



# **“We Need Access”**

## **Ending Preventable Deaths from Cervical Cancer in Rural Georgia**

***Summary and Recommendations***

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The Southern Rural Black Women's Initiative for Economic and Social Justice (SRBWI) was founded in 2001 to promote the first human rights agenda in the United States aimed at eradicating historical race, class, cultural, religious, and gender barriers experienced by southern rural Black women. Over the past 20 years, SRBWI has engaged over 3,000 women in 77 counties across the Blackbelt of Alabama and Georgia, and the Mississippi Delta in countering the generational impact of unrelenting systemic, institutionalized discrimination and abuse faced by rural Black women in the US South. SRBWI's programs range from policy and advocacy reform to intergenerational leadership, asset building, and economic empowerment. SRBWI believes that the battle against poverty and inequity cannot be fought or won without the voice and participation of southern rural Black women, who are trying desperately to provide for their families in under-resourced, economically distressed, and persistently poor counties.

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## **In Memoriam: Deborah Ann Thomas**

Often when we read statistics such as cervical cancer unnecessarily claimed the lives of an estimated 4,290 women in the United States in 2021, our tendency is to calculate the loss as compared to losses resulting from other causes, failing to grasp completely the gravity of the fact that these numbers represent actual lives.

This report is dedicated to the life of Deborah Ann Thomas, who served as co-coordinator of participatory, community-based research for the Southern Rural Black Women's Initiative on this project and whose life was taken by cancer only a few months before the report's release.

The loss of Deborah is a staggering reminder of the value of one life and its reverberating resonance with the multitude of lives that one life touches, shapes, and, at its utmost, embraces, inspires, and motivates. Like the rising sun, Deborah consistently brought into view the subtle magnificence that surrounds us and which is within each of us—rooted in her unrelenting recognition that everyone and everything is of consequence. This ability to see and uplift the human spirit and to innately see and know what was needed is, as they say, how Deborah rolled, every day, and in everything she did. The knowledge that every life counts was the quiet strength behind her fight and one of the many earnest lessons she left with family members, friends, colleagues, and with the children, women, and families she served who had the fortune of experiencing her grace.

This report is dedicated to Deborah's resolute commitment to the value of a life, and by extension, to uplifting the human right to quality, accessible, reproductive health care, and removing barriers to access. Our charge to continue the fight to eradicate cervical cancer deaths, which impacts one and a half times as many Black women as white and who are more likely to die from the disease each year, is our promise to Deborah to continue this charge with the integrity that she infused in it and with the sobering awareness that one life lost unnecessarily is one too many.



IN LOVING MEMORY

*Deborah R. Thomas*

"I have fought a good fight, I have finished my course,  
I have kept the faith"  
2 Timothy 4:7





# Summary

Cervical cancer is not a disease that anyone should die from. It just doesn't make any sense. We know too much about it for it to be something that people die from.

—Dr. Favors, obstetrician gynecologist in Albany, Georgia, June 6, 2021

Cervical cancer is highly preventable and treatable. It typically develops over several years, providing ample time to detect and treat abnormal changes in cervical cells that could eventually lead to cancer. With access to information, preventive services, and routine gynecological care, most cases of the disease can be prevented and successfully treated at an early stage. If caught early before cancer has spread, the five-year survival rate is over 90 percent. Despite this, the National Cancer Institute (NCI) estimated that 4,290 women would die of cervical cancer in the United States in 2021.

Although almost no one should die from the disease, some groups—those that are historically marginalized and neglected in the US, including women of color, women living in poverty, and those without health insurance—die more often than others. There are glaring racial disparities in cervical cancer deaths in the US and Black women die of the disease at a disproportionately high rate. Black women have a higher risk of late-stage diagnosis, and they are more likely to die from the disease than any other racial or ethnic group in the country. In the state of Georgia, Black women are almost one and a half times as likely to die of cervical cancer as white women and these disparities increase at alarming rates as they age. Black Georgian women are more likely to have never been screened for cervical cancer, are diagnosed at a later stage, and have lower five-year survival rates.

Preventable deaths from cervical cancer thrive in contexts of structural racism, discrimination, poverty, and inequality. Disparities in cervical cancer for Black women and other marginalized and neglected individuals reflect exclusion from the healthcare system and unequal access to the information, interventions, and services necessary to prevent and treat the disease. These preventable deaths also represent a failure of the federal, state, and local governments to protect and promote human rights for all people and to

ensure adequate and affordable access to the lifesaving reproductive healthcare services and information all people need and have a right to.

Between November 2020 and August 2021, the Southern Rural Black Women’s Initiative for Economic and Social Justice (SRBWI) and Human Rights Watch partnered with nine community-based researchers to document factors contributing to disproportionate cervical cancer death rates for Black women in Georgia. Community-based researchers carried out 148 interviews with Black women between the ages of 18 and 82 living primarily in 3 counties—Baker, Coffee, and Wilcox—in rural southwest Georgia. The women described the challenges they face in accessing reproductive healthcare services and information to prevent and treat cervical cancer. SRBWI and Human Rights Watch also spoke with community members, academics, medical providers, public health officials, and members of nongovernmental health and reproductive rights and justice groups in Georgia to better understand cervical cancer prevention and care, and barriers to adequate health care in the state.

This research found that Georgia state and local agencies, and the US federal government are not doing enough to facilitate access to reproductive healthcare services and information to prevent cervical cancer deaths and address racial disparities in health outcomes. Georgia does not ensure access to comprehensive and affordable reproductive health care, and instead relies on a patchwork of multiple, publicly funded programs to extend healthcare coverage to low-income women in the state, including for gynecological care. Georgia has not expanded Medicaid through the US Affordable Care Act (ACA) to extend healthcare coverage to more low-income individuals, for which the state is losing out on \$3 billion in federal funding each year. Over 255,000 Georgians have no options for affordable healthcare coverage. Without a comprehensive plan to guarantee access to consistent and affordable health care, the state has left low-income and uninsured Georgian women—who are more likely to be Black—struggling to navigate gaps in health insurance coverage and enormous financial barriers to cervical cancer care. For many women, especially those who are uninsured, their inability to afford reproductive healthcare services means that they often avoid medical appointments and skip cancer screenings and follow-up care altogether, forgoing lifesaving opportunities to prevent and treat the disease.

Limited access to gynecological care also creates barriers to cervical cancer care for marginalized women, especially those living in rural and underserved areas. Georgia faces a severe shortage of obstetrician gynecologists and almost half of the state's 159 counties do not have one. State policies have contributed to the closure of rural hospitals, which has helped fuel this shortage. Since 2010, 7 rural hospitals have closed in Georgia and 38 labor and delivery units have shut down since 1994, leaving entire communities without access to essential pregnancy and gynecological services. Georgia could increase healthcare coverage for more low-income people in the state, decreasing the cost of uncompensated care and providing a financial lifeline for hospitals struggling to stay afloat, especially in rural areas, by expanding Medicaid. Its decision not to do so has contributed to a shortage of obstetrical and gynecological care in rural areas.

The Georgia government's failure to provide adequate public transportation throughout the state, especially in rural counties, creates additional challenges to obtaining cervical cancer care. For women who have to travel long distances for gynecological care and for those who lack adequate transportation, including money for gas or to pay someone to take them to appointments, accessing cervical cancer care is often burdensome, costly, and, at times, even impossible.

Structural racism and discrimination in the healthcare field, coupled with many Black women's related distrust of medical providers, also impacts the quality of care some women receive and their willingness to seek out reproductive health care. SRBWI and Human Rights Watch spoke with women who said they felt that their health concerns were dismissed and the quality of care they received was inadequate because of racism and medical providers' bias against them as Black women. Many others described how callous treatment, an inadequate level of care, and concerns around confidentiality have undermined the trust they have in doctors, alienated them from gynecological care, and contributed to poor reproductive health outcomes.

Georgia state policies do not facilitate widespread access to lifesaving information to prevent and treat cervical cancer. Georgia's government has not adopted adequate policies to ensure that all residents have access to accurate and comprehensive information on the human papillomavirus (HPV) vaccine—an effective cancer prevention tool. HPV Cancer Free Georgia—the Georgia Cancer Control Consortium (GC3) working group that focuses on implementing the Georgia Cancer Control Plan's HPV

objectives— along with numerous organizations and some state legislators, has tried to fill this gap, for example, by increasing education around HPV, the vaccine, and HPV-related cancers through strategic engagement and outreach and working together in recognition of cervical cancer and HPV awareness days. Many Georgian residents, including about a third of the women that SRBWI and Human Rights Watch interviewed, lack information on the HPV vaccine, and vaccination rates in the state are below the national average. At the same time, the government is failing to ensure that all young people in schools receive comprehensive, inclusive, and accurate information on their sexual and reproductive health. Inadequate access to this lifesaving information undermines Georgian women and girls’ understanding of cervical cancer and the preventive steps people can take to lower risk and stay healthy and safe. It also contributes to misinformation, fear, and stigma around sexual and reproductive health that makes many women reluctant to discuss or seek out cervical cancer care.

The Covid-19 pandemic has created new obstacles to accessing preventive health care and disrupted cervical cancer care, which could widen racial health disparities. HPV vaccination rates and cervical cancer screenings—both essential aspects of cervical cancer prevention—dropped dramatically at the start of the pandemic in March 2020. Vaccination and screening rates started to increase in June 2020 as stay-at-home orders and restrictions eased. However, these delays and disruptions in preventive care may contribute to poor cervical cancer outcomes and an increase in preventable deaths from cancer over the long term, with the greatest impact on marginalized individuals and those who already faced multiple barriers to accessing adequate and affordable health care. While the dramatic rise in telehealth services in response to the pandemic has the potential to expand access to medical care, it has also underscored the need to ensure that these services adequately address existing broadband and technology inequalities and promote equal access to affordable and quality health care for everyone.

The Georgia state and the US federal governments have allowed substantial barriers to cervical cancer care for marginalized women to become embedded and have failed to protect and promote Georgian women and girls’ rights under international human rights law to health, information, equality, and nondiscrimination. The state government should invest in policies and programs that address persistent racial and socioeconomic inequalities in access to health care and take concrete steps to reduce racial disparities in cervical cancer outcomes by expanding Medicaid to increase affordable healthcare

coverage for more low-income Georgians; enacting policies to ensure affordable and accessible cervical cancer care for all women, including those in rural and underserved communities; and adopting legislation to support comprehensive sexual health education in all Georgia schools.

# Recommendations

## To the Georgia State Government

### *To the Governor of Georgia*

- Support the expansion of Medicaid under the Affordable Care Act (ACA) to increase affordable access to healthcare services for Georgian residents.
- Withdraw the Section 1115 Demonstration proposal, including the imposition of work requirements for Medicaid eligibility, and expand coverage to all low-income adults through Medicaid (as intended under the ACA).
- Develop and implement a comprehensive, rights-respecting plan to eliminate cervical cancer deaths in Georgia and obtain funding support from the state legislature.

### *To the Georgia State Legislature*

- Pass legislation to expand Medicaid under the ACA to increase access to healthcare services for the residents of Georgia.
- Appropriate funds for cervical cancer prevention, treatment, and maintenance care, including increased funding for the Georgia Breast and Cervical Cancer Program.
- Enact legislation to support awareness of the human papillomavirus (HPV) vaccine and to increase HPV vaccination rates in Georgia. Legislation should:
  - disseminate information on Advisory Committee on Immunization Practices (ACIP)-recommended adolescent vaccines to the parents or guardians of all students in Georgia completing the 5<sup>th</sup> grade;
  - require education around HPV and prevention of HPV-related cancers for all students starting in 6<sup>th</sup> grade; and
  - allocate funding to community-based organizations for public awareness and outreach campaigns around HPV, the HPV vaccine, and the prevention of HPV-related cancers.
- Develop and fund a plan to address high cervical cancer mortality rates disproportionately impacting older Black women in Georgia, including a review of current cervical cancer screening guidelines to ensure that they do not lead to inequitable outcomes on the basis of age or race.

- Support community health outreach programs and legislation to establish a formal community health worker certification program in Georgia.
- In collaboration with communities and community-based development and advocacy organizations and agencies, develop and fund initiatives and programs to address barriers to accessing healthcare services linked to the unavailability of public transportation.
- Institute and expand incentives for obstetrician gynecologists to practice in rural, underserved communities in Georgia.
- Adopt measures to expand accessible and affordable telehealth services in rural areas.
- Repeal funding for crisis pregnancy centers, and mandate that all women’s health funding is appropriated to healthcare providers that offer scientifically based, comprehensive, and preventive reproductive health services.
- Adopt legislation and appropriate funds to support comprehensive sexual health education in all Georgia schools. Sexual health education should be age-appropriate, scientifically and medically accurate, and responsive to the needs of all young people.
- Expand the vaccine protocol to allow pharmacists to administer the HPV vaccine without a prescription in accordance with the Advisory Committee on Immunization Practices (ACIP) standard immunization schedule.

*To State Agencies, including the Georgia Department of Public Health and the Georgia Department of Education*

- Ensure reproductive health and cervical cancer resources are available and accessible in areas of the state where there is little access to reproductive health care.
- In full collaboration with local communities, conduct a public awareness campaign to inform Georgians of:
  - services offered by county health departments and state programs;
  - cervical cancer prevention and care, including how to access services that can help reduce cervical cancer risk; and

- the importance of catching up on cervical cancer screenings and HPV vaccinations that may have been delayed as a result of the Covid-19 pandemic.
- Develop and implement programs to ensure affordable and accessible cervical cancer follow-up care, including colposcopies, in rural and underserved communities.
- Ensure medical providers and women over 50 have access to information on the importance of adequate screening leading up to age 65 and the need for continued screening for women at high-risk or with irregular or undetermined screening histories.
- Support community health workers and community-based approaches to reproductive health care that address healthcare access and the social determinants of health.
- Partner with local communities, groups, and organizations to implement community-based initiatives to educate young people, including those who are out of school, on healthy sexual behaviors and to address stigma around sexual health.
- Increase targeted outreach, awareness-raising, and provider trainings to ensure high coverage for the HPV vaccine as an effective cancer prevention tool.
- Establish inclusivity policies that:
  - support linguistic and racial diversity, including in county public health departments; and
  - acknowledge, confront, and seek to remedy historic and current experiences of racial discrimination in public health.
- Provide cultural competency, implicit bias, and anti-racism training to address the ways in which structural racism manifests within the healthcare field and impacts the treatment and quality of care patients receive.
- Create an official, confidential, and accessible complaint mechanism for patients who use public health departments; widely disseminate information on the complaint mechanism, including how to use it, aggregate data on complaints received, and remedies implemented.
- Develop and circulate a model curriculum on sexual health education based on best practices and national and international sexual health education standards for all schools to follow that is comprehensive, medically and scientifically accurate, and inclusive of all students.

- Create and implement methods for tracking the content of sexual health education curriculum of all Georgia schools, requiring annual reporting to the Georgia Department of Education.
- Disseminate information on HPV, the HPV vaccine, and the prevention of HPV-related cancers to parents and guardians.
- Conduct outreach to inform parents and guardians of the importance of catching up on wellness visits and adolescent vaccinations that may have been delayed or skipped due to the Covid-19 pandemic.

## To the United States Government

### *To the President*

- Adopt policies to support full Medicaid expansion under the ACA to all 50 US states.
- Establish the White House Office of Sexual and Reproductive Health and Wellbeing (OSRHW), under the Domestic Policy Council, to promote sexual and reproductive health and well-being through a human rights, reproductive justice, and racial equity framework.

### *To Congress*

- Pass legislation aimed at addressing high rates of preventable cervical cancer deaths, including racial disparities in mortality rates.
- Enact the Promoting Resources to Expand Vaccination, Education and New Treatments for HPV Cancers Act of 2021 (the PREVENT HPV Cancers Act) to increase HPV vaccination rates and prevent and treat cancers associated with HPV, including cervical cancer.
- Expand the options for states to extend Medicaid eligibility, per the National Breast and Cervical Cancer Prevention and Treatment Act of 2000, to provide for maintenance care and continued surveillance for women who have been successfully treated for breast or cervical cancer.
- Reinstate and appropriately fund the Breast and Cervical Cancer Early Detection and Control Advisory Committee.
- Support Medicaid expansion into all states as an important measure for addressing preventable gynecological cancer deaths.

- Enact the Medicaid Saves Lives Act to create a federal Medicaid-style program to expand affordable healthcare coverage to low-income individuals in the 12 states that have not expanded Medicaid.
- Fund a study and demonstration project on barriers to transportation impacting the ability of low-income women, particularly women of color, in rural areas to travel to appointments for cervical cancer screenings and follow-up care.
- Stop funding abstinence-only education grants and ensure adequate funding for scientifically and medically accurate comprehensive sexual health education programs.
- Adopt the Real Education for Healthy Youth Act, or similar legislation, to support comprehensive sexual health education and restrict funding to health education programs that are medically inaccurate or unresponsive to the needs of all students.
- The Senate should ratify the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the Convention on the Rights of Persons with Disabilities.

*To Federal Agencies, including the US Centers for Disease Control and Prevention and the Department of Health and Human Services*

- Reject Georgia’s Section 1115 Demonstration proposal, which would institute work requirements for Medicaid eligibility.
- Recommend that colposcopy, diagnostic testing for cervical cancer and precancerous lesions, and early interventions like excisional and ablative treatments, all of which help in the prevention of cervical cancer, be included as preventive care under the ACA’s essential health benefits mandate.
- Review and adjust the current methodology for cervical cancer data analysis to ensure that it reflects the true rates of cervical cancer incidence and mortality. The review should consider whether including women with hysterectomies in the at-risk population artificially lowers reporting on racial disparities in cervical cancer rates.
- Publicize a strategic plan with clear benchmarks for how the Centers for Disease Control and Prevention (CDC) will operationalize its recent commitment to fund health programs that address health inequities rooted in racism. In particular, direct more allocated funding into support for community-based projects including

- the Social Determinants of Health Accelerator Plans and Social Determinants of Health Community Pilots and regularly report on outcomes of funded projects.
- Guide states to ensure National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funds support community-based healthcare workers serving Black women.
  - Target funds allocated for the CDC’s Community Approaches to Reducing STDs project under the Division of STD Prevention’s Health Equity initiative to support programming to remove barriers to accessing the HPV vaccine for rural Black women and youth.

## **To the United Nations**

### *To the United Nations Committees on Human Rights and the Elimination of Racial Discrimination*

- Call upon the US to comply with its international obligations to eliminate disparate racial impacts in public health, including racial disparities in cervical cancer outcomes.
- Call upon the US to improve oversight, establish incentives, and take other necessary steps to ensure compliance with human rights obligations at the state and local levels.



# **ELIMINATING CERVICAL CANCER DEATHS THROUGH A HUMAN RIGHTS FRAMEWORK**

# CERVICAL CANCER DEATHS ARE HIGHLY PREVENTABLE AND TREATABLE

Cervical cancer is both highly preventable and treatable. When women have access to routine, affordable, and quality health care, most cervical cancer deaths can be prevented. The disease typically progresses slowly, providing time to detect and treat early changes in cervical cells that could eventually lead to cancer. When detected early, the five-year survival rate is over 90 percent.<sup>1</sup> The survival rate falls dramatically if the cancer is detected at a late stage or after it has spread.<sup>2</sup>

Almost all cases of cervical cancer are caused by a virus called human papillomavirus (HPV), which is the most common sexually transmitted infection in the United States.<sup>3</sup> Although most strains of HPV typically clear away on their own within a few years, persistent infection with certain high-risk strains of HPV can cause changes in cervical cells that can lead to cancer.<sup>4</sup>

Cervical cancer deaths can largely be prevented through four key interventions: prevention; regular Papanicolaou (Pap) tests and HPV screenings; timely follow-up after abnormal test results; and early and appropriate treatment. Most cervical cancer deaths in the US can be attributed to a failure at one or more of these points.

## 1. PREVENTION, INCLUDING ACCESS TO INFORMATION AND THE HPV VACCINE

Access to information on sexual and reproductive health can have a profound impact on rates of cervical cancer. Young people need accurate information about their bodies to make informed decisions to stay healthy and safe. Comprehensive sexual health education in schools can provide young people with lifesaving information on their reproductive and sexual health to prevent cervical cancer.<sup>5</sup> This includes information on guidelines for routine gynecological screenings, how to recognize abnormal gynecological symptoms, where to access free and low-cost confidential reproductive healthcare services, the increased risk of cervical cancer as a result of tobacco usage, and the HPV vaccine.<sup>6</sup>

The HPV vaccine is a safe and effective cancer prevention tool.<sup>7</sup> It prevents against the majority of HPV infections

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<sup>1</sup> The five-year survival rate is 92 percent when cervical cancer is localized and has not spread beyond the organ of origin. American Cancer Society, “Cancer Facts and Figures 2018,” 2018, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2018/cancer-facts-and-figures-2018.pdf> (accessed June 17, 2021), p. 27.

<sup>2</sup> The five-year survival rate “falls to 57 percent and 17 percent for women diagnosed with regional and distant stage disease, respectively.” Ibid.

<sup>3</sup> National Cancer Institute, “HPV and Cancer,” January 22, 2021, <https://www.cancer.gov/about-cancer/causes-prevention/risk/infectious-agents/hpv-and-cancer> (accessed June 17, 2021). See also, Centers for Disease Control and Prevention (CDC), “Human Papillomavirus- Genital HPV Fact Sheet,” January 19, 2021, <https://www.cdc.gov/std/hpv/stdfact-hpv.htm> (accessed June 17, 2021).

<sup>4</sup> National Cancer Institute, “HPV and Cancer.”

<sup>5</sup> Human Rights Watch, “*It Wasn’t Really Safety, It Was Shame: Young People, Sexual Health Education, and HPV in Alabama*,” July 2020, <https://www.hrw.org/report/2020/07/08/it-wasnt-really-safety-it-was-shame/young-people-sexual-health-education-and-hpv>.

<sup>6</sup> “Women who smoke are about twice as likely as those who don’t smoke to get cervical cancer. Tobacco by-products have been found in the cervical mucus of women who smoke. Researchers believe that these substances damage the DNA of cervix cells and may contribute to the development of cervical cancer. Smoking also makes the immune system less effective in fighting HPV infections.” See American Cancer Society, “Risk Factors for Cervical Cancer,” January 3, 2020, <https://www.cancer.org/cancer/cervical-cancer/causes-risks-prevention/risk-factors.html> (accessed August 2, 2021).



that cause cervical cancer. The vaccine available in the US, Gardasil 9, offers protection against the nine strains of HPV known to cause 90 percent of cervical cancers.<sup>8</sup> The Centers for Disease Control and Prevention (CDC) recommends two doses of the vaccine for all adolescents ages 11 and 12 years, although the vaccine can be given to children as early as 9 years old.<sup>9</sup> The vaccine is most effective if received before the initiation of sexual activity and any exposure to HPV. However, it does offer protection even after a person becomes sexually active and is recommended for adults and individuals with previous HPV infection to guard against new infections.<sup>10</sup> The Food and Drug Administration (FDA) has approved Gardasil 9 for adults up to age 45.<sup>11</sup>

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<sup>7</sup> CDC, “Human Papillomavirus (HPV) Vaccine,” September 9, 2020, <https://www.cdc.gov/vaccinesafety/vaccines/hpv-vaccine.html> (accessed July 29, 2021).

<sup>8</sup> American Cancer Society, “HPV Vaccines,” July 21, 2020, <https://www.cancer.org/cancer/cancer-causes/infectious-agents/hpv/hpv-vaccines.html> (accessed July 29, 2021).

<sup>9</sup> CDC, “Immunization Schedules: Table 1. Recommended Child and Adolescent Immunization Schedule for ages 18 years or younger, United States, 2019,” February 12, 2021, <https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html#adolescent> (accessed June 17, 2021).

<sup>10</sup> CDC, Advisory Committee on Immunizations Practices (ACIP), “Evidence to Recommendations for HPV Vaccination of Adults, Ages 27 through 45 years,” August 16, 2019, <https://www.cdc.gov/vaccines/acip/recs/grade/HPV-adults-etr.html> (accessed June 17, 2021).

<sup>11</sup> US Food and Drug Administration (FDA), “FDA Approves Expanded Use of Gardasil 9 to Include Individuals 27 Through 45 Years Old,”

## 2. REGULAR PAP TESTS AND HPV SCREENINGS

Cervical cancer can usually be prevented with routine screenings that can help detect abnormal changes in cervical cells at an early and treatable stage. Since it typically takes several years for abnormal cervical cells to develop into cancer, routine screenings can detect abnormal and precancerous changes before they become cancer.<sup>12</sup> Pap tests detect if abnormal cells are present on the cervix and HPV tests determine the presence of high-risk HPV strains.<sup>13</sup> While exact screening recommendations depend on age and medical history, regular screening should begin at age 21 and continue until 65.<sup>14</sup> After 65, cervical cancer screenings are generally not recommended for patients who have been regularly screened in the last 10 years with no abnormal test results, although they still may be recommended for some women who are high risk.<sup>15</sup> A medical provider will be able to advise an individual on what screening tests are best for them.

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October 5, 2018, <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm622715.htm> (accessed June 17, 2021).

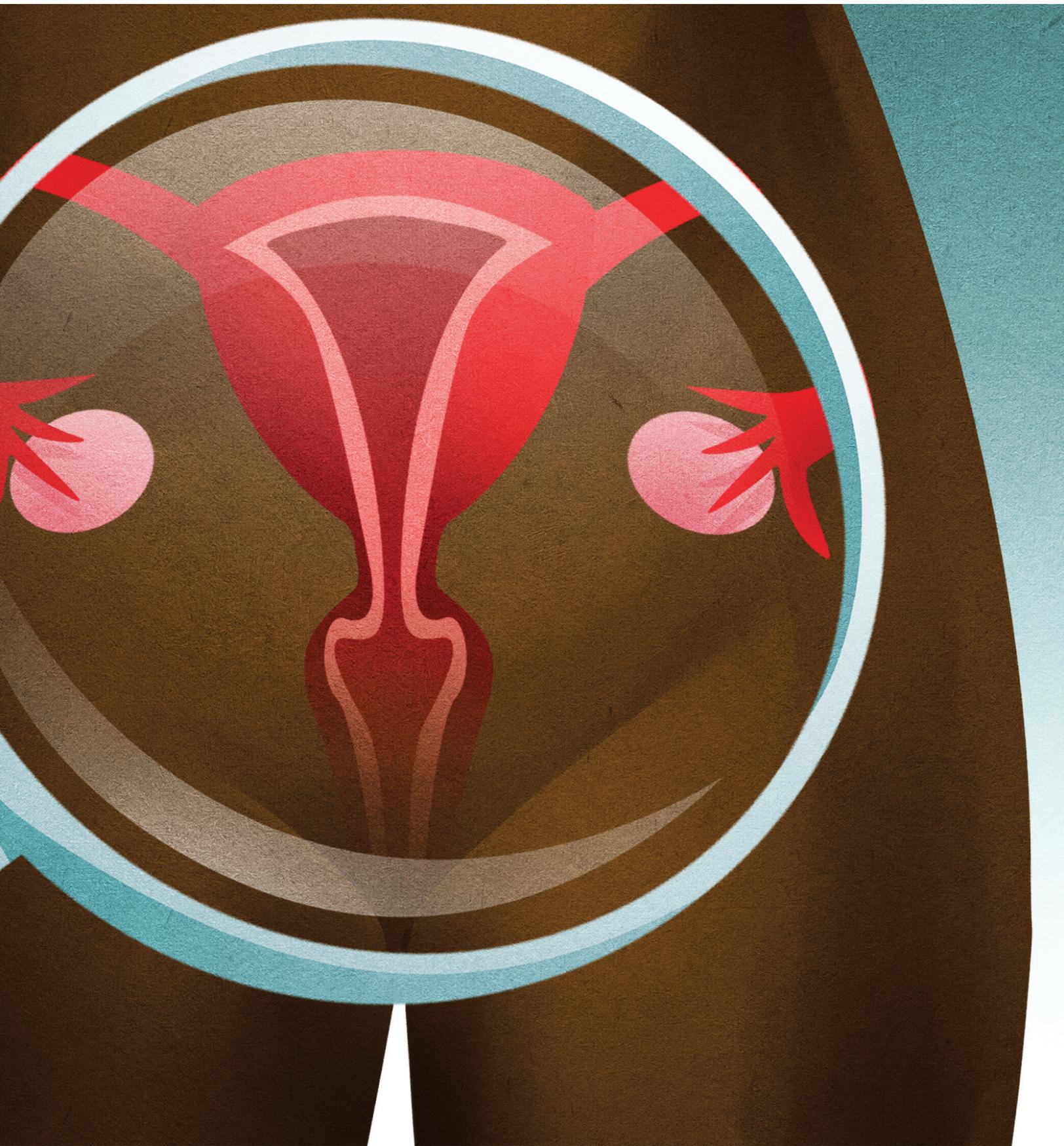
<sup>12</sup> American College of Obstetrics and Gynecology (ACOG), “Cervical Cancer Screening,” May 2021, <https://www.acog.org/Patients/FAQs/Cervical-Cancer-Screening> (accessed June 17, 2021).

<sup>13</sup> Ibid.

<sup>14</sup> ACOG, “Updated Cervical Cancer Screening Guidelines,” April 2021, <https://www.acog.org/clinical/clinical-guidance/practice-advisory/articles/2021/04/updated-cervical-cancer-screening-guidelines> (accessed June 17, 2021).

<sup>15</sup> “The only way to know it is safe to stop being tested after age 65 is if you have had several tests in a row that didn’t find cancer within the previous 10 years, including at least one in the previous five years: For the Pap test alone, you should have three normal tests in a row; For the Pap-HPV co-test, you should have two normal tests in a row.” CDC, “Some Older Women Are Not Getting Recommended Cervical Cancer Screenings,” July 27, 2020, <https://www.cdc.gov/cancer/dcpc/research/articles/older-women-cervical-cancer-screenings.htm> (accessed June 17, 2021).





### 3. TIMELY FOLLOW-UP AFTER ABNORMAL TEST RESULTS

If screening test results are abnormal, timely follow-up with a medical provider is necessary. Depending on the results, further testing and treatment options differ with some individuals requiring only monitoring and repeated testing. Others may need a colposcopy, a procedure that examines the cervix more closely with a microscope to identify the areas that may have abnormal changes. If an abnormal area of tissue is detected during the procedure, a medical provider will typically perform a biopsy to remove cells or tissues from areas of concern.<sup>16</sup> These biopsies are then sent to a lab for further evaluation. Based on the findings, a medical provider and individual will discuss next steps in screening or treatment.

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<sup>16</sup> ACOG, "Colposcopy," May 2021, <https://www.acog.org/womens-health/faqs/colposcopy> (accessed June 17, 2021).





## 4. EARLY AND APPROPRIATE TREATMENT

There are several procedures to treat and remove pre-cancerous cervical lesions found during screenings and diagnostic testing: *conization*, often called a cone biopsy, which removes a cone-shaped piece of tissue from the cervix, including abnormal tissue; *loop electrosurgical excision procedure (LEEP)*, which uses an electrical wire loop to remove abnormal tissue; *laser ablation*, which destroys abnormal tissue using a laser beam; and *cryotherapy*, a procedure that freezes and destroys abnormal cells.<sup>17</sup> Before any procedure is performed, a medical provider should thoroughly explain all treatment options, take time to answer questions, and discuss any foreseeable health risks with patients.



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<sup>17</sup> American Cancer Society, “Cancer Facts and Figures 2021,” 2021, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf> (accessed June 17, 2021), p. 28.



# CERVICAL CANCER DEATHS ARE A HUMAN RIGHTS FAILURE

Cervical cancer thrives in the United States in a context of structural racism, discrimination, poverty, and inequality. Almost no one should die from the disease, but some groups—those that are historically marginalized and neglected—do more often than others.

There are marked disparities in rates of cervical cancer deaths in the US, reflecting exclusion from the healthcare system and unequal access to the interventions and services necessary to prevent and treat the disease, particularly in its early and treatable stages. Medical advances in diagnostic testing and treatment options have led to sharp declines in cervical cancer incidence and mortality rates over the past few decades, yet the National Cancer Institute estimated that 4,290 women would die of cervical cancer in the US in 2021.<sup>18</sup> For women of color, women living in poverty, women without health insurance or regular access to health care, and those who fall into more than one of these categories, cervical cancer is more likely to be a death sentence.

Racial disparities in cervical cancer mortality rates are glaring, and Black women die of cervical cancer at a disproportionately high rate in the US.<sup>19</sup> Women are less likely to be screened as they get older and death rates are especially high for older Black women.<sup>20</sup> Black women have a higher risk of late-stage diagnosis and they are more likely to die from the disease than any other racial or ethnic group in the country.<sup>21</sup> They are almost twice as likely to die from cervical cancer as white women in the US, and the disparity is even greater when national data is corrected to exclude women who have had hysterectomies.<sup>22</sup> Research has found that while controlling for socioeconomic status reduces the higher cervical cancer mortality risk Black women face, it does not erase it entirely.<sup>23</sup> Even among women with similar stages of the disease, Black women are less likely to receive adequate treatment and research has found that later-stage diagnosis and treatment differences contribute to the lower relative survival and higher mortality rates for Black women.<sup>24</sup>

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<sup>18</sup> National Cancer Institute, “Cervical Cancer Treatment (PDQ)—Health Professional Version,” January 22, 2021, <https://www.cancer.gov/types/cervical/hp/cervical-treatment-pdq> (accessed June 17, 2021).

<sup>19</sup> American Cancer Society, “Cancer Facts and Figures for African Americans, 2019-2021,” 2019, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf> (accessed June 17, 2021), p. 3

<sup>20</sup> CDC, “Some Older Women Are Not Getting Recommended Cervical Cancer Screenings”; Mary White et al., “Cervical Cancer Screening and Incidence by Age: Unmet Needs Near and After the Stopping Age for Screening,” *American Journal of Preventive Medicine*, vol. 53 (2017), doi:10.1016/j.amepre.2017.02.024; Anna Beavis et al. “Hysterectomy-Corrected Cervical Cancer Mortality Rates Reveal a Larger Racial Disparity in the United States,” *Cancer*, vol. 123, no. 6 (May 15, 2017), pp. 1044-1050, doi:10.1002/cncr.30507.

<sup>21</sup> American Cancer Society, “Cancer Facts and Figures for African Americans, 2019-2021,” p. 19; CDC, “United States Cancer Statistics: Data Visualizations-Cancer Statistics at a Glance 2018,” undated, <https://gis.cdc.gov/Cancer/USCS/#/AtAGlance/> (accessed July 29, 2021).

<sup>22</sup> American Cancer Society, “Cancer Facts and Figures for African Americans, 2019-2021,” p. 9. See also, Beavis et al., “Hysterectomy-Corrected Cervical Cancer Mortality Rates Reveal a Larger Racial Disparity in the United States.,” *Cancer*.

<sup>23</sup> Candace Sheppard et al., “Assessment of Mediators of Racial Disparities in Cervical Cancer Survival in the United States,” *International Journal on Cancer*, vol. 138, no. 11 (2016), pp. 2622-30, doi:10.1002/ijc.29996.

<sup>24</sup> Sarah Markt et al., “Insurance Status and Cancer Treatment Mediate the Association Between Race/Ethnicity and Cervical Cancer Survival,” *PLoS One*, vol. 13, no. 2 (February 2018), doi:10.1371/journal.pone.0193047; Sheppard et al., “Assessment of Mediators of Racial Disparities in Cervical Cancer Survival in the United States”; American Cancer Society, *International Journal on Cancer*; “Cancer Facts and Figures for African Americans, 2019-2021,” pp. 10 and 19.

In addition to patterns of racial discrimination, economic deprivation is also strongly and independently associated with cervical cancer mortality. Women living in poverty and those without health insurance have lower cervical cancer screening rates, a higher risk of late-stage diagnosis, and lower rates of cervical cancer survival in the US.<sup>25</sup> Research has shown that women living in states that have not expanded Medicaid under the Affordable Care Act are less likely to receive cervical cancer screenings than those living in states that have expanded Medicaid, with the greatest impact on uninsured women.<sup>26</sup>

The failure of the federal and state governments to protect and promote the right to health for all people leaves Black women at a greater risk of dying from this preventable and treatable disease. In the US, Black people are more likely to live in poverty and are less likely to have health insurance.<sup>27</sup> Economic deprivation compounds racial discrimination, together creating barriers to accessing the reproductive healthcare services and information Black women need to prevent and treat cervical cancer.<sup>28</sup> Research from Human Rights Watch and the Southern Rural Black Women’s Initiative for Economic and Social Justice in Alabama and Georgia has shown that federal and state policies across the US neglect the reproductive healthcare needs of Black women and contribute to an environment in which they are dying of cervical cancer at alarming rates.<sup>29</sup> Any preventable death from cervical cancer represents a failure of government to ensure adequate and affordable access to the lifesaving reproductive healthcare services and information all people need and have a right to.

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<sup>25</sup> Thomas Churilla et al., “Disparities in the management and outcome of cervical cancer in the United States according to health insurance status,” *Journal of Gynecologic Oncology*, vol. 141, no. 3 (2016), pp. 516-523; Lindsay Sabik et al., “State Medicaid Expansion Decisions and Disparities in Women’s Cancer Screening,” *American Journal of Preventive Medicine*, vol. 48, no. 1 (2015), pp. 98-103, doi:10.1016/j.amepre.2014.08.015.

<sup>26</sup> Sabik et al., “State Medicaid Expansion Decisions and Disparities in Women’s Cancer Screening,” *American Journal of Preventive Medicine*.

<sup>27</sup> Kaiser Family Foundation, “State Health Facts: Poverty Rate by Race/Ethnicity-2019,” undated, <https://www.kff.org/other/state-indicator/poverty-rate-by-raceethnicity> (accessed July 30, 2021); Center for American Progress, “Health Disparities by Race and Ethnicity,” May 7, 2020, <https://www.americanprogress.org/issues/race/reports/2020/05/07/484742/health-disparities-race-ethnicity/> (accessed July 30, 2021).

<sup>28</sup> Human Rights Watch, *It Should Not Happen: Alabama’s Failure to Prevent Cervical Cancer Death in the Black Belt*, November 2018, <https://www.hrw.org/report/2018/11/29/it-should-not-happen/alabamas-failure-prevent-cervical-cancer-death-black-belt>; Human Rights Watch and the Southern Rural Black Women’s Initiative for Economic and Social Justice, “*We Need Access*”: *Ending Preventable Deaths from Cervical Cancer in Rural Georgia*, January 2022, <https://www.hrw.org/report/2022/01/20/we-need-access/ending-preventable-deaths-cervical-cancer-rural-georgia>.

<sup>29</sup> *Ibid.*