are covered if the individual is considered high-risk for colorectal cancer. In October 2014, the Centers for Medicare & Medicaid Services granted Medicare coverage for Cologuard, a DNA alteration test that screens for pre-cancer [54]. Medicare pays for genetic testing, e.g., for the high-risk condition Lynch syndrome, when it is considered medically necessary in those diagnosed with cancer [48,55].

“Medicare for All” (introduced 116th U.S. Congress), or cradle-to-grave protection, is a possible incremental target for the future [56]. Such a proposal would seem quite favorable to members of various racial-ethnic groups, such as African Americans and Latinos, in whom weekly earnings are 25 % or less compared to whites, and uninsured rates are 35 % higher [57,58]. Diagnostic tests and preventive services, which are part of Medicare for All’s “primary and preventive services” and are essential for cancer early detection and management, would be covered [59]. Alternate proposals to lower the age of eligibility

from 65 to either 60 or 50 years would be in alignment with ACA policy, which covers screening colonoscopies starting age 50–64 [10]. For individuals living within the coverage gap, Medicare for All could be positive, but they are also likely to experience changes in their income induced by increased premiums to be paid by their employers, as well as increases in payroll taxes brought about by the program [60].

An alternative granting a “public option” would offer insurance plans to small businesses and individuals unable to afford the private market, and would likely preserve essential health benefits [61,62]. Germany offers a public option based on opt-out (for upper-income individuals) rather than opt-in (for lower-income persons) [4].

A study of 16 Surveillance, Epidemiology and End Results (SEER) regions revealed African American and Latino were less likely than white Medicare beneficiaries to receive screening colonoscopies for the pre-ACA period 1996–2005 [63]. The Medical Expenditure Panel Survey study performed by Bhandari et al. identified a 40 % jump in CRC screening rates among Latino Medicare beneficiaries from 2009 to 2011, the latter being a year in which significant Medicare changes went into effect [37]. This team and Cooper et al. detected a subsequent flattening and decrease in screening rates among white and minority Medicare beneficiaries from 2011 to 2012 [37,64], though Bhandari et al. also showed a rise in CRC screening for Latinos and African Americans between 2012 and 2014 with a statistically significant 44 % increase for Latinos compared to the 2009 reference year [37].

3.3. Essential health benefits

The ACA requires health insurance plans sold to individuals and small businesses to provide a minimum package of health services falling within ten categories, called “essential health benefits,” applying to adults, women, including pregnant women, and children [65]. In 2013 the Department of Health and Human Services decided to give each state substantial leeway in defining required benefits. Each state engages in a “benchmarking” process, selecting within- and out-of-state design options to fulfill coverage of the essential health benefit categories. The notion of a defined package of benefits has precedent in countries outside the U.S., such as the Netherlands and Switzerland [4], and is included in ACA section 2713 according to value- [66] and evidence-based criteria [67].

Within the ACA’s list of ten essential services, preventive and wellness services and chronic disease management address cancer prevention and control [10]. The ACA eliminates cost-sharing on a number of cancer services that have received an “A” or “B” rating by the U.S. Preventive Services Task Force (USPSTF) or are provided for in Health Resources and Services Administration comprehensive cancer guidelines, such as breast cancer screening including mammography, and genetic counseling for HBOC with provider-indicated *BRCA1/2* testing. The question remains whether the essential health benefits adequately reflect the needs of members of marginalized groups at risk for cancer.

3.3.1. Coverage of hereditary breast and ovarian cancer—The ACA has emerged as a champion of women at risk for breast and ovarian cancer. In 2005 the USPSTF recommended that women whose family history may be associated with an increased risk for deleterious *BRCA1/2* mutations be referred for genetic counseling and evaluation for

BRCA testing (Table 2) [68,69]. This evidence-based recommendation has been used to generate one of the two Healthy People 2020 Genomics objectives [70].

BRCA1/2 counseling and mammography coverage were written directly into the text of the ACA [3]. The ACA “Preventive health services” website at [HealthCare.gov](https://www.healthcare.gov) also indicates that women ages 50–74 are eligible for biennial mammography (Table 1) [10]. Two large medical claims database studies (N > 50,000 women each) noted distinct increases in *BRCA1/2* testing rates in the first year the state Exchanges opened, 2014 [76,77].

3.3.2. Shortcomings in policies relating to women and men with *BRCA1/2* mutations—The USPSTF’s original 2005 recommendations do not apply to women with a family history of breast or ovarian cancer that includes a relative with a known deleterious mutation in *BRCA1/2* genes [68]. Because the ACA defers to the USPSTF, this constraint represented a shortcoming for women at risk for such mutations.

Of additional concern, section 2713(a) of the ACA is so specific that the essential health benefits address children’s and women’s needs, but not men’s [3]. Both the Act’s text and USPSTF policies reflect this absence. The 2013 USPSTF policy on *BRCA* mutations openly states: “These recommendations do not apply to men, although male family members may be identified for testing during evaluation” [78]. Overall, the risk for breast cancer in men carrying a *BRCA* mutation of any kind is about seven to ten times that of the general male population [79]. A 2015 estimate placed the number of new breast cancer cases and resultant deaths in U.S. males at 2,350 and 400, respectively [80]. Men carrying a *BRCA2* mutation also have a 3-fold elevated risk of high-grade, aggressive prostate cancer [81]. Despite these figures, the proportion of unaffected men tested for HBOC in the 2015 U.S. National Health Interview Survey data was about one-tenth that of unaffected women [82]. In this analysis Childers et al. showed that an unaffected male would be half as likely to undergo testing as an unaffected woman. A retrospective analysis of high-risk patients referred to the Loma Linda University Breast Health Center a year before the ACA was passed reported that 4 out of the 5 referred males did receive *BRCA* testing, but this small number (N = 213 for the entire study) failed to achieve statistical significance (P = .37) [83].

Due to the risks facing males, the National Comprehensive Cancer Network Genetic/Familial High-Risk Assessment Guidelines recommend that men at elevated risk for breast cancer begin self-exam training and clinical breast examination starting age 35, and that men diagnosed with breast cancer undergo *BRCA1/2* genetic testing [84]. Also considering prostate cancer, they recommend provision of *BRCA1/2* information if these mutations are known to exist in the family, and risk assessment and counseling for *BRCA* testing if clinical criteria, including Gleason score ≥ 7 along a 10-point range of prostate cancer aggressiveness, are met.

African American men suffer a greater prostate cancer incidence, more advanced disease at the time of diagnosis, and double the rate of prostate cancer mortality compared to white men [85,86]. They are also more likely than white men to harbor *BRCA1/2* variants of unknown pathogenic significance [87]. While it is difficult to disentangle the relative effects

of biological and socioeconomic factors, the conditions under which *BRCA* testing in men might be covered are worthy of further consideration.

3.3.3. Coverage of colorectal cancer and Lynch syndrome—Colorectal cancer is the second most frequent cause of cancer-related death in the United States and globally [88]. Though the essential health benefits section of the ACA does not address CRC specifically, the ACA [HealthCare.gov](https://www.healthcare.gov) website “Preventive health services” does [10]. For persons ages 50–75, a payer may not impose cost-sharing with respect to screening for colorectal cancer or polyp removal performed as part of a screening procedure. In addition to Medicare coverage, screening colonoscopies are fully covered by private insurance under the ACA if the condition meets USPSTF criteria (Table 2). More frequent use of colonoscopy for high-risk surveillance is outside the scope of the USPSTF CRC recommendations, and is not covered by the ACA for insurance purposes, though Medicare can pick it up for individuals who qualify (Table 1) [73].

In 2010, CRC screening rates for adults >50 years were reported to be lower in Latinos than non-Latino whites and African Americans, with some variation according to location of origin (Puerto Ricans having higher rates than Mexicans and Dominicans, for example) [89]. For the period 2012–2015, annual colorectal cancer screening rates increased for both Latinos (by 1.29 per 100 adults in a study by Mbah et al. using the Medical Expenditure Panel Survey) and non-Latinos (by 0.58 per 100 adults) [90]. These figures represent positive gains, though the difference in trend increases between the two groups was not statistically significant, suggesting more needs to be done to close the screening gap.

While the ACA treats CRC screening as an essential health benefit, it fails to address screening or testing for its most common hereditary form, considered by the Centers for Disease Control and Prevention and Healthy People 2020 to be of prime importance [70,91]. Lynch syndrome (LS) is a particularly pernicious form of CRC – polyps can progress to the cancerous state in just 30 months, compared to 10 or more years for the general population [92]. The ideal would be for insurance plans to universally address high-risk CRC irrespective of the ACA. A 2012 review of the largest U.S. insurers (Aetna, Blue Cross Blue Shield) revealed that only 4/6 (67 %) had coverage policies addressing microsatellite instability (MSI) screening for LS [93]. In a web survey of coverage policies (2011–2012) belonging to moderate-to-large health insurance carriers, 47/66 (72 %) insurers addressed genetic tests for LS in their coverage policies [94]. Payer policies do not necessarily translate into straightforward usage. In a 2018 web-based survey of 442 U.S. gastroenterologists, 11–33% of respondents (depending on routineness of test ordering) indicated the cost of MSI or immunohistochemistry testing was a barrier to test ordering for LS [95]. The Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group found sufficient evidence, though, to recommend offering genetic testing for Lynch syndrome to all individuals with newly diagnosed CRC [96].

Despite EGAPP’s recommendation, rural and racial-ethnic disparities persist for LS testing. A population-based study of 274 Louisiana Tumor Registry CRC patients from 2011 found that a medical facility’s being located in a rural in contrast to urban location was a statistically significant barrier to Lynch syndrome screening (O.R. = .40) [97]. A

retrospective survey of colorectal tumors tested from 2012 through 2016 at four academic medical centers found that minority patients were significantly less likely to be referred for genetic evaluation than white patients [98]. The odds ratio for germline genetic testing being performed was 0.65 for Latinos and 0.39 for African Americans. Being African American and the particular medical center examined were negative predictors of testing, suggesting structural factors that could benefit from reform.

4. Discussion

Recent shifts in healthcare reform in the U.S. – removal of the individual mandate and promotion of short-term insurance – increase individual autonomy but are likely to have untoward effects on members of marginalized groups requiring affordable cancer services (Table 3) [99–103].

The Urban Institute estimates that if government were to revert to the ACA standards existing prior to 2017 (individual mandate penalties, cost-sharing reduction subsidy payments to insurers, and a 3-month limit on short-term plans), the number of people with inadequate health insurance could be reduced by at least 15 % [62,104]. Including a public option in the Marketplace, increasingly popular, could reduce premiums by about 7–8% [62,105]. In a country where autonomy is prioritized, state-level introduction of mandates based on successful state model programs is also a reasonable alternative [99].

The American Health Care Act, part of the former “Repeal and Replace” legislation, offered states the option of block grants for families on Medicaid based on the argument that state departments know their population best [106,107]. As a national program, federal agencies would need to monitor outcomes to avoid inequities among states. With block grants, states can find financing their share of health care expenditures daunting [62].

It is possible that shifts in the range of benefits states mandate could offer a population-oriented solution to cancer services disparities. In April 2019 Health and Human Services revisited the essential health benefits (EHB) benchmark plans available to states by allowing one state to adopt another’s benchmark plan, or to select its own set of benefits, subject to coverage considerations within each EHB category [101,102]. It has been suggested that state benchmark plans incorporate value-based design, a move that has already been undertaken by Covered California and Oklahoma’s Medicaid drug coverage program [66]. Affordable Care Act provisions can also be legislatively amended. For example, the Medicare Access and CHIP Reauthorization Act of 2015 combined measures established for Medicare’s value-based payment modifier with measures from other preexisting programs [103]. Value-based changes at the federal or state level could offer an inlet for insurance coverage of Lynch syndrome genetic testing.

The Community Health Needs Assessments (CHNAs) mandated by the ACA [108] perform an honest broker function in helping assure health care services, cancer services (cancer screening, information provision, facilities access, support groups) among them, reach urban and rural neighborhoods displaying high racial-ethnic diversity and low reported household income [109,110]. They serve as a form of institutional-level quality control.

Patient advocacy is a necessary element for motivating change from the grassroots level (Table 4). Dialogue between USPSTF and FORCE resulted in the USPSTF's acceptance (2013) of genetic counseling and testing for women who have one or more family members with a known potentially harmful *BRCA1/2* mutation [72,78]. Additionally, in October 2015 following advocacy by FORCE, three federal agencies issued a joint clarification that ACA coverage can conditionally apply to a currently asymptomatic woman who has been previously diagnosed with cancer [111]. Comparable advocacy organizations exist for families with Lynch syndrome that promote greater awareness of the condition and population screening [112]. The achievements made through advocacy, though incremental, can be uniquely helpful to those in need.

Limitations: Though this effort incorporated input from community advocates, community-based dialogue would contribute additional perspective on public acceptability of the strategies considered. Due to national organization membership, discussions were limited to conference calls and breakout sessions at two annual meetings; face-to-face collaboration would benefit further research. Timing issues exist in the survey literature – private insurance data on *BRCA* testing following the opening of the Exchanges in 2014 only began to surface in 2019. Nevertheless, the project's lifespan also created an opportunity to examine the varied solutions to cancer services disparities.

5. Conclusion: activating the future

While Medicaid expansion has led to increased *BRCA1/2* testing availability, remaining counseling and testing disparities in African Americans and Latinos call for attention to the way cost concerns are addressed in these groups now that the no cost-sharing policy is in effect in the Marketplace. Colorectal cancer screening rates have improved in rural areas, though cultural tailoring is needed to improve rates in Latino populations. Continued data monitoring is imperative. Public insurance steps - continued efforts to expand Medicaid and make Medicare available to a wider audience – could help bolster screening rates in racial-ethnic groups. Reinstating mandates and extending short-term insurance can be expected to have opposite impacts on service utilization in marginalized groups. Community efforts at making basic cancer screening available and institutional policies reducing roadblocks to testing following genetic counseling can have an impact. Professional societies, community-based and disease advocacy organizations must at times serve as catalysts for government to bring about progressive change.

By drawing on evidence-based USPSTF guidelines, the ACA has provided an anchor for change. Incorporation of policy recommendations from other professionally recognized sources – the National Comprehensive Cancer Network, Healthy People 2020, and Evaluation of Genomic Applications in Practice and Prevention (EGAPP) – could refine the coverage criteria used for *BRCA1/2* counseling and testing, and bring testing for Lynch syndrome within reach. Any changes to coverage will require an honest appraisal of value gained and the amounts needed to continue bringing healthcare to those at risk in each state. Provision of genetic testing to those least well-off yet most in need, as a goal of prevention-oriented reform, is the barometer.

Acknowledgments

The authors extend their appreciation to past American Public Health Association Genomics Forum Policy Committee chairs Chikezie C. Maduka and Heather Honoré Goltz, and to project start Policy Committee chairs Samantha E. Greenberg and Marie T. Kumerow for their inspiration and influential comments. We are grateful to Toby Citrin (decd.), Sharon L.R. Kardia, and Peter D. Jacobson for their expert suggestions, and Yacoub Haydin for his research assistance.

Funding

A U.S. National Institutes of Health F99/K00 Individual Predoctoral to Postdoctoral Fellow Transition Award (CA) supported development of this policy review (1F99CA253576-01).

Abbreviations:

ACA	Patient Protection and Affordable Care Act
CHNA	community health needs assessment
CRC	colorectal cancer
EGAPP	Evaluation of Genomic Applications in Practice and Prevention Working Group
FORCE	Facing Our Risk of Cancer Empowered
FPL	federal poverty level
HBOC	hereditary breast and ovarian cancer
LS	Lynch syndrome
USPSTF	United States Preventive Services Task Force

References

- [1]. Chokshi N, Historians Take Note: What America Looked Like Before Obamacare [Accessed January 16, 2020]; March 26, Washington Post, 2014, <http://www.washingtonpost.com/blogs/govbeat/wp/2014/03/26/historians-take-note-what-america-looked-like-before-obamacare>.
- [2]. Moonesinghe R, Zhu J, Truman BI, Health insurance coverage – United States, 2004 and 2008, *MMWR* 60 (1 Suppl) (2011) 35–37.
- [3]. Patient Protection and Affordable Care Act, Pub Law 111–148, 124 Stat 119–111th U.S. Congress, 2010.
- [4]. Tuohy CH, Political accommodations in multipayer health care systems: implications for the United States, *Am. J. Public Health* 109 (11) (2019) 1501–1505. [PubMed: 31536406]
- [5]. Goldman AL, Woolhandler S, Himmelstein DU, et al. , Out-of-pocket spending and premium contributions after implementation of the Affordable Care Act, *JAMA Intern. Med* 178 (3) (2018) 347–355. [PubMed: 29356828]
- [6]. U.S. Census Bureau, Health Insurance Coverage in the United States: 2018. Report No. P60-267 (RV) [Accessed January 10, 2020], 2019, <http://www.census.gov/library/publications/2019/demo/p60-267.html>.
- [7]. Keith K, Uninsured rate rose in 2018, says Census Bureau report, *Health Aff.* (2019) [Accessed January 5, 2020]; September 11, <http://www.healthaffairs.org/doi/10.1377/hblog20190911.805983/full>.

- [8]. Medicaid and, CHIP Payment and Access Commission. Medicaid Enrollment Changes Following the ACA [Accessed December 28, 2019], 2019, <http://www.macpac.gov/subtopic/medicaid-enrollment-changes-following-the-aca>.
- [9]. Brooks T, Wagnerman K, Antiga S, et al., Medicaid and CHIP Eligibility, Enrollment, Renewal, and Cost-sharing Policies As of January 2017: Findings From a 50-state Survey [Accessed February 28, 2017], 2017, <http://kff.org/medicaid/report/medicaid-and-chip-eligibility-enrollment-renewal-and-cost-sharing-policies-as-of-january-2017-findings-from-a-50-state-survey>.
- [10]. U.S. Department of Health & Human Services, Preventive Services Covered Under the Affordable Care Act [Accessed February 17, 2016], 2016, <http://www.healthcare.gov/coverage/preventive-care-benefits>.
- [11]. Iqbal J, Ginsburg O, Rochon PA, et al. , Differences in breast cancer stage at diagnosis and cancer-specific survival by race and ethnicity in the United States, *JAMA* 313 (2) (2015) 165–173. [PubMed: 25585328]
- [12]. Yao N, Alcalá HE, Anderson R, Balkrishnan R, Cancer disparities in rural Appalachia: incidence, early detection, and survivorship, *J. Rural Health* 33 (4) (2017) 375–381. [PubMed: 27602545]
- [13]. Institute of Medicine, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, The National Academies Press, Washington, DC, 2003.
- [14]. U.S. Census Bureau, Race [Accessed January 11, 2020], 2018, <http://www.census.gov/topics/population/race/about.html>.
- [15]. U.S. Census Bureau, Hispanic Origin [Accessed January 11, 2020], 2018, <http://www.census.gov/topics/population/hispanic-origin.html>.
- [16]. Senier L, Tan C, Smolin L, Lee R, Understanding the potential of state-based public health genomics programs to mitigate disparities in access to clinical genetic services, *Genet. Med* 21 (2) (2019) 373–381. [PubMed: 29895854]
- [17]. American Public Health Association, Advancing Cancer Genomics in Public Health. Policy No. 201317 [Accessed June 2, 2015], American Public Health Association, Washington, DC, 2013, <http://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/23/10/25/advancing-cancer-genomics-in-public-health>.
- [18]. Office of Public Health Genomics, Centers for Disease Control and Prevention, Genomics Implementation [Accessed January 21, 2020], 2016, <http://www.cdc.gov/genomics/implementation/index.htm>.
- [19]. Modell SM, Mathew E, Greenberg SE, Status report: oncogenomic testing in the wake of health care reform, *Ann. Public Health Res* 2 (2015) 1022 [Accessed September 16, 2015], <http://www.jsmedcentral.com/PublicHealth/publichealth-2-1022.pdf>.
- [20]. Keith K, The short-term, limited-duration coverage final rule: the background, the content, and what could come next, *Health Aff.* (2018) [Accessed March 19, 2020]; August 1, <http://www.healthaffairs.org/doi/10.1377/hblog20180801.169759/full>.
- [21]. Cost Helper Health, Colonoscopy Cost [Accessed May 10, 2018]; February, 2017, <http://health.costhelper.com/colonoscopy.html>.
- [22]. Levitis JA, State Individual Mandates [Accessed March 13, 2020], Brookings Institution, Washington, DC, 2018, https://www.brookings.edu/wp-content/uploads/2018/10/Levitis_State-Individual-Mandates_10.29.18.pdf.
- [23]. Kamal R, Cox C, Fehr R, et al., How Repeal of the Individual Mandate and Expansion of Loosely Regulated Plans Are Affecting 2019 Premiums [Accessed March 13, 2020], Kaiser Family Foundation, 2018, <http://www.kff.org/health-costs/issue-brief/how-repeal-of-the-individual-mandate-and-expansion-of-loosely-regulated-plans-are-affecting-2019-premiums>.
- [24]. Norris L, Why Do Health Insurance Out-of-pocket Maximums Increase Each Year? [Accessed October 4, 2020], 2020, <http://www.verywellhealth.com/why-are-health-insurance-out-of-pocket-maximums-going-up-again-3962860>.
- [25]. eHealth, Lower Premiums but Higher Out-of-pocket Costs for 2020 ACA Consumers [Accessed October 4, 2020], 2019, <http://news.ehealthinsurance.com/insights-blog/lower-premiums-but-higher-out-of-pocket-costs-for-2020-acaconsumers>.

- [26]. U.S. Census Bureau, Real Median Household Income by Race and Hispanic Origin: 1967 to 2018 [Accessed February 5, 2020], 2018, <http://www.census.gov/content/dam/Census/library/visualizations/2018/demo/p60-263/figure1.pdf>.
- [27]. Manchanda R, Patel S, Antoniou AC, et al. , Cost-effectiveness of population based *BRCA* testing with varying Ashkenazi Jewish ancestry, *Am. J. Obstet. Gynecol* 217 (5) (2017) 578.e1–578.e12. [PubMed: 28690137]
- [28]. Levy DE, Byfield SD, Comstock CB, et al. , Underutilization of *BRCA1/2* testing to guide breast cancer treatment: black and Hispanic women particularly at risk, *Genet. Med* 13 (4) (2011) 349–355. [PubMed: 21358336]
- [29]. Armstrong K, Micco E, Carney A, et al. , Racial differences in the use of *BRCA1/2* testing among women with a family history of breast or ovarian cancer, *JAMA* 293 (14) (2005) 1729–1736. [PubMed: 15827311]
- [30]. Jones T, McCarthy AM, Kim Y, Armstrong K, Predictors of *BRCA1/2* genetic testing among Black women with breast cancer: a population-based study, *Cancer Med.* 6 (7) (2017) 1787–1798. [PubMed: 28627138]
- [31]. Sussner KM, Jandorf L, Thompson HS, Valdimarsdottir HB, Interest and beliefs about *BRCA* genetic counseling among at-risk Latinas in New York City, *J. Genet. Couns* 19 (3) (2010) 255–268. [PubMed: 20151317]
- [32]. Vadaparampil ST, McIntyre J, Quinn GP, Awareness, perceptions, and provider recommendation related to genetic testing for hereditary breast cancer risk among at-risk Hispanic women: similarities and variations by sub-ethnicity, *J. Genet. Couns* 19 (6) (2010) 618–629. [PubMed: 20798982]
- [33]. Gupta S, Ashfaq R, Kapur P, et al. , Microsatellite instability among individuals of Hispanic origin with colorectal cancer, *Cancer* 116 (21) (2010) 4965–4972. [PubMed: 20665498]
- [34]. Cruz-Correa M, Perez-Mayoral J, Dutil J, et al. , Puerto Rico Clinical Cancer Genetics Consortia. Hereditary cancer syndromes in Latino populations: genetic characterization and surveillance guidelines, *Hered. Cancer Clin. Pract* 15 (2017) 3. [PubMed: 28127413]
- [35]. Cragun D, Weidner A, Lewis C, et al. , Racial disparities in *BRCA* testing and cancer risk management across a population-based sample of young breast cancer survivors, *Cancer* 123 (13) (2017) 2497–2505. [PubMed: 28182268]
- [36]. Armstrong J, Toscano M, Kotchko N, et al. , Utilization and outcomes of *BRCA* genetic testing and counseling in a national commercially insured population: the ABOUT Study, *JAMA Oncol.* 1 (9) (2015) 1251–1260. [PubMed: 26426480]
- [37]. Bhandari NR, Li C, Impact of the Affordable Care Act’s elimination of cost-sharing on the guideline-concordant utilization of cancer preventive screenings in the United States using Medical Expenditure Panel Survey, *Healthcare (Basel)* 7 (1) (2019) 36.
- [38]. Williams CD, Bullard AJ, O’Leary M, et al. , Racial/ethnic disparities in *BRCA* counseling and testing: a narrative review, *J. Racial Ethn. Health Disparities* 6 (3) (2019) 570–583. [PubMed: 30963508]
- [39]. Whitworth P, Beitsch P, Arnell C, et al. , Impact of payer constraints on access to genetic testing, *J. Oncol. Pract* 13 (1) (2017) e47–e56. [PubMed: 28084878]
- [40]. Hall MJ, Olopade OI, Disparities in genetic testing: thinking outside the *BRCA* box, *J. Clin. Oncol* 24 (14) (2006) 2197–2203. [PubMed: 16682739]
- [41]. Fogleman AJ, Zahnd WE, Lipka AE, et al. , Knowledge, attitudes, and perceived barriers towards genetic testing across three rural Illinois communities, *J. Community Genet* 10 (3) (2019) 417–423. [PubMed: 30673953]
- [42]. Kolor K, Chen Z, Grosse SD, et al. , *BRCA* genetic testing and receipt of preventive interventions among women aged 18–64 years with employer-sponsored health insurance in nonmetropolitan and metropolitan areas – United States, 2009–2014, *Surveill. Summ* 66 (15) (2017) 1–11.
- [43]. Zahnd WE, McLafferty SL, Eberth JM, Multilevel analysis in rural cancer control: a conceptual framework and methodological implications, *Prev. Med* 129 (Suppl) (2019), 105835.
- [44]. Suther S, Kiros G-E, Barriers to the use of genetic testing: a study of racial and ethnic disparities, *Genet. Med* 11 (9) (2009) 655–662. [PubMed: 19752639]

- [45]. Office of the Assistant Secretary for Planning and Evaluation,, U.S. Department of Health & Human Services, 2019 Poverty Guidelines [Accessed February 19, 2020], 2019, <http://aspe.hhs.gov/2019-poverty-guidelines>.
- [46]. Artiga S, Orgera K, Damico A, Changes in Health Coverage by Race and Ethnicity Since Implementation of the ACA, 2013–2017 [Accessed February 5, 2020], Kaiser Family Foundation, 2019, <http://www.kff.org/disparities-policy/issue-brief/changes-in-health-coverage-by-race-and-ethnicity-since-implementation-of-the-aca-2013-2017>.
- [47]. Garfield R, Damico A, The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid – an Update [Accessed February 5, 2020], Kaiser Commission on Medicaid and the Uninsured, 2016, <http://pdfs.semanticscholar.org/90a7/c881cd630eb9445b8c87ce43d96edf9635d7.pdf>.
- [48]. Facing Our Risk of Cancer Empowered (FORCE), Medicare and Medicaid Cover Genetic Testing for Some People [Accessed October 8, 2020]; Available at, 2020, <http://www.facingourrisk.org/support/insurance-paying-for-care/genetic-services/medicare-medicaid#Medicaid>.
- [49]. Zerhouni YA, Trinh QD, Lipsitz S, et al. , Effect of Medicaid expansion on colorectal cancer screening rates, *Dis. Colon Rectum* 62 (1) (2019) 97–103. [PubMed: 30407931]
- [50]. O’Leary MC, Lich KH, Gu Y, et al. , Colorectal cancer screening in newly insured Medicaid members: a review of concurrent federal and state policies, *BMC Health Serv. Res* 19 (1) (2019) 298. [PubMed: 31072316]
- [51]. Komenaka IK, Nodora JN, Madlensky L, et al. , Participation of low-income women in genetic cancer risk assessment and *BRCA 1/2* testing: the experience of a safety-net institution, *J. Community Genet* 7 (3) (2016) 177–183. [PubMed: 26690931]
- [52]. Gan T, Sinner HF, Walling SC, et al. , Impact of the Affordable Care Act on colorectal cancer screening, incidence, and survival in Kentucky, *J. Am. Coll. Surg* 228 (4) (2019) 342–353, e1. [PubMed: 30802505]
- [53]. Centers for Medicare & Medicaid Services, Screening Colonoscopies [Accessed December 21, 2019], 2019, <http://www.medicare.gov/coverage/screening-colonosopies>.
- [54]. Centers for Medicare & Medicaid Services, Decision Memo for Screening for Colorectal Cancer – Stool DNA Testing [Accessed March 2, 2017], 2017, <http://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=277>.
- [55]. GeneDx, Medicare Checklist for Hereditary Cancer [Accessed December 21, 2019], 2019, <http://www.genedx.com/wp-content/uploads/2019/05/91720-Medicare-Checklist.pdf>.
- [56]. Oberlander J, Navigating the shifting terrain of US health care reform – Medicare for All, single payer, and the public option, *Milbank Q.* 97 (4) (2019) 939–953.
- [57]. Bureau of Labor Statistics,, U.S. Department of Labor, Asian Women and Men Earned More Than Their White, Black, and Hispanic Counterparts in 2017 [Accessed May 7, 2019], 2018, <http://www.bls.gov/opub/ted/2018/asian-women-and-men-earned-more-than-their-white-black-and-hispanic-counterparts-in-2017.htm>.
- [58]. Kaiser Family Foundation, Uninsured Rates for the Nonelderly by race/ethnicity [Accessed May 7, 2019], 2018, <http://www.kff.org/uninsured/state-indicator/rate-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.
- [59]. DiGrande S, 5 Things to know about Medicare for All, *Am. J. Managed Care* (2018) [Accessed May 6, 2019]; March 8, <http://www.ajmc.com/newsroom/5-things-to-know-about-medicare-for-all>.
- [60]. Committee for a Responsible Federal Budget, Choices for Financing Medicare for All: a Preliminary Analysis [Accessed February 16, 2020], 2019, <http://www.crfb.org/papers/choices-financing-medicare-all-preliminary-analysis>.
- [61]. Hellmann J, Democratic proposals to overhaul health care: a 2020 primer. The Hill, 2019 [Accessed May 7, 2019]; April 14, <http://thehill.com/policy/healthcare/438704-democratic-proposals-to-overhaul-healthcare-a-2020-primer>.
- [62]. Glied S, Options for dialing down from single payer, *Am. J. Public Health* 109 (11) (2019) 1517–1520. [PubMed: 31536411]

- [63]. White A, Vernon SW, Franzini L, Du XL, Racial and ethnic disparities in colorectal cancer screening persisted despite expansion of Medicare's screening reimbursement, *Cancer Epidemiol. Biomarkers Prev* 20 (5) (2011) 811–817. [PubMed: 21546366]
- [64]. Cooper GS, Kou TD, Schluchter MD, et al. , Changes in receipt of cancer screening in Medicare beneficiaries following the Affordable Care Act, *JNCI J. Natl. Cancer Inst* 108 (5) (2016) djv374. [PubMed: 26640244]
- [65]. Cassidy A, Essential health benefits (updated), *Health Aff.* (2013) [Accessed October 8, 2020]; May 2, <http://www.healthaffairs.org/doi/10.1377/hpb20130502.454771/full>.
- [66]. Chernew ME, Fendrick AM, Improving benefit design to promote effective, efficient, and affordable care, *JAMA* 316 (16) (2016) 1651–1652. [PubMed: 27668808]
- [67]. Lin JS, Piper MA, Perdue LA, et al. , Screening for colorectal cancer: updated evidence report and systematic review for the US Preventive Services Task Force, *JAMA* 315 (23) (2016) 2576–2594. [PubMed: 27305422]
- [68]. U.S. Preventive Services Task Force, Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement, *Ann. Intern. Med* 143 (5) (2005) 355–361. [PubMed: 16144894]
- [69]. Centers for Medicare & Medicaid Services, Affordable Care Act Implementation FAQs – Set 12 [Accessed October 16, 2015], 2015, http://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/aca_implementation_faqs12.html.
- [70]. Healthy People 2020, Genomics [Accessed December 18, 2013], 2010, <http://www.healthypeople.gov/2020/topics-objectives/topic/genomics>.
- [71]. Siu AL, U.S. Preventive Services Task Force, Screening for breast cancer: U.S. Preventive Services Task Force recommendation statement, *Ann. Intern. Med* 164 (4) (2016) 279–296. [PubMed: 26757170]
- [72]. US Preventive Services Task Force, Owens DK, Davidson KW, Krist AH, et al. , Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer: US Preventive Services Task Force recommendation statement, *JAMA* 322 (7) (2019) 652–665. [PubMed: 31429903]
- [73]. U.S. Preventive Services Task Force, Bibbins-Domingo K, Grossman DC, Curry SJ, et al. , Screening for colorectal cancer: US Preventive Services Task Force recommendation statement, *JAMA* 315 (23) (2016) 2564–2575. [PubMed: 27304597]
- [74]. US Preventive Services Task Force, Grossman DC, Curry SJ, Owens DK, et al. , Screening for prostate cancer: US Preventive Services Task Force recommendation statement, *JAMA* 319 (18) (2018) 1901–1913. [PubMed: 29801017]
- [75]. Moyer VA, U.S. Preventive Services Task Force, Screening for prostate cancer: U. S. Preventive Services Task Force recommendation statement, *Ann. Intern. Med* 157 (2) (2012) 120–134. [PubMed: 22801674]
- [76]. Chen Z, Kolor K, Grosse SD, et al. , Trends in utilization and costs of *BRCA* testing among women aged 18–64 years in the United States, 2003–2014, *Genet. Med* 20 (4) (2018) 428–434. [PubMed: 28933789]
- [77]. Guo F, Hirth JM, Lin Y-L, et al. , Use of BRCA mutation test in the U.S., 2004–2014, *Am. J. Prev. Med* 52 (6) (2017) 702–709. [PubMed: 28342662]
- [78]. Moyer VA, U.S. Preventive Services Task Force, Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: U.S. Preventive Services Task Force recommendation statement, *Ann. Intern. Med* 160 (4) (2014) 271–281. [PubMed: 24366376]
- [79]. Thompson D, Easton D, Breast Cancer Linkage Consortium. Variation in cancer risks, by mutation position, in BRCA2 mutation carriers, *Am. J. Hum. Genet* 68 (2) (2001) 410–419. [PubMed: 11170890]
- [80]. Ferzoco RM, Ruddy KJ, The epidemiology of male breast cancer, *Curr. Oncol. Rep* 18 (1) (2016) 1–6. [PubMed: 26694922]
- [81]. Agalliu I, Gern R, Leanza S, Burk RD, Associations of high-grade prostate cancer with *BRCA1* and *BRCA2* founder mutations, *Clin. Cancer Res* 15 (3) (2009) 1112–1120. [PubMed: 19188187]

- [82]. Childers KK, Maggard-Gibbons M, Macinko J, Childers CP, National distribution of cancer genetic testing in the United States: evidence for a gender disparity in hereditary breast and ovarian cancer, *JAMA Oncol.* 4 (6) (2018) 876–879. [PubMed: 29710084]
- [83]. Olaya W, Esquivel P, Wong JH, et al. . Disparities in BRCA testing: when insurance coverage is not a barrier, *Am. J. Surg* 198 (4) (2009) 562–565. [PubMed: 19800469]
- [84]. Daly MB, Pilarski R, Berry M, et al. , NCCN Guidelines insights: genetic/familial high-risk assessment: breast and ovarian, Version 2.2017, *J. Compr. Canc. Netw* 15 (1) (2017) 9–20.
- [85]. DeSantis CE, Siegel RL, Sauer AG, Miller KD, et al. , Cancer statistics for African Americans, 2016: progress and opportunities in reducing racial disparities, *CA Cancer J. Clin* 66 (4) (2016) 290–308. [PubMed: 26910411]
- [86]. Ziehr DR, Mahal BA, Aizer AA, et al. , Income inequality and treatment of African American men with high-risk prostate cancer, *Urol. Oncol* 33 (1) (2015) 18, e7–e13.
- [87]. Petrovics G, Ravindranath L, Chen Y, et al. , Increased frequency of germline *BRCA1* and *BRCA2* mutations in African American prostate cancer, *J. Urol* 195 (4 Suppl) (2016) e548.
- [88]. Bray F, Ferlay J, Soerjomataram I, et al. , Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries, *CA Cancer J. Clin* 68 (6) (2018) 394–424. [PubMed: 30207593]
- [89]. Jackson CS, Oman M, Patel AM, Vega KJ, Health disparities in colorectal cancer among racial and ethnic minorities in the United States, *J. Gastrointest. Oncol* 7 (Suppl 1) (2016) S32–S43. [PubMed: 27034811]
- [90]. Mbah OM, Kinlaw AC, Trogdon JG, et al. , The Affordable Care Act and ethnic disparities in colorectal cancer screening, *Am. J. Prev. Med* 58 (2) (2020) 175–181. [PubMed: 31959320]
- [91]. Office of Public Health Genomics, Centers for Disease Control and Prevention. IMore Detailed Information on Key Tier 1 Applications - Lynch Syndrome [Accessed October 3, 2020], 2014, http://www.cdc.gov/genomics/implementation/toolkit/lynch_1.htm.
- [92]. Dinh TA, Rosner BI, Atwood JC, et al. , Health benefits and cost-effectiveness of primary genetic screening for Lynch syndrome in the general population, *Cancer Prev. Res. (Phila)* 4 (1) (2011) 9–22. [PubMed: 21088223]
- [93]. Hresko A, Haga SB, Insurance coverage policies for personalized medicine, *J. Pers. Med* 2 (4) (2012) 201–216. [PubMed: 25562360]
- [94]. Graf MD, Needham DF, Teed N, Brown T, Genetic testing insurance coverage trends: a review of publicly available policies from the largest US payers, *Per. Med* 10 (3) (2013) 235–243. [PubMed: 29768740]
- [95]. Noll A, Parekh PJ, Zhou M, et al. , Barriers to Lynch syndrome testing and preoperative result availability in early-onset colorectal cancer: a National Physician Survey study, *Clin. Transl. Gastroenterol* 9 (9) (2018) 185. [PubMed: 30237431]
- [96]. Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group, Recommendations from the EGAPP Working Group: genetic testing strategies in newly diagnosed individuals with colorectal cancer aimed at reducing morbidity and mortality from Lynch syndrome in relatives, *Genet. Med* 11 (1) (2009) 35–41. [PubMed: 19125126]
- [97]. Karlitz JJ, Hsieh M-C, Liu Y, et al. , Population-based Lynch syndrome screening by microsatellite instability in patients <=50: prevalence, testing determinants, and result availability prior to colon surgery, *Am. J. Gastroenterol* 110 (7) (2015) 948–955. [PubMed: 25601013]
- [98]. Muller C, Lee SM, Barge W, et al. , Low referral rate for genetic testing in racially and ethnically diverse patients despite universal colorectal cancer screening, *Clin. Gastroenterol. Hepatol* 16 (12) (2018) 1911–1918, e2. [PubMed: 30130624]
- [99]. Gasteier AM, With the Federal Individual Mandate Gone, States Might Step up: Lessons From Massachusetts. *Health Aff.* [Accessed February 27, 2018]; January 16, 2018, www.healthaffairs.org/doi/10.1377/hblog20180108.464274/full.
- [100]. Palanker D, Lucia K, Curran E, New Executive Order: Expanding Access to Short-term Health Plans Is Bad for Consumers and the Individual Market, To the Point (The Commonwealth Fund). [Accessed May 9, 2018]; October 11, 2017, http://www.commonwealthfund.org/blog/2017/new-executive-order-expanding-access-short-term-health-plans-bad-consumers-and-individual?redirect_source=/publications/blog/2017/aug/short-term-health-plans.

- [101]. Gibson C, Hernandez-Delgado H, Penan H, Turner W, Overview of Changes to the Essential Health Benefits Standards in NBPP 2019, National Health Law Program. [Accessed December 22, 2019], 2018, <http://healthlaw.org/resource/overview-of-changes-to-the-essential-health-benefits-standards-in-nbpp-2019>.
- [102]. Centers for Medicare & Medicaid Services, HHS Notice of Benefit and Payment Parameters for 2019 [Accessed December 22, 2019], 2018, <http://www.cms.gov/newsroom/fact-sheets/hhs-notice-benefit-and-payment-parameters-2019>.
- [103]. Mach AL, Kinzer J, Legislative Actions to Modify the Affordable Care Act in the 111th-115th Congresses, Congressional Research Service Report R45244. [Accessed September 28, 2020], 2018, <http://fas.org/sgp/crs/misc/R45244.pdf>.
- [104]. Blumberg LJ, Holahan J, Buettgens M, Wang R, A Path to Incremental Health Care Reform: Improving Affordability, Expanding Coverage, and Containing Costs [Accessed January 11, 2020], Urban Institute, 2018, http://www.urban.org/sites/default/files/publication/99530/qs_incremental_reform_final_2.pdf.
- [105]. Rovner J, Biden's 'Incremental' Health Plan Still Would Be a Heavy Lift [Accessed March 15, 2020]; July 22, Kaiser Health News, 2019, <http://khn.org/news/bidens-incremental-health-plan-still-would-be-a-heavy-lift>.
- [106]. Kaiser Family Foundation, Summary of the American Health Care Act [Accessed April 20, 2017], 2017, <http://files.kff.org/attachment/Proposals-to-Replace-the-Affordable-Care-Act-Summary-of-the-American-Health-Care-Act>.
- [107]. Artiga S, Hinton E, Rudowitz R, Musumeci M, Current Flexibility in Medicaid: an Overview of Federal Standards and State Options [Accessed May 10, 2017], 2017, <http://kff.org/medicaid/issue-brief/current-flexibility-in-medicaid-an-overview-of-federal-standards-and-state-options>.
- [108]. Centers for Disease Control and Prevention, Community Health Assessments & Health Improvement Plans [Accessed March 15, 2020], 2018, <http://www.cdc.gov/publichealthgateway/cha/index.html>.
- [109]. Mercy Medical Center, Community Health Needs Assessment. Trinity Health of New England [Accessed August 29, 2019], 2019, <http://www.mercycares.com/documents/Mercy%20CHNA%20and%20appendices%206.27.19-1.pdf>.
- [110]. SBH Health System, Bronx, Community Health Needs Assessment and Community Service Plan [Accessed February 22, 2019], 2016, <http://www.sbhny.org/wp-content/uploads/2016/12/CHNA-CSP-Final-Documents-For-Submission-to-NYS.pdf>.
- [111]. Centers for Medicare & Medicaid Services, Affordable Care Act Implementation FAQs (Part XXVI) [Accessed March 9, 2017], 2017, http://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/aca_implementation_faqs26.pdf.
- [112]. Mange S, Bellcross C, Cragun D, et al. . Creation of a network to promote universal screening for Lynch syndrome: the Lynch Syndrome Screening Network, *J. Genet. Couns* 24 (3) (2015) 421–427. [PubMed: 25220566]

Table 1

Abridged Affordable Care Act (ACA) Policies Relating to Cancer Coverage.

Condition	Affordable Care Act (ACA) P.L. 111–148 [3] statement (Abridged)	ACA HealthCare.gov website [10] preventive services description	ACA HealthCare.gov website [10] interventions covered
Breast and ovarian cancer	SEC. 2713 (a). Group health plans and insurers shall not impose cost sharing requirements for evidence-based items or services that: have an ‘A’ or ‘B’ rating from the USPSTF; or with respect to women, are provided for in HRSA comprehensive cancer guidelines; or that fit with USPSTF recommendations on breast cancer screening, mammography, and prevention	The Affordable Care Act covers mammograms for women over age 50–74; and requires health insurance plans to cover these services for women at higher risk of breast cancer: <ul style="list-style-type: none"> • Counseling about <i>BRCA</i> genetic testing • Counseling about breast cancer chemoprevention 	For women only: <ul style="list-style-type: none"> • Screening mammography • <i>BRCA1/2</i> genetic counseling • <i>BRCA1/2</i> genetic testing where indicated • Breast cancer chemoprevention counseling
Colorectal cancer	SEC. 2713 (a). Group health plans and insurers shall not impose cost sharing requirements for evidence-based items or services that: have an ‘A’ or ‘B’ rating from the USPSTF SEC. 4104. Medicare. The amount paid will be 100 percent for the services under this part. ... included in the initial preventive physical examination	Under the Affordable Care Act, most insurance plans must cover screening for colorectal cancer for persons age 50–75. The physician helps decide which test is appropriate and how often to get screened. Some tests are done every 1–3 years; others every 5–10 years.	The ACA website does not list specific colorectal diagnostic interventions. USPSTF recommendations: <ul style="list-style-type: none"> • Screening fecal occult blood test • Screening fecal immunochemical test • Screening colonoscopy • Screening flexible sigmoidoscopy
Prostate cancer	SEC. 4103. Section 1861 of the Social Security Act is amended by adding a new subsection on the Medicare Annual Wellness Visit that contains a list of risk factors and conditions identified through an initial preventive physical examination, and a screening schedule for the next 5–10 years	The ACA Preventive Services website does not specifically list prostate cancer. Medicare covers digital rectal examination in men over 50 (20 % copay after yearly Part B deductible).	<ul style="list-style-type: none"> • Digital rectal examination

Table 2

Condensed U.S. Preventive Services Task Force (USPSTF) Policies Relating to Cancer Coverage.

Condition	Relevant policies (Condensed)	Issue areas and groups impacted
Hereditary breast and ovarian cancer (HBOC)	The U.S. Preventive Services Task Force recommends biennial screening mammography for women aged 50–74 years. Women at higher risk may benefit from beginning screening in their 40 s [71]. Screen women who have family members with breast, ovarian, tubal, or peritoneal cancer or who have an ancestry associated with <i>BRCA1/2</i> gene mutations with an appropriate brief familial risk assessment tool. Women who are positive should receive genetic counseling and, if indicated, genetic testing [72]. This recommendation applies to women who are asymptomatic for <i>BRCA</i> -related cancer [72].	Women who are currently symptomatic or receiving treatment for HBOC and associated cancers are not covered by the ACA no copay provision. African American women – higher incidence and greater mortality from early-stage breast cancer than other groups – are particularly affected. Men at risk for or symptomatic with breast cancer or who might pass a <i>BRCA1/2</i> mutation to their children are not covered by the ACA.
Hereditary nonpolyposis colorectal cancer – Lynch syndrome	Screen for colorectal cancer starting at age 50 years and continuing until age 75 years. The risks and benefits of different screening methods vary [73]. This recommendation applies to asymptomatic adults 50 years and older who are at average risk of colorectal cancer and who do not have a family history of known genetic disorders that predispose them to a high lifetime risk of colorectal cancer (such as Lynch syndrome or familial adenomatous polyposis) [73].	Men and women, beginning age 50, are eligible for routine screening. USPSTF recommendations unclear on screening African Americans earlier. Individuals newly diagnosed with colorectal cancer are not covered for Lynch syndrome genetic counseling, screening and mutation testing. At risk low-income, rural populations doubly hit by lack of physician follow-through on family history and lack of ACA coverage.
Prostate cancer	The decision to undergo periodic PSA-based screening for prostate cancer should be an individual one. Men should discuss the potential benefits and harms, and their values and preferences, with their clinician [74]. This recommendation does not include the use of the PSA test for surveillance after diagnosis or treatment of prostate cancer and does not consider PSA-based testing in men with known <i>BRCA</i> gene mutations who may be at increased risk for prostate cancer [75]. Based on the available evidence, the USPSTF is not able to make a separate, specific recommendation on PSA-based screening for prostate cancer in African American men ... [or] men with a family history of prostate cancer [74].	Men with germline mutations leading to increased risk for prostate cancer (<i>BRCA2</i>) are not covered by the ACA. African American men - higher incidence and greater mortality from prostate cancer than other groups – are particularly affected.

Table 3

Healthcare Reform Strategies and Impacts.

Reform strategy	Advantages	Disadvantages	Impact on marginalized groups	References
Institute state-specific mandates	Prevent adverse selection (withdrawal of healthy people from the insurance Marketplace)	Can drive up health care costs; Loss of individual autonomy	Reduce overall cost of insurance for low-income individuals	Levitts 2018 [22]; eHealth 2019 [25]; Gasteier 2018 [99]
Increase opportunity to purchase and hold short-term insurance	Increased availability and affordability of insurance; Greater freedom of choice	Could divert healthy individuals away from the insurance Marketplace; Coverage of ten essential benefit categories no longer guaranteed	Costs of <i>BRCA1/2</i> genetic testing, colonoscopy and polyp removal increased; Denial of insurance to individuals with preexisting conditions	Palanker et al. 2017 [100]
Engage more states in Medicaid expansion	Decreased rate of uninsured; Earlier cancer detection	Greater federal and state healthcare costs; Reduced quality of care, e.g., in appointment availability and wait time	Reduced number of low-income and racial-ethnic minority uninsured	Artiga et al. 2019 [46]
Enact Medicare for All	Decreased rate of uninsured, aided by unrestricted or lowered age of enrollment	Sizeable increase in federal budget; Increased insurance premiums or payroll taxes depending on strategy used	<i>BRCA1/2</i> counseling and genetic testing and colonoscopy covered; increased availability to low income and racial-ethnic minority groups	Oberlander 2019 [56]; Committee for a Responsible Federal Budget 2019 [60]
Enact Medicare for All variations (e.g., a public option)	Decreased rate of uninsured; Allowing a public option would be non-disruptive to current insurance Marketplace	Disparity between public and private insurance payment rates; Possible employer “dumping” of sickest into public plans	Supports individuals at high-risk, e.g., those with a family history of breast or colorectal cancer; increased availability to low-income and racial-ethnic minority groups	Hellmann 2019 [61]; Gihed 2019 [62]
Permit state-specific benchmarking of benefits plans	States can select benefit plans according to their particular population’s needs	Conservative states could select least generous benefits	Increased flexibility could work either way – increase benefits (e.g., Lynch syndrome genetic testing) or reduce benefits (e.g., pre-cancer screening) for those in need	Gibson et al. 2018 [101]
Federal agency revised guidance on or legislative amendment of ACA	Provide changes to ACA benefits that apply nationally	Incremental increases to insurance costs; Value of changes depends on rigor of evidence	Introduce changes that increase covered services (e.g., Lynch syndrome testing, <i>BRCA</i> genetic testing) for groups in need	CMS 2018 [102]; Mach and Kinzer 2018 [103]

Table 4

Action Areas and Organizational Involvement.

Application	Obstacles	Action areas	Organizations	Websites
Racial-Ethnic Minority Health	Lack of awareness of the insurance Marketplace; Ineligibility for Medicaid; Inadequate referral for genetic counseling and testing	Connecting the uninsured with available services (in-person and in-community); Awareness-raising of services that exist; Community-based organization – professional society partnerships	American Public Health Association; American Medical Association; American Nurses Association; Community- and faith-based organizations	apha.org/facism ; www.ama-assn.org/ama-health-reform-vision ; www.nursingworld.org/Principles-HealthSystemTransformation ; ww5.komen.org/WhatWeDo/ ; MissionPartnershipsandPrograms/Collaborations/Collaborations.html
Women's Health – hereditary breast and ovarian cancer (HBOC)	Medicaid does not cover <i>BRCA1/2</i> testing in all states; Symptomatic women (HBOC) not covered under ACA	Communication between advocacy organizations, professional policymaking bodies (USPSTF), and state Medicaid policymakers	FORCE, Bright Pink, Sister's Network, Sharsheret, Ovarian Cancer Research Fund Alliance	www.facingourrisk.org ; www.brightpink.org ; www.sistersnetworkinc.org ; sharsheret.org ; ocrf.org
Men's Health – HBOC and prostate cancer	Men not covered for <i>BRCA1/2</i> testing under ACA	Promoting testing among professional organizations and with healthcare plans; Informing legislators of coverage needs	American Cancer Society (ACS), National Comprehensive Cancer Network (NCCN); Men's Health Network	www.cancer.org/involved/volunteer/advocate.html ; www.nccn.org/about ; www.menshealthnetwork.org
Individuals and families at risk for hereditary nonpolyposis colorectal cancer (Lynch syndrome)	ACA colorectal cancer screening coverage limited to >50 years of age; Lynch syndrome testing not covered by ACA	Testing company interaction with Centers for Medicare and Medicaid Services, state Medicaid offices, insurance companies. Disease advocacy and professional organizations to communicate risk to the public, professionals, healthcare plans	Exact Sciences (Cologuard ©), Color, Myriad Genetics, Ambry Genetics; Lynch Syndrome International; CCARE Lynch Syndrome; NCCN, NCI	www.exactsciences.com ; www.color.com ; myriad.com ; www.ambrygen.com ; lynchcancers.com ; fightlynch.org ; www.nccn.org