Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods.

Julie Fish
Lesbian and bisexual women: a review of the worldwide literature using systematic methods

Report commissioned by: NHS Cervical Screening Programme

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Executive summary

This review has been commissioned by the NHS Cervical Screening Programme (NHSCSP) as part of its commitment to the delivery of actions to reduce inequalities set out in the Cancer Reform Strategy (CRS); specifically, ‘promoting research to meet gaps in the evidence’ about lesbian and bisexual women and cervical screening (CRS, 2007: 85). The review will make available current knowledge about transmission of the human papilloma virus (HPV); prevalence and risk factors; health behaviours; screening experiences and risk perceptions and contribute to the identification of good practice and of further actions to reduce health inequalities. The intention is that the final report will be useful both for the NHSCSP and for the NHS more widely.

Systematic review methods were used to map the worldwide literature in English on lesbians and bisexual women and cervical screening. A total of 2290 papers were identified in 11 electronic databases and these were supplemented by the ‘grey’ literature.

Concern about lesbian and bisexual women’s access to cervical screening has been a central issue for more than a quarter of a century for researchers in lesbian health because so little is known about the nature of lesbians’ participation in the screening programme. Their pattern of sexually transmitted disease is said to be quite different from that of heterosexual women. By synthesising data from a range of studies, this review appraises what is known about cervical screening and lesbian and bisexual women in relation to:

Transmission of the human papilloma virus (HPV) and the relation to sexual behaviour between women.

- Lesbian and bisexual women may contract HPV through their own previous sexual behaviour with men; in addition, HPV may also be transmitted
through lesbian sex by a female partner who has had previous heterosexual sex.

- Modes of transmission are commonly understood to include vaginal penetration with fingers and skin to skin contact. HPV may also be transmitted through the use of sex toys.

**Prevalence rates for HPV and cervical cancer in lesbians and bisexual women.**

- HPV has been diagnosed among lesbian and bisexual women and prevalence rates range from 3.3% to 30%.
- Among LB women with no reported history of heterosexual sex, prevalence was 19%.

**Risk factors for cervical cancer among lesbian and bisexual women**

- Certain known risk factors may be more common in this population (smoking prevalence rates among lesbians exceeded US national norms for women).
- Other risk factors include early age of first intercourse and the numbers of male partners.

**Uptake of screening and rates of never screening**

- Participation rates in cervical screening increase with age among lesbian and bisexual women.
- Time intervals between screenings appear to be greater than for heterosexual women. Lesbian and bisexual women were up to 10 times less likely to have had a test in the past three years.
- Lesbian and bisexual women who have never had sex with men were less likely to be screened than LB women with a history of heterosexual sex; rates of *never* being screened range from 12% - 17% in UK studies.
Lesbian and bisexual women’s risk perceptions for cervical cancer.

- Lesbians were more likely to consider themselves at lower risk of cervical cancer than bisexual or heterosexual women. Sex with men was often cited as a risk factor.

Barriers to cervical screening

- Cervical screening is sometimes considered unnecessary for lesbian and bisexual women;
- Lesbians and bisexual women believe themselves to be low risk of the disease;
- Lesbians and bisexual women may be more have adverse experiences of healthcare than heterosexual women;
- There may be a reluctance to come out among some lesbian and bisexual women.
- Heterosexual assumptions pose a barrier to healthcare.

Conclusion

The report makes nine recommendations for healthcare services:

1. Introduce screening guidelines
2. Target health information for lesbians and bisexual women
3. Include lesbian and bisexual women’s health in medical education programmes.
4. Avoid assumptions of heterosexuality
5. Develop specialist services
6. Routinely collect data about service usage
7. Monitor satisfaction of LB women as health service users
8. Develop a welcoming practice environment
9. Further research into barriers to cervical screening for LB women
1. Background

1.1 Introducing the social and policy context for cancer inequalities

This review has been commissioned by the NHS Cervical Screening Programme (NHSCSP) as part of its commitment to the delivery of actions to reduce inequalities set out in the Cancer Reform Strategy (CRS); specifically, ‘promoting research to meet gaps in the evidence’ about lesbian and bisexual women and cervical screening (DH, 2007: 85). The review will make available current knowledge about transmission of the human papilloma virus (HPV); prevalence and risk factors; health behaviours; screening experiences and risk perceptions and contribute to the identification of good practice and of further actions to reduce health inequalities. The intention is that the final report will be useful both for the NHSCSP and for the NHS more widely; specifically, the National Cancer Equality Initiative (NCEI), Pacesetters Programmes in Primary Care Trusts and also for third sector initiatives (c.f. NCEI, 2008a).

Current policy and legislative changes offer possibilities for improvement in the health of lesbian and bisexual (LB) women. The introduction of the 2007 Equality Act (Sexual Orientation) Regulations offers the protection of equal treatment in public services, including the NHS. Regulatory bodies have responded by providing patient information (e.g. GMC, 2007). But lesbians and bisexual women have often been invisible patients within health services and their needs are poorly understood. Although there is increasing recognition that sexual orientation is a ground for health inequalities (Fish, 2007), these inequalities are not consistently acknowledged across the NHS. In a recent policy statement, a leading UK cancer research organisation called for stakeholders to commission research in order to better understand the lesbian, gay, bisexual and trans (LGBT) cancer inequalities agenda including: cervical cancer and HPV rates, unmet need for information and support, lifestyle behaviours which impact on cancer rates, experiences of individuals accessing cancer services and awareness of the needs of LB women among health professionals (CRUK, 2008). This review of knowledge about lesbian and bisexual
women and cervical screening fits with this agenda and with current priorities for the Department of Health, specifically the National Cancer Equality Initiative. It seeks to inform current diversity initiatives, such as Pacesetters, which are concerned to ensure that the design and delivery of services take account of the needs of all patients.

1.2 Background to cervical screening and cervical cancer risk
Cervical cancer risk is associated with sexual behaviour (e.g. multiple partners or partners who have had multiple partners, early age of intercourse and unprotected sex). These behaviours increase the risk of acquiring HPV, which is one of the most common types of sexually transmitted infections (Solarz, 1999). High risk types of HPV can lead to cervical cancer; however, the disease can take many years to develop. Changes in the cells of the cervix resulting from HPV infection can be detected by liquid based cytology (this screening test has replaced the smear test). If these changes are treated sufficiently early, cervical cancer can be prevented.
Although a programme of vaccination among young women has been introduced in the UK - preventing 7 in 10 of the most common types of cervical cancer - women will still need to attend for cervical screening and it will be many decades before the population consists mostly of vaccinated women. Cervical screening has been estimated to prevent approximately 5,000 deaths each year in the UK over the next 30 years (Peto et al. 2004); it continues to be the important screening tool used to diagnose and prevent cervical cancer. Many women who develop cervical cancer have never been screened (or have been inadequately screened). Despite the emphasis on the relationship between heterosexual sex and cervical cancer the greatest risk factor for the disease, is not sex, but not being screened (NHSCSP, 2004).

1.3 Lesbians and bisexual women form a hard to reach population
Sexual orientation is the only equality strand not included in the census (Grew, 2009). Although there are limited data available on cancer incidence and mortality for other equality strands such as ‘race’, the lack of data for sexual orientation has
been described as a ‘statistical silence’ (Reynolds, in McManus, 2003: 38). There are an estimated 3.6 million lesbian, gay and bisexual people living in the UK (DTI, 2004); however, there is no detailed information relating to their geographical distribution in the UK or to other demographic characteristics. The Office of National Statistics has recently announced that six UK public sector surveys will include questions on sexual orientation; however, none of them collect data relating to health (ONS, 2008).

Despite longstanding concerns about the lack of surveillance data on sexually transmitted infections between women (Ford and Clarke, 1998), the Health Protection Agency does not routinely collect data on lesbian and bisexual women. To date, there are no available data on cervical cancer incidence, stage distribution or mortality among lesbians and bisexual women (Marrazzo et al. 2001). The dearth of data poses particular difficulties for research on cervical cancer and screening among lesbian and bisexual women. Population-based studies using random methods are considered to provide the most reliable data, yet only a small number of such studies have been conducted, predominantly in the USA. Because lesbians and bisexual women form a relatively small proportion of the female population, few studies are sufficiently large to produce a meaningful sub-sample of lesbian and bisexual women.

A recent survey of UK cancer services conducted by the NCEI (2008b) found only one initiative (out of a total of 77) which specifically targeted sexual orientation and cancer. None of the other equality strands (e.g. ‘race’, class, gender) were so poorly represented in projects and this reflects the low priority often afforded to sexual orientation in health service delivery.

1.4 Methodological critique of papers
In order to contextualise the barriers to understanding cervical screening among lesbian and bisexual women, it is important to characterise some of the difficulties in conducting research among this population group. Although there is a growing
body of work being published in high ranking peer reviewed journals, the lack of relevant data is one of the key differences between the health of lesbian and bisexual women and their heterosexual counterparts. Table 1 identifies some of the benefits and methodological limitations of research among LB women.

Table 1: Methodological critique of papers

<table>
<thead>
<tr>
<th>Population based studies</th>
<th>Disadvantages</th>
</tr>
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<tbody>
<tr>
<td>Advantages</td>
<td></td>
</tr>
<tr>
<td>Use random methods</td>
<td>Small sub sample of lesbians and bisexual women;</td>
</tr>
<tr>
<td>Large scale</td>
<td>Homogenous sample (population based studies often sample among LB communities who are most accessible (i.e. well-educated, white women);</td>
</tr>
<tr>
<td>Internal comparison group</td>
<td>Lesbians tend to be geographically dispersed;</td>
</tr>
<tr>
<td>Possibility of including a sexual orientation boost, similar to the ethnic boost.</td>
<td>Refusal to disclose sexual orientation;</td>
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<td></td>
<td>Lack of specific questions relevant to lesbians e.g. discrimination on the grounds of sexual orientation, disclosure.</td>
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<table>
<thead>
<tr>
<th>Community surveys</th>
<th>Disadvantages</th>
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</thead>
<tbody>
<tr>
<td>Advantages</td>
<td>Methodological limitations;</td>
</tr>
<tr>
<td>Large numbers of lesbians in sample;</td>
<td>Limits to generalisability;</td>
</tr>
<tr>
<td>Possibility of recruiting a more diverse sample;</td>
<td>Barriers to publication.</td>
</tr>
<tr>
<td>Relevance of questions for lesbians.</td>
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</table>

In summary, systematic data are minimal about lesbian and bisexual women even in comparison to that available for gay men. Multiple factors have led to the lack of data including: investigators have been disinclined to include questions about sexual orientation in studies citing concerns that heterosexual women would be deterred from participating (Solarz, 1999); the historic reluctance of many lesbian and bisexual women to disclose their sexual orientation; beliefs about the small size of the LGBT population and perceptions that LB women do not engage in risky health behaviours. The following review of the literature (in section 3 below) needs to be understood in this research context.
1.5 Definitions of sexual orientation
The report of the Institute of Medicine identifies how sexual orientation is defined. Sexual orientation may be described as including behavioural (i.e. sexual behaviour), affective (i.e. desire or attraction) and cognitive (i.e. identity) dimensions and is likely to include different (but sometimes overlapping) populations of women (Solarz, 1999). Some studies use the term “lesbian” or “self-identified lesbian” and this describes women who describe their identity as lesbian (they may or may not engage in sexual behaviour with women). Other terms include “women who have sex with women” and this may include heterosexual women who have sex with women (but do not describe themselves as LB women) in addition to lesbian and bisexual women. “Sexual minority women” refers to lesbian and bisexual women.

2. Methods
Systematic review methods were used to map the worldwide literature in English on lesbians and bisexual women and cervical screening. In the early stages, a pilot was undertaken to identify the most relevant search terms (appendix 1). A protocol was then drawn up which specified the research questions, the purpose, aims and objectives of the study, the contextual and policy background, definitions of sexual orientation and terms for cervical cancer (appendix 2). Feedback was obtained from colleagues and those with expertise in conducting systematic reviews. The aim of the search was to systematically collect a comprehensive, transparent and replicable review of knowledge in the topic area.

In stage 1, a combination of electronic database searching was undertaken alongside hand searches, searches of the ‘grey’ literature and key websites. These included: the US Department of Health and Human Services; Ministerial Advisory Committee for Gay and Lesbian Health, Australia; the New Zealand Cancer Society; and the British Columbia Cervical Screening Programme, Canada and other government and voluntary sector websites worldwide. Databases searched included: Medline,
CINAHL plus, PsycInfo, Academic Search Premier, Ingenta Connect, Proquest, Science Citation Index, Scopus, Biomed Central, Science Direct and HMIC. Experts in the field were contacted for details of studies and unpublished papers were examined. At this stage studies were searched by title, papers considered not relevant to the topic and duplicates were rejected. Figure 1 (see page 12) outlines the process and the numbers of papers located at each stage. A second reviewer checked a 10% sample.
Fig 1: Search outcomes

Total references retrieved
N = 2290

Stage 1 references deleted
- Rejected at title
N = 2212

Total abstracts screened
N = 78

Stage 2
Rejected at abstract
N = 35

Total full papers screened
N = 43 + 7 = 50

Stage 3 Rejected full papers
N = 36

Total papers hand search
N = 7

Total papers final
N = 14

Clinic studies
N = 4

Population based studies
N = 4

Comparison studies
N = 2

Community studies
N = 4
At Stage 2, abstracts were screened and checked against the inclusion criteria. The second reviewer read all 78 abstracts and agreement was reached on inclusion and exclusion. At stage 3, papers were obtained for those studies which appeared to be most relevant to this review. Full papers were screened using a data extraction checklist (appendix 3) that drew on models of appraising the quality of papers (Coren and Fisher, 2006; Eppi-centre, 2008). Papers were graded independently and further discussed at a meeting. Seventy-four per cent of papers were quality assessed and agreement was reached on all except two papers; differences were resolved by discussion. In the final stage, 19 papers were included. Tables 2-5 (see pages 14-17) identify the most important studies for this review and they are grouped according to the type of study; in the subsequent discussion, these findings will be considered first, followed by supporting or contrary evidence from other studies.
<table>
<thead>
<tr>
<th>ID</th>
<th>Study</th>
<th>Country of study</th>
<th>Aims</th>
<th>Sample</th>
<th>Method</th>
<th>Main Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bailey et al.</td>
<td>UK London</td>
<td>To provide laboratory diagnoses of cervical cytology in lesbians.</td>
<td>N= 606 485 had heterosexual histories 121 exclusively lesbian.</td>
<td>Case notes and self administered questionnaire</td>
<td>17% reported no prior cervical smear 25% over 4 years ago Cervical abnormalities more common in women who had been sexually active with men than in exclusively lesbian group 10.9% vs 4.9% HPV found in 3.3% 20/603 more common in women with heterosexual experience. Cytology changes consistent with moderate or severe dyskaryosis in 5 (0.83%).</td>
</tr>
<tr>
<td>2</td>
<td>Fethers et al.</td>
<td>Australia Sydney</td>
<td>To assess the prevalence of STIs, risk behaviours and demographics in WSW.</td>
<td>N= 1408 and 1432 controls Exclusive WSW 283 (no sex with a man in previous 12 months).</td>
<td>Retrospective cross sectional study</td>
<td>Abnormalities on cervical cytology were equally prevalent in WSW and controls. Median numbers of lifetime sexual partners significantly greater for WSW than controls Sexual contact with a gay or bisexual man more common and with Intravenous Drug User. WSW have a similar prevalence of cervical atypias to women with no history of sex with women</td>
</tr>
<tr>
<td>3</td>
<td>Marrazzo et al.</td>
<td>USA Seattle</td>
<td>To examine frequency of and attitudes toward Pap test screening in women who have sex with women (WSW) and to determine prevalence of genital human papillomavirus (HPV).</td>
<td>Clinic study N= 248 &gt; 40 years HPV detected by PCR. 14 (50%) had not had sex with a male in more than a year. Women who reported sex with men significantly more likely to have HPV detected. 10% had been told by a health care provider that they did not need a pap. Among the 28 women with HPV 14 (50%) had not had sex with a male in more than a year. Women who reported sex with men significantly more likely to have HPV detected. 10% had been told by a health care provider that they did not need a pap.</td>
<td>Convenience sample. Standardized Questionnaire. HPV detected by PCR.</td>
<td>80% reported sex with men during lifetime HPV detected in 13%, 23 (74%) had oncogenic types</td>
</tr>
<tr>
<td>4</td>
<td>Skinner et al.</td>
<td>UK London</td>
<td>To evaluate and compare the range of genital infections diagnosed in a group of lesbians attending an inner city genitourinary clinic with a control group of heterosexual women.</td>
<td>N= 241 lesbians N= 241 heterosexual controls</td>
<td>Case controlled</td>
<td>Genital warts more common in heterosexual women Cervical cytology abnormalities uncommon but only found in lesbians. Lesbians more likely to request cervical cytology. (failure to use primary care). Two lesbians with severe dyskaryosis had not had sexual contact with a man for 16 and 20 years respectively.</td>
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</table>
## Table 3: Population based studies

<table>
<thead>
<tr>
<th>ID</th>
<th>Study</th>
<th>Country of study</th>
<th>Aims</th>
<th>Sample</th>
<th>Method</th>
<th>Main Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Diamant, Wold et al. (2000).</td>
<td>USA Los Angeles</td>
<td>To compare women of different sexual orientations within a population based sample regarding health risk behaviours, health status, access to and barriers to health care and receipt of preventive services.</td>
<td>N= 4697 (4610 heterosexual women, 51 lesbians, and 36 bisexual women)</td>
<td>1997 Los Angeles County Health Survey Population based study</td>
<td>Lesbians are one third less likely to have a pap test than heterosexual women. Lesbian and bisexual women significantly more likely to have encountered some difficulty receiving health care services during preceding year. Heterosexual women were more likely to be very satisfied with the care they received from their regular provider.</td>
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<tr>
<td>6</td>
<td>Frisch et al. (2003).</td>
<td>Denmark</td>
<td>To systematically study cancer patterns among women in registered partnerships.</td>
<td>N= 1614</td>
<td>Cancer registry data of women who had a registered Civil Partnership.</td>
<td>Women in homosexual partnerships had cancer risks similar to those of Danish women in general, but only one woman developed cervical carcinoma in situ versus 5.8 women expected.</td>
</tr>
<tr>
<td>7</td>
<td>Kerker et al. (2006).</td>
<td>USA New York City</td>
<td>To examine the relationship between sexual behaviour and health care utilisation.</td>
<td>Two population based surveys. N = 9 764 N = 9 585</td>
<td>Cross sectional computer assisted telephone surveys</td>
<td>Women who have sex with women (WSW) were less likely to have had a Pap test in the past 3 years than other women. WSW who identified as lesbians were more likely to have received timely Pap tests than those who identified as heterosexual.</td>
</tr>
<tr>
<td>8</td>
<td>Valanis et al. (2000).</td>
<td>USA</td>
<td>To compare heterosexual and nonhetero-sexual women on screening practices, and other health-related behaviors associated with increased risk for developing particular diseases.</td>
<td>Population based study. N= 93 311 women aged 50-79 Lesbians N= 573 (0.6%)</td>
<td>Women’s Health Initiative.</td>
<td>Lesbians and bisexual women had lowest rate of never smoking and were more likely to be current smokers. Cervical cancer higher among bisexual women. Heterosexual women were most likely to have had a Pap test in last year.</td>
</tr>
<tr>
<td>Study Number</td>
<td>Authors (Year)</td>
<td>Location</td>
<td>Study Title</td>
<td>Study Details</td>
<td>Findings</td>
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<td>9</td>
<td>Matthews et al. (2004)</td>
<td>USA Minneapolis, New York, Chicago.</td>
<td>To examine cervical cancer risk factors, screening patterns, and predictors of screening adherence in demographically similar samples of lesbian and heterosexual women.</td>
<td>Chicago Community Cancer Project N= 550 lesbians N= 279 heterosexual women.</td>
<td>Differences in sexual behavior risk factors for cervical cancer were observed with lesbians reporting earlier onset of sexual activity, more sexual partners, and lower use of safer sex activities. Lesbian and heterosexual women were equally likely to have ever had a Pap test; however, lesbians were less likely to report routine screening. Higher but not statistically significant numbers of lesbians to heterosexual women were more likely to report perceived bias associated with their sexual orientation.</td>
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<td>10</td>
<td>Price et al. (1996).</td>
<td>USA</td>
<td>To examine women’s perceptions and practices regarding cervical screening by sexual orientation.</td>
<td>N = 330 177 heterosexual 46 bisexuals 107 lesbians</td>
<td>Lesbians only a third as likely as heterosexual women to be told they were at risk for developing cervical cancer. Lesbians and bisexual women were significantly more likely than heterosexual respondents to acknowledge sexual intercourse with men as a risk factor for cervical cancer.</td>
<td></td>
</tr>
<tr>
<td>ID</td>
<td>Study</td>
<td>Country of study</td>
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<td>11</td>
<td>Brown et al. (2003).</td>
<td>Australia Victoria</td>
<td>To investigate cervical screening practice within the lesbian community.</td>
<td>Community survey, N=409</td>
<td>Self administered questionnaire. Compared data within sample</td>
<td>66% of respondents were well screened, 22% were under-screened, and 12% had never had a Pap test. Women were more likely to be well screened if they were aged &lt; 40 years, if their health care provider knew they were lesbian and was aware of lesbian-specific health issues, and if they had never been advised as ineligible.</td>
</tr>
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<td>12</td>
<td>Diamant, Schuster, et al. (2000).</td>
<td>USA</td>
<td>To assess whether a disparity exists between lesbians and comparable women in the general US population</td>
<td>Community survey, N=6935</td>
<td>Self administered questionnaire. Compared data to national data</td>
<td>Young lesbians at increased risk for not having Pap smear relative to their counterparts in general population. 8% of women had never had pap smear. Risk factors for cervical dysplasia may not be very different from that of heterosexual women. Lesbians in this sample appeared to have higher rates of abnormal smears.</td>
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<td>13</td>
<td>Fish &amp; Anthony (2005)</td>
<td>UK</td>
<td>To examine whether risk perceptions, experiences of health care, and health-seeking behavior are correlated.</td>
<td>Community survey, N=1066</td>
<td>Self administered questionnaire.</td>
<td>12% (132) had never been tested. 15% no longer attended. Increasing age associated with frequency of smear tests. Good experiences were associated with the increased likelihood of attendance (p&lt;0.001). 51% believed that lesbians’ risk for cervical cancer is lower than that of heterosexual women.</td>
</tr>
<tr>
<td>14</td>
<td>Rankow &amp; Tessaro (1998).</td>
<td>USA North Carolina</td>
<td>To better understand the attitudes, behaviors, beliefs, and experiences affecting lesbians and other women who partner women.</td>
<td>N = 512</td>
<td>Community survey. Self administered questionnaire and focus groups.</td>
<td>Risk factors: multiple past or current sexual partners (both male and female), early age at first coitus, history of sexually transmitted diseases and cigarette smoking. 25% had not had a pap test in past 3 years including nearly 8% who had never had one. Positive experiences with health providers associated with receipt of pap test.</td>
</tr>
</tbody>
</table>
3. Results from the review of cervical screening in lesbians and bisexual women.

Concern about lesbian and bisexual women’s access to cervical screening has been a central issue for more than a quarter of a century for researchers in lesbian health because so little is known about the nature of lesbians’ participation in the screening programme (e.g. Robertson and Schachter, 1981). Their pattern of sexually transmitted disease is said to be quite different from that of heterosexual women (Evans et al. 1998). By synthesising data from a range of studies, this review appraises what is known about cervical screening and lesbian and bisexual women.

3.1 To appraise what is known about transmission of the human papilloma virus (HPV) and the relation to sexual behaviour between women.

Lesbian and bisexual women are believed to be at no risk or substantially lower risk of cervical cancer than heterosexual women. This belief is premised on assumptions that lesbians do not have sex with men: lesbians’ risk status and sexual behaviours have often been compared to those of nuns or virgins (Conway and Humphries, 1994). However, studies have suggested that up to four-fifths of lesbians have previously had sex with men in their lifetime (Diamant et al. 1999; Marrazzo et al. 2001). Human papillomavirus (HPV) has a long latency period with the pre-invasive stages potentially existing for a number of years (Carroll et al. 1997). This might mean that any heterosexual sex – even some years previously - may contribute to lesbians’ risk of cervical cancer.

The possibility of lesbians’ risk for cervical cancer has led to several hypotheses about the potential routes of transmission of the virus. Some suggest that HPV may be transmitted during oral sex between women, by vaginal penetration with the fingers, by sharing sex toys or only skin-to-skin contact (Ferris et al. 1996; O’Hanlan and Crum, 1996; Carroll et al. 1997; Marrazzo et al. 2001). Marrazzo et al (2001) suggest that HPV is sexually transmitted between women. Bailey et al. (2000) more cautiously conclude that it is biologically plausible that HPV could be passed from
woman to woman in sexual contact though less efficiently than through heterosexual intercourse.

- Lesbian and bisexual women may contract HPV through their own previous sexual behaviour with men;
- HPV may also be transmitted through lesbian sex by a female partner who has had previous heterosexual sex.
- Modes of transmission are commonly understood to include vaginal penetration with fingers and skin to skin contact. HPV may also be transmitted through the use of sex toys.

3.2 To establish the prevalence rates for HPV and cervical cancer in lesbians and bisexual women.

In an Australian case control study of 1408 lesbians and bisexual women and 1423 heterosexual women attending a sexual health clinic in Sydney, cervical abnormalities (CIN 1, CIN 2-3) were equally prevalent in both groups (Fethers et al. 2000). Although genital warts were significantly less prevalent among lesbians and bisexual women than among heterosexual controls, lesbians and bisexual women were significantly more likely to report a previous diagnosis of clinical warts (Fethers et al. 2000).

A US clinic sample of 248 lesbian and bisexual women found the prevalence of HPV was 13%; among this group 74% had oncogenic types of HPV (Marrazzo et al. 2001). Half of the women with detectable HPV reported that they had not had sex with a male partner in more than a year. Women who reported having had sex with a man in the past year were significantly more likely to have HPV detected (Marrazzo et al. 2001). In a previous study, Marrazzo (1998) found the prevalence of HPV was 30%; among women who reported no history of heterosexual sex, prevalence was 19%.

Evidence demonstrates the presence of cervical abnormalities in women who report never having sex with men (Bailey et al. 2001; Fethers et al. 2000; Marrazzo et al.)
Two case reports documented cervical lesions consistent with high grade CIN and described HPV infection in lesbians who gave no history of sexual activity with men (Ferris et al. 1996; O’Hanlan and Crum, 1996). Cervical abnormalities (borderline, mild, moderate or severe dyskaryosis) were more common in women who had been sexually active with men than in ‘exclusively’ lesbian subjects (10.9% vs 4.9%) (Bailey et al. 2000). Lesbians (who themselves have not had sex with men), but whose female sexual partners have had previous heterosexual sex, may be at some risk; in one case this was up to 11 years previously (Carroll et al. 1997; Marrazzo et al. 2001).

The findings confirm those of earlier studies conducted in the UK (Evans et al. 1997) and the USA (Marrazzo et al. 1998). In addition, a case control study of 241 lesbians with 241 matched controls found cervical abnormalities only in the lesbians (Skinner et al. 1996); cervical dysplasia among lesbians has been shown to be at a higher than expected rate, possibly due to the longer intervals between screenings (Robertson and Schachter, 1981). Furthermore, cervical abnormalities have been detected in lesbians with no history of heterosexual intercourse (Edwards and Thin, 1990).

The Women’s Health Initiative, a cluster study comprising 3 randomized control trials and a longitudinal study of 93,311 post-menopausal women aged 50-79 represents one of the few studies worldwide to measure differences between women in the prevalence of cervical cancer. Valanis et al. (2000) found that age-standardized prevalence of cervical cancer was higher among lesbians and bisexual women (2.2% and 2.1% respectively) than among heterosexual women (1.3%). Contrary findings were identified in a population-based study conducted among women in registered civil partnerships in Denmark. This study found that cancer incidence among women in same sex partnerships differed little from that of Danish women in general: the incidence of cervical carcinoma was close to that expected. However, only one woman developed cervical carcinoma in situ versus 5.8 women expected and this represented a statistically significant deficit (Frisch et al. 2003).
• Cervical abnormalities occur in lesbian and bisexual women;
• Oncogenic HPV types are found in lesbian and bisexual women, even those without a history of heterosexual sex.

3.3 Risk factors for cervical cancer in lesbian and bisexual women
In addition to sexual behaviour, lesbians may be subject to other risk factors for cervical cancer, specifically smoking. Studies suggest that lesbians are more likely to report current smoking or, if non-smokers, more likely to report a past history of smoking than heterosexual women (Gruskin et al. 2001; Valanis et al. 2000; Case et al. 2004). Cochran et al. (2001) reported that after standardization, both current and previous smoking prevalence rates among lesbians exceeded national norms for women.

It has been suggested that women who have sex with women have a higher number of lifetime male sexual partners than heterosexual women (Fethers et al. 2000); they were also significantly more likely to report past sexual contact with a gay or bisexual man and sexual contact with an intra-venous drug user. Early age of first intercourse, and a high number of male partners are both risk factors for the presence of cervical HPV infection which is necessary for the development of cervical cancer. Smoking is an important co-factor. Bailey et al (2000) propose that the high rates of these risk factors potentially place lesbians and bisexual women at risk of cervical cancer.

• Certain risk factors for transmission and persistence of HPV are more common amongst LB women than heterosexual women.

3.4 To consider lesbian and bisexual women’s participation rates in cervical screening programmes in comparison to heterosexual women.
An early study highlighted that the time interval between cervical screenings was almost three times higher for lesbians than for heterosexual women using the same clinic (Robertson and Schachter, 1981); lesbians are believed to delay seeking routine
tests or to avoid them altogether (Trippet and Bain, 1993). A population-based study of women of differing sexual orientations found that lesbians, but not bisexual women, were less likely than heterosexual women to have been screened in the previous two years (Diamant, Wold et al. 2000). These findings were supported by a population-based study in New York City which found that women who have sex with women (WSW) were significantly less likely than other women to have been tested in the past three years (66% vs. 88%, p<.0001). After accounting for other factors, such as insurance status, WSW were 10 times less likely to have had a test in the past three years than other women (Kerker et al. 2006). In a multi-site US study of 550 lesbians and 279 heterosexual women, lesbians were less likely to report routine screening (Matthews et al. 2004). Contrary findings were identified in the WHI study of post-menopausal women which found no differences in screening behaviour between US lesbians and bisexual women and their heterosexual counterparts (Valanis et al. 2000).

Of the 3.6 million women screened in 2002-3 in the UK, 0.9 million women were screened opportunistically at the suggestion of the sample taker or the woman herself (NHSCSP, 2008). It may be that lesbians and bisexual women are less likely to be offered opportunistic screening than heterosexual women because they are less likely to access contraceptive services or other similar occasions when this may be offered.

Rates of never screening appear to differ between sexual minority women and heterosexual women. Lesbian and bisexual women over the age of 25 are more than twice as likely (15% vs. 7%) as the general population to have never been tested (Hunt and Fish, 2008). Screening rates in lesbian and bisexual women appear to differ between studies conducted in different countries: in US studies, rates of never screening range from 8% -12% (Rankow and Tessaro, 1998; Brown et al. 2003). In the UK, these rates range from 12% - 17% (Fish and Anthony, 2005, Bailey et al. 2000).
Women’s screening behaviour differed significantly according to whether they reported having had sex with men (Marrazzo et al. 2001). Lesbians who had never had sex with men were more likely to report no prior screening than those who had been sexually active with men (42% vs. 12%, p<.001, Bailey et al. 2000). Women who were not currently sexually active with men had their first test at an older age, had fewer tests in the past five years and reported longer intervals between their two most recent tests (Marrazzo et al. 2001).

- Participation rates in cervical screening increase with age among lesbian and bisexual women.
- Time intervals between screenings appear to be greater for LB than for heterosexual women. Lesbian and bisexual women were up to 10 times less likely to have had a test in the past three years.
- Lesbian and bisexual women who have never had sex with men were less likely to be screened than LB women with a history of heterosexual sex; rates for these women of never being screened range from 12% - 17% in UK studies.

3.5 To evaluate lesbian and bisexual women’s risk perceptions for cervical cancer.

Few studies have investigated risk perceptions of cervical cancer among sexual minority women. Perceptions of risk are said to influence screening behaviour (Bailey et al. 2000): beliefs of reduced susceptibility are associated with decreased likelihood of attendance for screening. In a study which compared the health beliefs of lesbian, bisexual and heterosexual women, lesbians and bisexual women were significantly more likely than heterosexual women to acknowledge sex with men as a risk factor (Price et al. 1996). A UK community survey found that only 43% of lesbians believed that they were at the same risk of cervical cancer as heterosexual women (Fish and Anthony, 2005); perceptions of risk did not appear to influence screening behaviour. In comparison, 60% of lesbians perceived that they were equally at risk in a US study (Price et al. 1996). In a UK clinic sample, the majority
(75%) of lesbians attending perceived their need for cervical screening to be the same as that of heterosexual women (Bailey et al. 2000).

- A sizable proportion of lesbians considered themselves at lower risk of cervical cancer than bisexual or heterosexual women. Sex with men was often cited as a risk factor.

4. Barriers to cervical screening among lesbian and bisexual women

Few studies have specifically investigated lesbian and bisexual women’s experiences of cervical screening; for exceptions, see Fish and Wilkinson, 2000a; 2000b; Hunt and Fish, 2008). This section draws on qualitative research about lesbian and bisexual women’s perceptions of the barriers to cervical screening and the data are used to explain some of the particular differences and to give examples of some of the difficulties encountered. Most of the data extracts (indicated in italics) presented are taken from previously unpublished findings in a UK large scale study (Hunt and Fish, 2008).

4.1 Cervical screening is unnecessary for lesbian and bisexual women

A comparative study of the screening behaviour of lesbians, bisexuals and heterosexuals, found that lesbians were only a third as likely as heterosexual women to be told they were at risk of cervical cancer (Price et al. 1996). There is evidence that lesbians are explicitly told by health care workers that they do not need to be tested; Marrazzo et al. (2001) found that 10% had been told by a health care provider that they did not need to be screened because they were not sexually active with men, these providers were identified as doctors in all but one case. In a recent large-scale UK study (n = 5,909), 20% of lesbian and bisexual women reported that they had been similarly advised (Hunt and Fish, 2008); these findings have been confirmed in other UK studies (SHADY, 1996; Mantle, 1998). This advice may have implications
for their subsequent screening behaviour: women who were advised as being ‘ineligible for screening based on their sexuality’ were less likely to have been screened than women who were not similarly advised (Brown et al. 2003: 130). There is also evidence to suggest that lesbian and bisexual women have been refused cervical screening when they requested a test (Hunt and Fish, 2008). In one US study, a lesbian was refused a smear test on three occasions because of her sexual orientation (Ferris et al. 1996). Furthermore, her need for further examination, based on cervical abnormalities in her sexual partner was initially ignored. This is despite it being common practice in the US (where the study was conducted) to give a colposcopic examination in the female sexual partners of heterosexual men discovered to have a genital HPV related disease. In a small-scale qualitative study, women believed they were not being called for screening because it was known they were lesbians (Mugglestone, 1999).

Lesbian and bisexual women say they are advised that cervical screening is not necessary for them:

> GP’s (and nurses) should be better instructed about the health implications for gay women (in particular with regard to the necessity for gay women to have smear tests). Having been instructed by my GP’s surgery to make an appointment for a smear test (having told them at my registration that I am gay) they then told me that there was no necessity for gay women to have this test done. I had to argue to actually have the test carried out.

Some say that they have been refused cervical screening:

> Doctors and Nurses should be educated to not assume everyone is heterosexual. I was told by a nurse once that I didn’t need a smear as I was gay, even though in my past I had slept with men but didn’t at the time of the smear. She refused to give me a smear saying I didn’t warrant one. I think the terminology they use should be asked in a way
that they do not assume we are all straight. Have been asked on several occasions if my partner uses a condom during sex.

They also report that they were given conflicting advice about the need for screening:

Clarity (is needed) about sexual health risks etc. A GP told me I did not need a smear test as I’ve never had sex with a man? What is the truth?

More specific information. I have been told that I don’t need a smear test if I only sleep with women.

I’d like all the confusion about smear tests cleared up – i.e. should lesbians have them? There seems to be A LOT of confusion about this.

There should be a consistent NHS policy on smear tests for women who have only ever slept with women. If not a policy there needs to be clear information on the risks dependent on your sexuality so that one can make an informed decision.

4.2 Lesbians and bisexual women believe themselves to be low risk

There is some evidence to suggest that women believe they are not susceptible to cervical cancer and other sexually transmitted infections (STIs) simply by virtue of being lesbian (Dolan and Davis, 2003). According to this perception, sex between women is considered safe and is not perceived to be a transmission route for disease. There may be a number of different explanations for such perceptions. During the HIV pandemic of the early 1990s, lesbians were widely considered to be at no risk of HIV and they were removed from the AIDS case-reporting protocol; consequently, they may believe they are not at risk from other STIs (Richardson, 1994).
Few studies have investigated the perceptions of lesbians who have never been screened. Lesbians themselves associate sex with men as a risk factor; in one study this was the most frequent explanation given and specifically mentioned was not having sex with men (Fish and Wilkinson, 2000).

The absence of lesbians in sexual health policy guidelines is potentially another explanation. For example, neither the National Strategy for Sexual Health and HIV (DH, 2001) or the recent update (IAG, 2008) includes reference to lesbian or bisexual women. Henderson et al. (2002) argue that the omission is symbolic of the invisibility of lesbian and bisexual women in sexual health services: it is widely considered that they do not engage in risky sexual behaviour.

A third explanation is the lack of health promotion targeting lesbian and bisexual women. A search of relevant websites revealed few UK resources (Table 8); there are no materials identified in the comprehensive ninth edition of the directory of information produced by Macmillan Cancer Support (MCS, 2008). As a population, they have not been included in screening recommendations or health education messages; thus, they may be ‘highly likely to ignore a general message’ to women or assume that such information only relates to heterosexual women (Phillips-Angeles et al. 2004: 321). In a recent UK survey, lesbians and bisexual women said they were unsure about the risks in sex with women; they expressed a view that, in comparison to gay men and heterosexual women, there was less health promotion material available on which they could make decisions about sexual health. Some said that they had never been given information about their sexual health; information for younger lesbians was considered to be particularly needed (Hunt and Fish, 2008). By contrast, five Australian states have produced health promotion materials targeted to lesbians and bisexual women and these are widely available (Table 8) (Hall et al. 2008).
I’d like a clearer idea on whether as a lesbian I really need a smear test when there is no penetration - I don’t want to become another of my GP’s stats on getting patients tested!

I think lesbians (particularly women who have never slept with men) really need to be educated about cervical cancer and the level of risk and whether they should be having smears with the same frequency

4.3 The screening experiences of lesbians and bisexual women

Cervical screening programmes rely upon a high proportion of women participating in the service; women’s attendance may be influenced by the degree to which they find services acceptable. Sexual minority women’s reduced participation in cervical screening may be partly attributable to their experiences of the smear test. Studies have revealed barriers in lesbian and bisexual women’s access to appropriate and effective health care (Brogan, 1997; White and Dull, 1997; Scherzer, 2000). Healthcare providers are sometimes uncomfortable with providing care to lesbian and bisexual patients and have difficulties in establishing effective communication (Hinchliff et al. 2005). Findings suggest that sexual orientation formed a barrier to discussion about sexual health matters for almost half the GPs in a study. Difficulties related to ignorance of lesbian lifestyles; homophobic attitudes were identified among a minority (Hinchliff et al. 2005).

Healthcare providers may also lack specific knowledge of lesbian and bisexual women’s needs and be unable to provide relevant health information (Hughes and Evans, 2003; McNair, 2003). Studies point to the absence of lesbian, gay, bisexual and transgender health concerns on undergraduate and post-qualifying medical curricula and highlight the need for cultural competence, including sensitive communication and informed values (Hutchinson et al. 2006). Positive experiences of cervical screening were associated with the increased likelihood of re-attendance (Rankow and Tessaro, 1998; Fish and Anthony, 2005). In a UK study, lesbians were more likely to report adverse experiences of screening than were reported in US
studies (44% vs. 26%, Fish and Anthony, 2005; Marrazzo et al. 2001). Heterosexual women were more likely than lesbians to be very satisfied with the care they received from their regular provider (Diamant, Wold et al. 2000).

For a period of almost 10 years my partner had failed to get a successful smear test. She was told that this was her fault as she had not had sex with a man. …..Gay women are sometimes made to feel the problem when health care workers are poorly trained or have little experience - and may miss out vital health care screening because of painful or aggressive treatment in clinics.

I am very reluctant to go back to my ‘family’ GP for a smear test after bad experiences the last time. There needs to be some serious training for ALL NHS staff - this is the only area of my life where I consistently experience problems as a result of my sexuality.

4.4 Disclosure to the healthcare provider

Coming out to a healthcare worker has been a common theme in lesbian health research; questions have included whether non-disclosure is associated with a delay in preventive health behaviour and whether disclosure is facilitated or impeded by the attitudes of staff. Whether or not a lesbian or bisexual woman chooses to come out has consequences for their health. Disclosure is often considered to bring benefits while non-disclosure is said to bring risks. There are, however, benefits and risks in both decisions. The risks of non-disclosure are that health may be negatively affected: lesbians and bisexual women who hide their sexual orientation may be subject to inappropriate questioning, inaccurate diagnoses, irrelevant health information and they may experience anxiety about inadvertently revealing (or avoiding questions about) their sexual identity in the health encounter.

Disclosure on the other hand is seen to be associated with health benefits, lesbians and bisexual women are likely to be more satisfied and comfortable with the care they receive, they experience greater ease in communicating with their doctor and by
disclosing, they allow for the possibility of including their same-sex partner in treatment decisions. But the risks of disclosing can be high. Sexual minorities may be more likely to believe that disclosure would adversely affect their health care rather than improve it: passing as heterosexual provides a safeguard against poor treatment (Beehler, 2001).

A Canadian study investigated factors associated with disclosure; it found that enquiry about sexual orientation and perceived cultural competence of services were more likely to influence lesbians’ willingness to disclose than were patient-related characteristics, such as ‘being out’ (Steele et al. 2005).

In cervical screening, failure to disclose sexual orientation may mean that healthcare workers may assume that the woman is heterosexual and are therefore unable to elicit a relevant sexual history.

Lesbian and bisexual women say that they often had to ‘come out’ to counter heterosexual assumptions and the circumstances in which this occurred were often far from optimal:

*I think nurses should be encouraged to ask more inclusive questions when giving smears. I find it amusing when nurses ask “Do you have sex?” followed by “Do you use contraception” and “Are you pregnant or seeking to become pregnant?” when I give the answers yes, no and no respectively - but then I’m a confident person and am happy to explain that I only have sex with a female partner. Not everyone would feel like this. Once a nurse asked me these questions in the middle of performing the smear - it wasn’t the MOST comfortable moment at which to declare “I’m a lesbian” but I did it anyway. She went very quiet indeed... More seriously, afterwards, I asked her whether penetrative sex with toys was risky re. cervical cancer or whether the risk factor only related to penetration by a penis. She had no idea. That’s not really good enough, is it?*
There is a need for appropriate responses from health care professionals when LB women disclose their sexual orientation:

Sexual orientation should not be a silent taboo, not asked about and if mentioned by us, brushed over by health care staff e.g. whenever I go for a smear I am always being asked a) if I am sexually active b) if I use birth control and when I say not, I get a lecture at which point I have to say I am a lesbian, at which point the nurse changes the subject quickly!!.

4.5 Presumptions of heterosexuality

The NHS Cervical Screening Programme (NHSCSP) sends invitations by post to all women without enquiring about their sexual behaviour: it therefore should be unlikely that lesbians would be refused screening. However, the presumption of heterosexuality means that unless a healthcare professional is explicitly told about a woman’s sexual orientation, the discussion will be framed by these assumptions. Lesbian and bisexual women will also assume that issues raised will relate to heterosexuality. Questions asked during sexual history taking may be problematic for lesbians: ‘when did you last have sexual intercourse?’ Most lesbians would need to consider whether their sexual behaviour was relevant in responding to this question or second-guess what kinds of sexual activity the healthcare worker is referring to: sexual intercourse usually refers to heterosexual sex. Sometimes these questions are inferred; for example, the question ‘what contraception do you use?’ implicitly assumes the woman is heterosexual; lesbians mostly, do not need to control their fertility because sex is not linked to reproduction. Healthcare workers often ask these questions without realising they are doing so; the presumption of heterosexuality makes an association for lesbian and bisexual women between sex with men and cervical screening. This is also subtly communicated in cervical screening information materials where risk factors are identified as ‘women with many sexual partners’, followed by use of a condom as a protective factor (NHSCSP, 2004).
The presumption of heterosexuality is evident in relation to advice offered about contraception:

All cervical smear test workers should ask if you need contraception rather than if you use it, then the emphasis would shift away from the assumption that you’re heterosexual.

The meanings about sexual behaviour for lesbian and bisexual women differ from those for heterosexual women. Healthcare professionals usually understand heterosexual sex by the terms ‘sex’ or ‘sexual activity’:

Cervical smears should take account of lesbians. Having ‘sex’ to the professionals means having sex with men. Having sex with a woman is smiled at - at best.

What kind of sex does it mean!

5. **International screening recommendations**

Tables 6 and 7 present international and national recommendations for lesbian and bisexual women and cervical screening. The findings enable consideration of the inclusion of lesbian and bisexual women in screening guidelines for cervical screening programmes.

6. **International health promotion materials**

Table 8 presents health promotion materials from international sources about lesbian and bisexual women and cervical screening. By gathering information from international sources, it is intended to enable the production of appropriate health promotion materials targeted to lesbians.
7. Conclusion

Despite longstanding, worldwide concern about lesbian and bisexual women’s risk of cervical cancer and uptake of screening (AMA, 1996; MAC GLBTI, 2003), improvements are needed in the quality and consistency of clinical information for healthcare professionals, the extension of good practice in screening interventions and the availability of relevant health promotion materials for lesbian and bisexual women themselves.

This report provides comprehensive evidence drawn from the worldwide literature about the screening behaviours and needs of lesbian and bisexual women. It presents the most robust available data in relation to the transmission of HPV, prevalence of HPV infection and cervical abnormalities, risk factors, uptake rates, screening experiences and risk perceptions.

The report offers a number of explanations for the ‘hard to reach’ status of lesbian and bisexual women’s communities and provides a methodological critique of the research base. Lesbian and bisexual women comprise an invisible population: they are hidden as service users unless they disclose their sexual orientation, they have been unacknowledged in research and their exclusion from statistical data has meant that little is known about their demographic characteristics.

The commissioning of this report is timely: legislative and policy changes have created an environment in which lesbian and bisexual women will increasingly expect equal treatment in public services. The refusal of cervical screening to lesbian and bisexual women formed one of the examples in the DTI consultation document to prohibit discrimination in the provision of goods and services (DTI, 2006).

A major obstacle to change in clinical practice has been the lack of knowledge about the way in which these refusals occur: they may be direct refusals (the notion of eligibility through sex with men); or indirect refusals (through association with
heterosexual sex by questions about contraception) (Fish, 2006). The report has endeavoured to clarify these complexities through qualitative data about lesbian and bisexual women’s lived experiences of screening; in doing so, the report makes a unique contribution to what is known about the screening experiences of sexual minority women.

Finally the report makes a number of recommendations for good practice and to ensure that services meet the screening needs of lesbian and bisexual women.

8. Recommendations

Drawing on the findings of the review of the literature and UK research on lesbian and bisexual women’s screening experiences; this report makes nine recommendations for health policy makers, undergraduate and continuing medical education, for service planning and delivery. The production of targeted health information materials and the clarity of screening guidelines will also be of benefit to lesbian and bisexual women themselves.

8.1. Introduce screening guidelines

The NHSCSP should introduce screening guidelines for lesbian and bisexual women with recommendations for appropriate intervals. Guidelines should offer balanced information: LB women may choose not to attend for screening (as currently suggested on the website); they need to be provided with relevant information to make an informed choice about screening.

This review has identified international and national recommendations and these are included in Tables 6 and 7.
8.2. Target health information for lesbians and bisexual women
Health promotion materials targeting lesbian and bisexual women and specifically addressing their concerns should be made widely available. This review has found international examples of relevant health promotion materials provided by National Cervical Screening programmes of other countries such as Australia and the USA and these are included in Table 8.

8.3. Include LB women’s health in medical education programmes.
The curriculum should include (i) training in lesbian and bisexual women’s needs and risks (e.g. risk of transmission of HPV through lesbian sex) and (ii) training in cultural competence by displaying the attitudes and values to promote health and well being through appropriate communication with LB women, taking sensitive sexual histories and knowledge and understanding of sexual minority women’s health concerns.

8.4. Avoid assumptions of heterosexuality
Healthcare professionals should take steps to facilitate disclosure, to ask questions in ways which do not presume heterosexuality and to understand differences in meanings (e.g. when referring to sexual activity).

8.5. Develop specialist services
Sexual health clinics, such as the Orange Clinic in London (which offers specialist services for lesbian and bisexual women), should be supported to provide relevant and accessible services including cervical screening for lesbians and bisexual women.
8.6. Routinely collect data about service usage
The Health Protection Agency and other government bodies should routinely collect data on lesbian and bisexual women about cervical cancer incidence, stage distribution and mortality in order to provide accurate information about cervical cancer and HPV risk among sexual minority women.

8.7. Monitor satisfaction of LB women as health service users
In line with policy initiatives to promote a patient-led NHS, the views of LB women should be included in the design and delivery of services. There should be clear complaints procedures in the case of adverse experiences.

8.8. Develop a welcoming practice environment
Reception staff should develop cultural competence; GP surgeries and other clinical environments should have written policies on sexual orientation anti-discrimination; clear confidentiality policies; relevant intake forms; posters, brochures and other health promotion materials should be displayed or made available.

8.9. Further research
Further research using mixed methods approaches is needed to further understand the barriers to screening. Studies comprising lesbian, bisexual and heterosexual women recruited using the same sampling techniques would enable comparison in uptake and experiences. It is also important that sexual orientation is included in questions on large-scale studies.
## 9. Glossary of terms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AMA</td>
<td>American Medical Association</td>
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<td>BMA</td>
<td>British Medical Association</td>
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<tr>
<td>CIN</td>
<td>Cervical Intraepithelial Neoplasia (cervical lesions)</td>
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<td>CRUK</td>
<td>Cancer Research UK</td>
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<td>CRS</td>
<td>Cancer Reform Strategy (DH)</td>
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<td>DH</td>
<td>Department of Health</td>
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<td>DTI</td>
<td>Department of Trade and Industry</td>
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<td>GMC</td>
<td>General Medical Council</td>
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<td>HPV</td>
<td>Human Papilloma Virus</td>
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<td>IAG</td>
<td>Independent Advisory Group (for sexual health)</td>
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<td>ILGA</td>
<td>International Lesbian &amp; Gay Association</td>
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<tr>
<td>LB women</td>
<td>Lesbian and bisexual women</td>
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<tr>
<td>LGBT</td>
<td>Lesbian, Gay, Bisexual and Trans</td>
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<tr>
<td>MCS</td>
<td>Macmillan Cancer Support</td>
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<tr>
<td>NCEI</td>
<td>National Cancer Equality Initiative (DH)</td>
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<td>NHSCSP</td>
<td>NHS Cervical Screening Programme</td>
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<td>ONS</td>
<td>Office of National Statistics</td>
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<tr>
<td>SCIE</td>
<td>Social Care Institute for Excellence</td>
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<tr>
<td>WHI</td>
<td>Women’s Health Initiative (large scale study)</td>
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<tr>
<td>WSW</td>
<td>Women who have Sex with Women</td>
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References


**Selected other references consulted**


### Table 6: International recommendations for lesbians and cervical screening

<table>
<thead>
<tr>
<th>Organisation/Country</th>
<th>Recommendations</th>
<th>Targeted Health Promotion Material</th>
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<tbody>
<tr>
<td><strong>USA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American College of Obstetricians and Gynecologists, 2003</td>
<td>Screening of cervical cytology (cervical cells) should begin by approximately 3 years after first sexual intercourse or by age 21, whichever comes first.†</td>
<td>Health information lesbian health*</td>
</tr>
<tr>
<td>American Cancer Society,</td>
<td>All women should begin cervical cancer screening about 3 years after they begin having vaginal intercourse, but no later than when they are 21 years old.†</td>
<td>Cancer facts for lesbians and bisexual women. (see table 8)</td>
</tr>
<tr>
<td>US Department of Health and Human services</td>
<td>Lesbians are less likely to visit a doctor or nurse for routine screenings, such as a Pap, which can prevent or detect cervical cancer. The viruses that cause most cervical cancer can be sexually transmitted between women.</td>
<td><a href="http://www.womenshealth.gov/faq/lesbian-health.cfm#2">http://www.womenshealth.gov/faq/lesbian-health.cfm#2</a></td>
</tr>
<tr>
<td><strong>Canada</strong></td>
<td></td>
<td></td>
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<tr>
<td>British Columbia Cervical Screening Program, Canada. <a href="http://www.bccancer.bc.ca">www.bccancer.bc.ca</a></td>
<td>All women who have ever been sexually active (touching and intercourse) should be regularly screened. HPV is transmitted by sexual contact, not just sexual intercourse.</td>
<td>Manual for health professionals, includes reference to lesbians and cervical screening.</td>
</tr>
<tr>
<td><strong>New Zealand</strong></td>
<td></td>
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<tr>
<td>New Zealand Cancer Society</td>
<td>All women who have ever had sexual intercourse including lesbians should be tested</td>
<td>A guide for women (includes lesbians)</td>
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<tr>
<td><strong>Australia</strong></td>
<td></td>
<td></td>
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<tr>
<td>Australian National Cervical Screening Program,</td>
<td>All women who have ever been sexually active should start having Pap smears between the ages of 18 and 20 years, or one or two years after first having sexual intercourse, whichever is later.</td>
<td>Each of the five Australian states produces health promotion material for lesbians about cervical screening. (see table 8)</td>
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</table>

Key:
† Indicates that the recommendations do not specifically mention lesbian and bisexual women. Targeted health information is available on the website.

*This slide set, including nearly 100 slides on CD ROM, with corresponding lecture notes, glossary, and resource lists, is a training module on the health care issues for lesbian and bisexual women and has been created to disseminate accurate information on lesbian/bisexual health to health care providers. It was developed by the ACOG Committee on Health Care for Underserved Women to support the provision of relevant and effective healthcare.*
### Table 7: National screening recommendations

<p>| UK National Health Service Cancer Screening Programmes | The NHS Cervical Screening Programme invites all women between the ages of 25 and 64 for cervical screening. But if a woman has never been sexually active with a man, then the research evidence shows that her chance of developing cervical cancer is very low indeed. We do not say no risk, only very low risk. In these circumstances, a woman might choose to decline the invitation for cervical screening on this occasion. If a woman is not currently sexually active but has had male partners in the past, then we would recommend that she continues screening. | <a href="http://www.cancerscreening.nhs.uk/cervical/index.html#active">http://www.cancerscreening.nhs.uk/cervical/index.html#active</a> |
| Cancer Research UK | Evidence suggests that transmission of HPV is possible among lesbians and therefore regular cervical testing is required | <a href="http://info.cancerresearchuk.org/images/pdfs/lgbtpolicystatement2008">http://info.cancerresearchuk.org/images/pdfs/lgbtpolicystatement2008</a> |
| Society of Sexual Health Advisers (SSHA) <a href="http://www.ssha.info">www.ssha.info</a> | A number of factors influence the sexual health of WSW. Namely the nature of sexual activities, the number of partners, a history of having sex with men and previous exposure to STI. Traditionally WSW have been perceived as a low risk group and have been largely over-looked in terms of sexually transmitted infections and cervical cytology screening initiatives. | Manual for Sexual Health Advisors (2004). Funding provided by DH. Includes a chapter on lesbians |
| Manchester NHS PCT | There is evidence that lesbians are being misinformed by their GPs or practice nurses - they are told that they do not need a smear test and are being sent away when they ask for one or are routinely called. | Feeling Good, Feeling Sexy. This resource is no longer available. |</p>
<table>
<thead>
<tr>
<th>Organisation and country</th>
<th>Title of material</th>
<th>Available from</th>
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<tbody>
<tr>
<td>Australia</td>
<td></td>
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<tr>
<td>National Cervical</td>
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<td>Screening Program 2008</td>
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<td>Perth, Western Australia.</td>
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<td>for Healthy Communities (not for profit organisation)</td>
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<td>Women’s Health</td>
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<td>National Cervical</td>
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<td>Screening Program 2006</td>
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<td>South Australia</td>
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<td>Victoria, Australia</td>
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<td>Papscreen Victoria</td>
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<tr>
<td>USA</td>
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<tr>
<td>American Cancer Society</td>
<td>Cancer facts for lesbians and bisexual women</td>
<td><a href="http://www.glbthealth.org/documents/LesbianCFBrochures03.pdf">http://www.glbthealth.org/docsu\nte/LesbianCFBrochures03.pdf</a></td>
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<tr>
<td>Canada</td>
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<td>Sherbourne Health centre</td>
<td>Let’s talk about lesbian health (includes smear tests).</td>
<td><a href="http://www.sherbourne.on.ca/PDF%5Cns/Brochletstalkaboutlesbianhealth-06.pdf">http://www.sherbourne.on.ca/PDF\ns/Brochletstalkaboutlesbianhealth-06.pdf</a></td>
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<td>Toronto, Canada</td>
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<td>UK</td>
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<tr>
<td>Department of Health</td>
<td>Sexual health information for women who have sex with women (mainly sexual health</td>
<td><a href="http://www.stonewall.org.uk/docu%5Cnmments/safe_sx_for_women_who%5Cn_have_sx_with_women.pdf">http://www.stonewall.org.uk/docu\nmments/safe_sx_for_women_who\n_have_sx_with_women.pdf</a> (Not available on DH website.)</td>
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<td>rather than cervical screening).</td>
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<td>PCT</td>
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<td>and wellbeing, Edinburgh</td>
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<td>Bolton PCT</td>
<td>When did you last have a smear test? Information for lesbians.</td>
<td><a href="http://86.54.120.198/Library/Leaf%5Cnets/patient/Lesbian%20Smear%20Guide.pdf">http://86.54.120.198/Library/Leaf\nets/patient/Lesbian%20Smear%20Guide.pdf</a></td>
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<tr>
<td>Middlesbrough Community</td>
<td>Have you had yours yet: Information for lesbians and wsw about cervical screening</td>
<td>Lesbian and Bisexual Women’S Network Officer on 01642 803607/01642 249300 or email: <a href="mailto:lesley.duggan@mvdauk.org.uk">lesley.duggan@mvdauk.org.uk</a></td>
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<td>Network</td>
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<td>Foundation Manchester,</td>
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<td>UK</td>
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<td>International Health</td>
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<td>Education Alliance</td>
<td>Learn about cervical cancer</td>
<td><a href="http://ihea.info/multicultural_health_education/files/glb_t_c05-01_cancer_info_0.pdf">http://ihea.info/multicultural_healt\nh_education/files/glb\nt_c05-01_cancer_info_0.pdf</a></td>
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<tr>
<td>International Lesbian</td>
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<tr>
<td>and Gay Association</td>
<td>For all women who love women: Are you at higher risk of developing breast or cervi\ncal cancer?</td>
<td><a href="http://www.ilga.org/news-upload/BreastBrochureENFinal.pdf">http://www.ilga.org/news-up\nload/BreastBrochureENFinal.pdf</a></td>
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