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POLICY FOCUS

# Promoting Cervical Cancer Screening Among Lesbians and Bisexual Women

 THE FENWAY INSTITUTE

# Promoting Cervical Cancer Screening Among Lesbians and Bisexual Women

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Lesbians and bisexual women are as likely as heterosexual women to develop cervical cancer, and yet are up to 10 times less likely to undergo regular screening for the disease. This disparity occurs within a broader context of marginalization of lesbian and bisexual women in the healthcare system. Lesbians are less likely to access preventive care compared to other women, and both lesbians and bisexual women are less likely to be insured compared to other women. Although cervical cancer was once one of the most deadly female cancers, early detection through regular screening has transformed this disease into the most preventable female cancer. Due to low rates of regular cervical cancer screening, lesbians and bisexual women are priority populations for cervical cancer control in this country.

In 2008, 12,410 American women were diagnosed with cervical cancer and 4,008 women died from the disease.<sup>1</sup> The five-year survival rate after diagnosis is 67.9%, though when caught early and localized, the rate is 90.7%.<sup>2</sup> Hispanic women suffer from the highest age-adjusted incidence rates, with Black women shouldering the highest mortality rates from cervical cancer. Risk peaks at middle age, with the median age of diagnosis 48 and median age of death from cervical cancer at 57.<sup>2</sup> The major risk factors for cervical cancer are human papilloma virus (HPV) infection, smoking, and immunosuppression (for instance, as caused by HIV).<sup>3</sup>

Several health disparities place lesbians and bisexual women at higher risk for cervical cancer relative to heterosexual women. Lesbians have higher rates of smoking and obesity, are less likely to be insured than heterosexual women, and are less likely to use preventive health services.<sup>4-9</sup> Data are less available for bisexual

women, but suggest bisexual women may also have higher rates of tobacco use and lower insurance rates than heterosexual women.<sup>4-5,7</sup> Women who are uninsured, obese or who smoke are less likely to undergo regular cervical cancer screening.<sup>10</sup> In addition to being associated with poor screening practices, these factors also lead to significantly higher rates of cervical cancer, and in the case of obesity, death from cancer.<sup>10</sup>

The heightened risk profile of lesbians and bisexual women, therefore, makes them a population of special concern in cervical cancer control in this country. There are signs that this heightened risk profile indeed leads to rates of cervical cancer equal to or higher than that of heterosexual women. Although race and age data are routinely collected on cancer cases and deaths, sexual orientation data are not routinely captured, so incidence among lesbians and bisexual women is not certain. However, one study of more than 90,000 heterosexual

women, 740 bisexual women, and 573 lesbians in the US found a higher prevalence of cervical cancer among bisexual women (2.2%) compared to heterosexual women (1.3%), while the prevalence of cervical cancer among lesbians was not statistically significantly different from that of heterosexual women.<sup>5</sup>

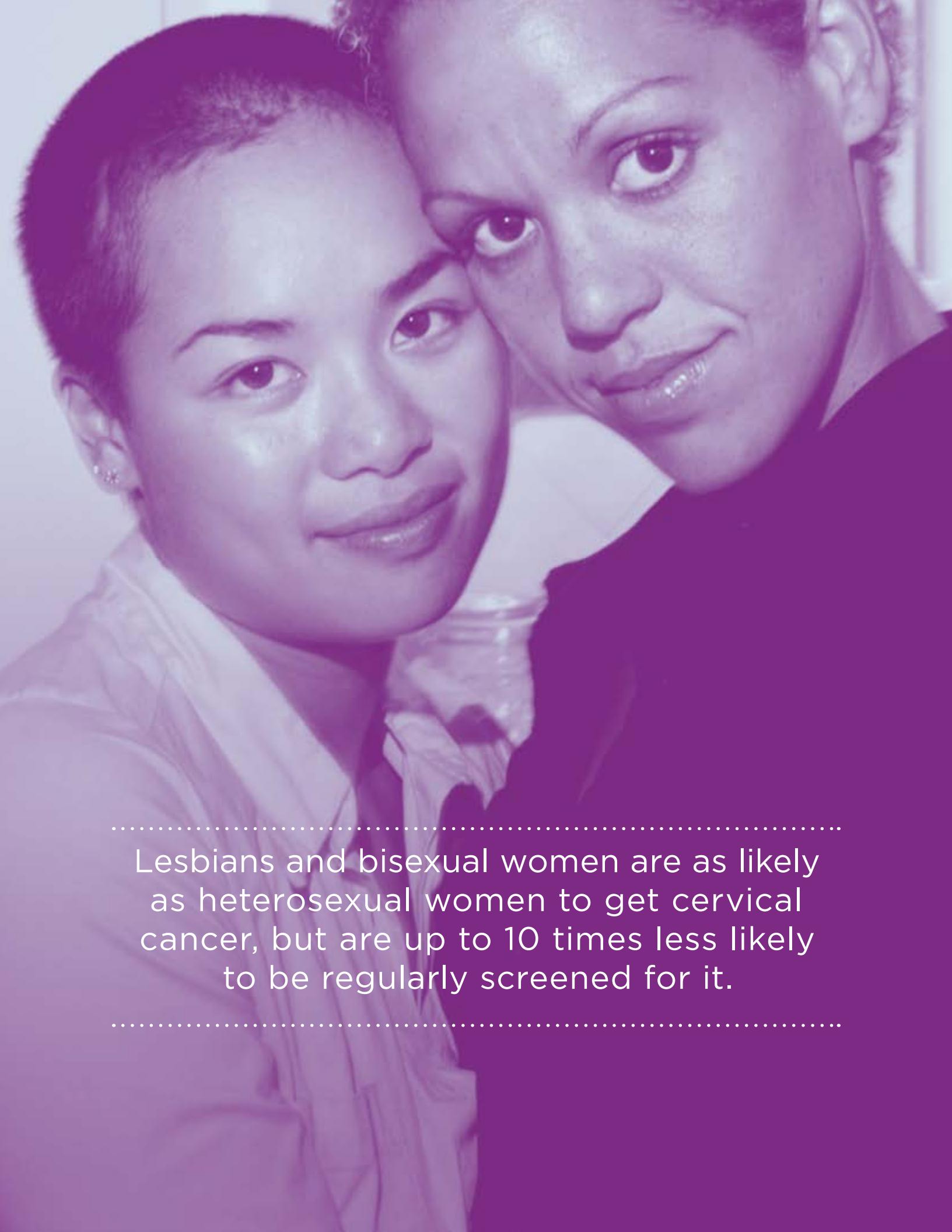
Incidence and mortality due to cervical cancer have fallen steadily over the last several decades,<sup>2</sup> largely as a result of increasingly widespread use of the Papanicolaou (Pap) test. The Pap test screens for changes in cervical cells that allow doctors to act before cancer has developed or to catch cancer in an earlier and more treatable stage.<sup>16</sup> One of the most important risk factors for developing cervical cancer is not undergoing regular screening: The majority of cervical cancers in the US occur among women who have never been screened or who were not screened within the past 5 or more years.<sup>16</sup>

The majority of studies on the issue suggest that lesbians and perhaps bisexual women have

significantly lower cervical cancer screening rates than heterosexual women.<sup>17</sup> For example, a study of young adult lesbians found a 75% lower odds of receiving a Pap test in the last year and an 87% lower odds of ever receiving a Pap test than heterosexual women; bisexual women had a 30% lower odds of having a Pap test in the past year compared to heterosexual women.<sup>18</sup> In a population-based study in New York City, women who have sex with women (WSW) were 10 times more likely to have not received a Pap test in the last 3 years after adjusting for health insurance coverage.<sup>19</sup> Though some studies have found that WSW are as likely as women who exclusively have sex with men to have had at least one Pap test in their lifetime, the evidence consistently shows that sexual minority women are less likely to have had a Pap test in the last one to three years.<sup>8,20–23</sup> A study in 2012 found that 38% of lesbians were not receiving routine screening according to guidelines.<sup>24</sup> Lower rates of regular screening put lesbians and bisexual women at greater risk of late diagnosis, when the disease is less treatable.

## HPV Vaccination

high-risk types (HPV16 and HPV18) causing approximately 70% of cervical cancers.<sup>11</sup> With the release of an effective HPV vaccine in 2006 that protects against the two highest-risk strains, the majority of cervical cancers could potentially be averted altogether. Currently, only 34.8% of teenage girls in the US have received all three doses.<sup>12</sup> There are no data available on the rates of vaccine use among young lesbian and bisexual women, but factors that lead to lower rates of cancer screening—such as lower use of preventive health services and the belief that lesbians cannot contract HPV from their sexual partners—could conceivably lead to lower vaccine uptake as well. Most insurance plans cover the full cost of the HPV vaccine. Under the Affordable Care Act, new insurance plans must fully cover the cost of vaccinations recommended by the Advisory Committee on Immunization Practices (ACIP).<sup>13</sup> ACIP recommends HPV vaccine for all females and males age 11 to 26.<sup>14</sup> Existing insurance plans are grandfathered in and not required to cover the cost of vaccines.<sup>15</sup> The Vaccine for Children Program also covers the cost of the HPV vaccine for Medicaid-eligible children. In Massachusetts, all the major private insurance providers and Medicaid (known as MassHealth) cover HPV vaccine for females and males age 11 to 26.



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## REASONS FOR INCREASED RISK

Lesbians and bisexual women are less likely to make full use of preventive healthcare, including cervical cancer screening, for a number of reasons. They are less likely to have insurance, in part because most employers do not extend insurance benefits to same-sex domestic partners.<sup>25</sup> Experiences of being discriminated against in healthcare settings, or fear of being discriminated against, can deter sexual minority women from receiving routine care. Discriminatory experiences and fears have also been associated with non-routine screening for cervical cancer among lesbians.<sup>26</sup>



Even women who exclusively have sex with women are at risk for HPV and cervical cancer.

Specific to cervical cancer screening, lesbians and bisexual women are less likely to have had a recent routine pelvic exam, perhaps due to reduced demand for birth control and therefore lower utilization of routine gynecological care.<sup>7</sup>

Additionally, lesbians and other WSW sometimes believe or are told by providers that they do not need to be screened for cervical cancer due to a mistaken belief that lesbians are not at risk for contracting HPV. HPV is transmissible via skin-to-skin genital contact, as well as potentially through oral-vaginal and digital-vaginal contact.<sup>27-29</sup> Therefore, even women who exclusively have sex with women are at risk for HPV and cervical cancer. HPV has been detected in the genital tract of between 13 and 30% of women who have only had sex with women, similar to rates in the general population.<sup>30-32</sup> Cervical abnormalities have been well documented in WSW, including women who have only had sex with women.<sup>33</sup> For example, in one study of women attending a sexual health clinic in Australia, lesbians and bisexual women were just as likely as heterosexual women to have cervical abnormalities.<sup>34</sup> Additionally, a recent survey of sexually active adolescents in the U.S. showed that 76% of lesbians and 96% of bisexual women reported having had sex with a man at some point during their lives; therefore, a history of penile-vaginal contact is another possible source of transmission for some lesbians and bisexual women.<sup>35</sup> Multiple studies of young American and Canadian lesbian and bisexual teenagers indicate that they may initiate sexual activity at younger ages on average than heterosexual peers and have higher rates of pregnancy.<sup>36-38</sup> Clearly many lesbian and bisexual women are heterosexually active at some point in their lives, exposing them to additional HPV transmission risk.

Lower rates of regular screening put lesbians at greater risk of late diagnosis, when the disease is less treatable.

## CURRENT POLICY

The American Cancer Society (ACS), US Preventive Services Task Force (USPSTF), and American College of Obstetricians and Gynecologists (ACOG) agree that screening should start for all women at age 21 regardless of HPV vaccination or age of sexual debut.<sup>16,39,40</sup> ACS and USPSTF recommend screening with a Pap test every 3 years until age 29; the screening interval may be lengthened to every 5 years for women ages 30–65 if HPV co-testing is done in addition to the Pap test. Women with a history of a prior abnormal Pap test or who are immune compromised (e.g. by HIV) should be screened yearly. Lesbians and bisexual women are not mentioned specifically in any of the major national guidelines for cancer screening. Although sexual minority women fall under the banner of “all women,” not all providers are following screening guidelines with lesbian and bisexual patients under the mistaken assumption that recent sex with a man is the only way to transmit HPV.

Other countries have guidelines with similar screening intervals, but have done more to proactively increase screening rates among lesbians. In the UK, the National Health Service specifically mentioned LGBT groups in its Cancer Reform Strategy as populations targeted for improvement in its 2007 National Cancer Equality Initiative.<sup>44</sup> Campaigns to increase cervical cancer screening among lesbians have been mounted in various regions of Britain.<sup>45</sup> In Australia, the Papscreen Victoria campaign specifically targets lesbians as one of several groups at risk for inadequate cervical cancer screening, and other provincial departments of health in the country have also funded similar outreach programs.<sup>17,46</sup> Although some individual health departments in the US, such as Public Health-Seattle and King County, have run outreach campaigns to sexual minority women,<sup>47</sup> the national response in this country has been neither coordinated nor robust.

# Transgender men and cervical cancer screening

The majority of female-to-male transsexuals do not undergo complete sex reassignment surgery and still retain a cervix if a total hysterectomy is not performed.<sup>41</sup> Cancers of female natal reproductive organs are still possible in these individuals, and cervical cancer has been documented in a male transgender patient.<sup>42</sup> Transgender men with a cervix should follow the same screening guidelines as natal females.<sup>43</sup> Pap tests can be difficult for transgender men for a number of reasons, including dissociation between biological and preferred genders, desire to ignore the existence of natal reproductive structures, lack of knowledge that they still have a cervix after receiving a supracervical hysterectomy, false positives resulting from testosterone-induced changes to the cervical epithelium that mimic dysplasia, and testosterone-induced atrophy of the vagina that makes passage of a speculum more painful.<sup>41,43</sup> Sensitivity to these unique barriers is important while still emphasizing the importance of regular screening. If the cervix is completely removed and there was no prior history of high-grade cervical dysplasia or cervical cancer, no Pap tests are necessary.<sup>43</sup> There are no data currently available on the rates of cervical cancer or cervical cancer screening among transgender men.

## RECOMMENDATIONS

Although there are a broad range of preventive care issues for lesbians and bisexual women, cervical cancer screenings are an important focus. While it was once one of the most deadly female cancers, cervical cancer is now described by the Centers for Disease Control and Prevention (CDC) as the most preventable cancer among women due to advances in screening and immunization.<sup>48</sup> These advances should be shared among all women.

**Cervical cancer screening should be promoted among lesbians and bisexual women through patient in-reach and community outreach.** Because rates of cervical cancer are as high for lesbians as for heterosexual women, and because limited research indicates that rates may be higher for bisexual women, cervical cancer screening should be promoted for all women, including lesbian and bisexual women. Patient education can be conducted through pamphlets with imaging and wording sensitive to lesbians and bisexual women, and outreach in lesbian and bisexual communities through peer health educators, media messaging, and other tools. These approaches will empower lesbians and bisexual women to know that cervical cancer screening is as important for them as it is for heterosexual women and to track when they are due for screening. Just as detailed screening guidelines include information for specific subpopulations of women, such as HIV-positive women and women with hysterectomies, detailed guidelines should reinforce the fact that even women who exclusively have sex with women should be screened according to usual guidelines.

**Providers should receive more education on LGBT health to dispel myths and improve communication.** It is important that providers are supported in becoming better educated about the health needs of sexual minority women so it is universally understood that these patients,

just like heterosexual patients, need to receive care according to standard guidelines. Medical schools in the US spend on average just 5 hours during their entire preclinical and clinical curricula devoted to LGBT-specific health, leaving many providers feeling ill-equipped to meet the health-care needs of their LGBT patients.<sup>49</sup> In addition to improving knowledge about the health needs of sexual minority patients, it is equally important that providers and other medical staff receive training in interacting with lesbian and bisexual patients so that they can discuss sexual behavior in a way that is comfortable for both provider and patient. Providers should take a sexual history in a nonjudgmental way that does not presume heterosexuality. Sexual minority women who feel more comfortable with their providers utilize routine preventive care at a higher rate than women who do not feel comfortable.<sup>20,50</sup> A recent study found that lesbian women who disclose their orientation to their primary care physician were 2.8 times more likely to undergo regular cervical cancer screening than those who did not, indicating that comfort and openness with a provider is crucial to improving screening rates in this population.<sup>24</sup> Organizations such as The National LGBT Health Education Center at The Fenway Institute offer training and technical assistance to equip providers to provide culturally competent care for LGBT patients.

**HPV vaccination should be promoted among lesbian and bisexual women as a primary prevention strategy.** Current Advisory Committee on Immunization Practices (ACIP) guidelines recommend HPV vaccination for all girls and women aged 11 to 26, as well as for boys and men aged 11 to 26, preferably before the onset of sexual activity to derive maximum benefit. Although the specific rate of HPV vaccination among teen girls and young women who are lesbian or bisexual is currently unknown, HPV vaccination should be

strongly promoted as a primary prevention measure among these populations in light of their heightened barriers to regular cancer screening. Because the vaccine does not protect against all strains of HPV, vaccinated women should still follow regular screening guidelines, but vaccination is an important part of a comprehensive cervical cancer control program. Campaigns that promote HPV vaccination should include WSW-specific or WSW-sensitive messages and images.



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Cervical cancer screening is as important for lesbian and bisexual women as it is for heterosexual women.

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**Sexual orientation and gender identity data should be gathered in cancer registries, health records and health surveys.** The Institute of Medicine first called for increased research on LGBT health and the inclusion of sexual orientation in population-based surveys (particularly federally funded surveys) in 1999, and repeated this call in 2011.<sup>51,52</sup> Today, 14 years after the publication of “Lesbian Health: Current Assessment and Directions for the Future,” we are still bound by research based on convenience samples, studies restricted to a particular state or locality, or studies otherwise non-representative of sexual minority women as a group. For many aspects of cervical cancer, including access to clinical trial participation, incidence, stage distribution,

survival, morbidity, and mortality, we have almost no information specific to sexual minority women.<sup>53,54</sup> Sexual orientation and gender identity data should be included in the same way that race/ethnicity information is collected in federally funded health surveys, electronic health records, and registries such as SEER.<sup>52</sup> As a healthcare provider and research institution, Fenway Health has fostered enormous growth in its own programs over the last 30 years by investing in lesbian- and bisexual-sensitive gynecological care, mental health, and other services; systematically collecting data on sexual orientation and behavior from patients; and bringing together a network of lesbian and bisexual health researchers.<sup>55,66</sup> These complementary clinical care and research efforts have significantly contributed to knowledge about lesbian health needs across the lifespan, and similar programs could be instituted at other health and research centers.

**Black and Hispanic lesbians and bisexual women should be prioritized in cervical cancer prevention and screening efforts.** Because Hispanic and Black women have higher incidence of and mortality from cervical cancer than White women, women who are members of both sexual minorities and racial minorities may be at particular risk of developing cervical cancer and should be particularly targeted for promotion of best screening and immunization practices.

**Transgender men should also be included in cervical cancer screening programs.** Transgender men who have not had their cervix removed are still at risk for cervical cancer, and should be screened. They may, however, have special emotional and physiological needs during screening (See page 5). Transgender men also face a general lack of provider knowledge about transgender health needs and cancer risk. Providers should seek training in how to respectfully address transgender individuals, create a welcoming office

environment, and put patients at ease when performing physical exams or taking a history. Better knowledge of transgender health needs and how to build trust between transgender male patients and providers should improve cervical cancer screening rates among this population.<sup>57</sup>

Outreach programs, official screening guidelines, and other cervical cancer screening promotion efforts should include transgender-specific information and transgender-sensitive wording and imaging.

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