

Summary report: Lesbian and bisexual women's experience of health care with an emphasis on cervical screening.

Introduction

This study began as an evaluation of work that was done in 2008/2009 to increase uptake of cervical screening by lesbians and bisexual (LB) women, but was extended to ask about experience of healthcare in general. Responses to an online survey were collected, with paper copies also available. The responses give an overview of the current picture regarding what happens to lesbians and bisexual women when they approach health professionals. Many women find staff accepting of their sexual preference but there is still some evidence of negative attitudes.

A longer report is available from lesley.hedges@btinternet.com

Background

The original work which is the subject of this evaluation was initiated following a health needs assessment of lesbian, gay and bisexual men and women's health in Bradford and District¹ which showed that lesbian and bisexual women attend for cervical screening (then known as 'smear' tests) less frequently than heterosexual women. 71.9% reported that they had had recent cervical smears. 14% had been refused a test or had been advised that they did not need one. A further survey in 2009² showed a lower proportion of LB women were having cervical screening, 59%, but only 6% had been refused screening at this time. The overall target for cervical screening for GP practices is 80% and the NHS screening programme's report for 2012 shows that 78.6% of eligible women were screened³.

The work included training for staff who delivered the screening; a leaflet for lesbian and bisexual women⁴; a leaflet for staff⁵ and publicity work including a stall and a speaker at Bradford Gay Pride. This was informed by focus group interviews with lesbians and bisexual women. Local media coverage was also used and an A5 flyer and A4 poster produced. The work was reported in Carter et al⁶.

A review by Julie Fish has now conclusively shown that lesbians are at risk of acquiring HPV (human papilloma virus) which can lead to pre-cancerous changes in the cells of the cervix, but

¹ Williams S. (2007) *Bradford and District LGB Health Needs Assessment* Equity Partnership: Bradford

² McCreddie, S., (2010) *The Challenge for Change: Health needs of lesbian, gay and bisexual people in Bradford and District* Equity Partnership: Bradford

³ NHS Cervical Screening Programme (2012) NHS Cervical Screening Programme 2012 Annual Review <http://www.cancerscreening.nhs.uk/cervical/publications/2012review.html>

⁴ Equity Partnership (2009) *Cervical screening for women who have sex with women* <http://www.equitypartnership.org.uk/resource-library/attachment/cervical-screening-for-women-who-have-sex-with-women-leaflet-for-communities/>

⁵ Equity Partnership (2010) *Cervical screening for women who have sex with women* Leaflet for health professionals <http://www.equitypartnership.org.uk/wp-content/uploads/2010/08/cervical-screening-for-women-who-have-sex-with-women-Leaflet-for-health-professionals.pdf>

⁶ Carter, L., Hedges, L., Congdon, S. (2012) *Using diversity interventions to Increase cervical screening of lesbian and bisexual women* Journal of Psychological Issues in Organisational Culture Volume 3 Number 2: 59-70

that they are less likely to attend when invited for cervical screening. She also found that some risk factors for changes in cervical cells which could lead to cancer, such as smoking, have been shown to be higher among lesbian women⁷.

There have been reports from many countries, now across several decades, indicating that lesbians and bisexual women, along with gay and bisexual men and trans people, receive poorer health care than the general population. Previous researchers ascribe this to the lasting effects of previous misconceptions about sexual minorities and the paucity of training in health issues important to these groups^{8,9}.

Method

The survey took the form of an online questionnaire, with paper copies available at events and venues likely to be attended by lesbian and bisexual women. This was intended to provide quantitative data to enhance the findings of the previous qualitative work.

The respondents

36 lesbians and bisexual women responded to the questionnaire and were included in the analysis. 24 were from Bradford and Airedale and a further 4 from elsewhere in West Yorkshire. 2 were from further afield and 6 did not give a postcode.

32 lesbians responded to the questionnaire, 88.9% of those who were eligible (the other 3 were male or heterosexual), and 4 bisexual women, that is, 11.2%. As the number of bisexual women was so small the responses have been aggregated. Most of the respondents were white with only two of those not being from the UK, and one was white and black Caribbean. Their ages ranged from teens to mid-60s with an average age of 43. The highest proportion were in their 40's, with most of the others in their 50's and 30's.

There were no results for trans people. We had included an open question for trans men as they might still need cervical screening but there were no answers to this question.

Experience of Health Care

The responses showed a mixed experience of health care, both between women and sometimes reported by the same person (see figure 1). A slight majority of women, 57.6%, said that they had found health care staff accepting of them as a lesbian (see figure 1). However a third, 11 of the 33 who responded to the question, said that they avoid telling health care

⁷ Fish, J. (2009). *Screening in lesbians and bisexual women: A review of the worldwide literature using systematic methods*. Leicester, UK: De Montfort University. Retrieved from www.cancerscreening.nhs.uk/cervical/publications/screening-lesbians-bisexual-women.pdf

⁸ Bjorkman, M. and Maltrud, K. (2009) *Lesbian women's experience with Healthcare: A qualitative study* Scandinavian Journal of Primary Healthcare 2009 27:238-243

⁹ Cochran S D and Mays V (2007) *Physical health complaints among lesbians, gay men and bisexual and homosexually experienced heterosexual individuals: Results from the California Quality of Life Survey* American Journal of Public Health (2007) November 97(11) 2048 - 2055

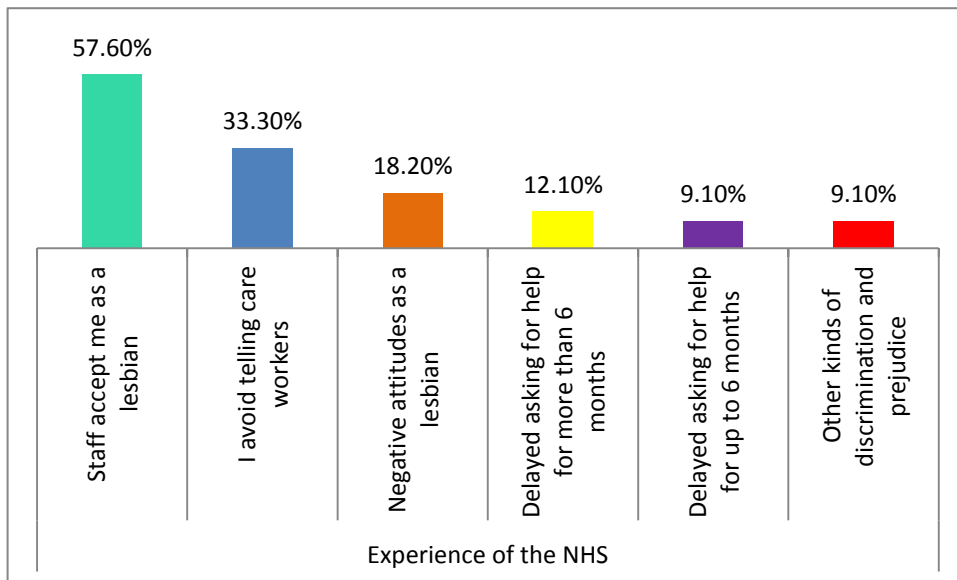
professionals that they have relationships with women. Three of the four bisexuals said that they avoid telling health workers that they have relationships with women.

Two of the women in the present study said that health professionals actually make it harder for them to be open about their sexuality by assuming that they were heterosexual.

One described her mixed experience and put in a nutshell how many respondents appear to feel about their treatment.

“My experience is mixed. I have been treated by some great health care professionals, I have also experienced workers who appear to be less comfortable with my sexuality and professionals who always make the assumption that you are heterosexual.”

Figure 1: Experience of the NHS in general



NB The totals add up to more than 100% because women were invited to give more than one answer if they wished.

18.2% said that they had experienced negative attitudes towards them as lesbians. It was worrying that 19.4% said that they had delayed asking for help with health problems, 11.1% for up to 6 months and 13.9% for more than 6 months. No bisexuals answered the questions about acceptance or negative attitudes towards bisexuals.

One of the respondents reported that she had not experienced overt homophobia, but said,

"I have not experienced aggressive homophobia but rather a passive form e.g. calling my girlfriend "mother", telling me that I don't need to tell them that I am a lesbian."

Just over half, 56.3%, said that they would tell a health or social care worker of their sexual orientation, with another third, 34.4%, saying that it depended on the circumstances, saying that they would tell the worker if there was a good reason to; if they had a trusting relationship with them; that it depended on the attitude of the person asking; and whether it was in the right

setting, such as not in an open ward. One said that for her this was not about fear of discrimination, but of privacy.

Nearly two fifths said that they thought that the NHS had become more accepting of lesbians and bisexual women over the last 3 years with one fifth saying it had not. It was clear from the comments added, though, that four thought it had always been good or had changed earlier than 3 years ago, with one saying that it has changed over the last 10 years and is now 'generally very good'. The other two fifths said that they didn't know. Experience obviously varied as one said that heterosexuality was assumed and another said

"I feel that it is no longer assumed by all professionals that you are heterosexual, though this is still not uncommon. I feel that professionals are more open to diversity and have perhaps had more diversity training."

One said there is now a better understanding of what a civil partnership is.

There was, however, a report of a bad experience with a doctor being rude and dismissive and 'bemused' by her partner being female. She was told by another member of staff that that was what he was like.

When asked what attitudes they anticipated, 71% said that they thought that health care staff would have the same attitudes as they would towards anyone who is not lesbian or bisexual.

One woman made a comment that shows how complex the interaction can be.

"Sometimes professionals make you feel uncomfortable about disclosure of your sexual orientation, it makes them less sure of you, they feel less sure of what is the 'right' way to respond, this can lead to you feeling less confident and worrying that you will not receive an equitable service."

One woman mentioned that it makes staff feel uncomfortable rather than having outright prejudice and another seemed to think that they try too hard and therefore fail "often they are so PC they are offensive and get it wrong".

It seems a shame that some health workers are trying hard, if her interpretation is correct, in that they are attempting to find the 'right' way to respond, but are not confident enough to be more relaxed about it.

Two mentioned culture and/or religion, one saying that lack of acceptance can be due to "prejudice that is grounded in religious doctrine".

There was also a detailed response about the fertility clinic. This criticised the service for the way lesbians are treated when undergoing fertility treatment. Aspects of the service which they found difficult were the need to justify the desire to have a child; having to explain how the lack of an obvious father figure will be compensated; references to Mr and Mrs and 'husband' in standard letters and records; 'scathing looks' from other couples: the attitudes of staff when they applied for PCT funding; and only one of a lesbian couple being allowed funding.

These comments were similar to those made at the time of the two health needs assessments carried out in Bradford and Airedale. In the first a comment was that the service is 'set up for

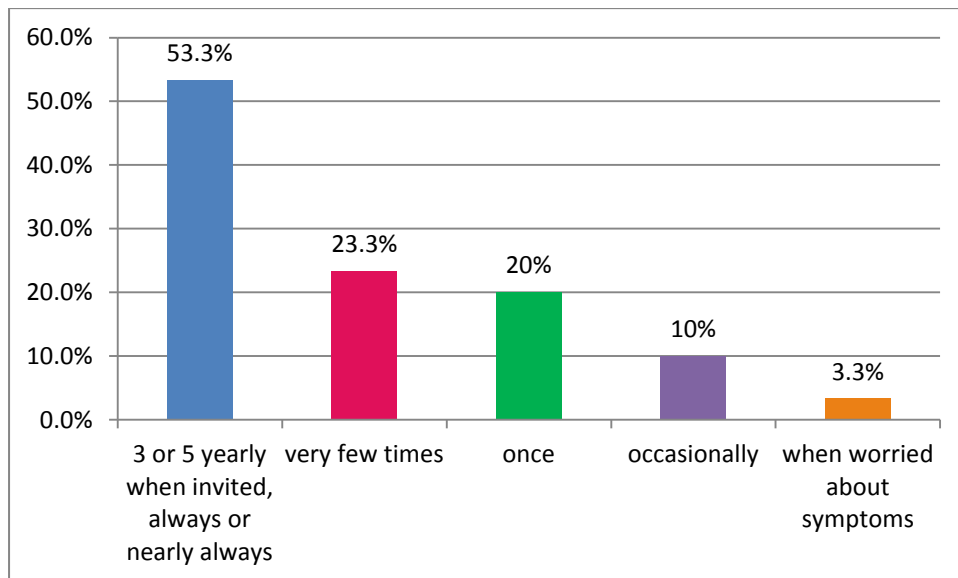
heterosexuality'. Some lesbians had been refused treatment, while others had misled the service providers about their sexual orientation, saying they were single.

Cervical Screening

The responses to questions on cervical screening show that there is more work to be done if lesbians and bisexual women are to be persuaded to attend for testing.

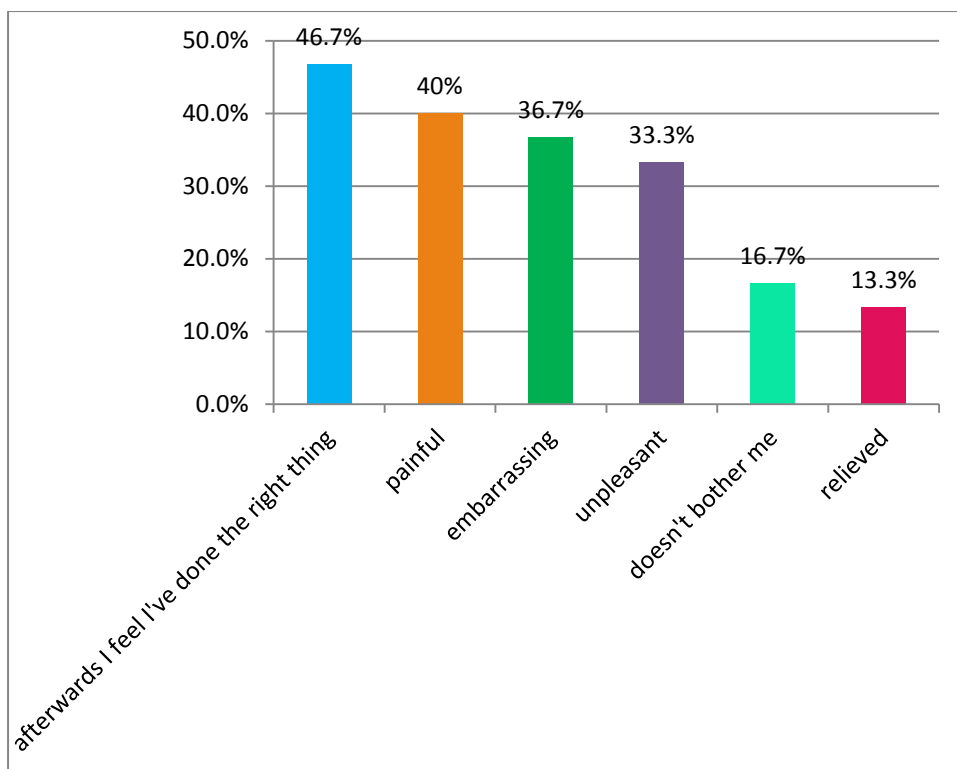
Only 53.3% said that they had a cervical screening test nearly always or always when invited, with a further woman saying that she has a test every year for health reasons. 93.3% said that they had had a smear test at some time with just 2 (6.1%) having never had one, but they were below the age when they would have been invited to have a test (now 25 in the UK), so in fact all the women who would have been invited had attended at least once. Worryingly, six had only been once and another third only occasionally or very few times.

Figure 2: Did women attend for cervical screening ?



Women were also asked about their experiences of being tested. Only 5 (16.7%) said that the test 'didn't bother' them, though 4 said they felt relieved when they went and 14 (46.7%) said that they felt afterwards that they had done the right thing. A third found it unpleasant, a few more embarrassing and 40% said it is painful.

Figure 3: Experiences of the screening test



Some gave reasons for not attending. It seems that some attend once but find the experience so negative that they will not go again.

“I won't go because it is so painful and health professionals don't seem to understand that if you are a woman who doesn't have penetrative sex it is not only hugely intrusive but very painful.” She knew she should have a test but hadn't been for 7 years. Other women gave similar answers.

One woman said that she found the test had become more painful as she grew older. A report on the BBC's Women's Hour in May gave examples of similar experiences¹⁰. This could explain why the proportion of women who attend for tests falls as women reach the later years of being invited.

They were asked whether the person performing the screening helped in various ways. The majority, nearly three quarters, said that the health worker explained what would happen during the test but only just over half said that they put them at their ease and less than half said the worker explained why the test was necessary. One said that their fears were dismissed and one said the staff member seemed embarrassed.

Most (93.3%) had their test at a GP practice, 2 at a sexual health clinic (CASH), one at the Trinity Centre (GUM) and 2 at women's health clinics (one in London).

They were asked whether they had been told that they did not need a test. Two thirds said they had never been told this, but 3 had been told by a health professional, 5 by friends and 6 by

¹⁰ BBC Women's Hour (2013) *Falling numbers of women having cervical cancer screening* Broadcast 11th June 2013: accessed 24th June 2013 on www.bbc.co.uk/programmes/p01b887r

others, which included 1 by practice staff. Although most women knew that they needed a test, some had been told they were at lower risk, and some had received or were aware of the existence of, 'mixed messages'. A few gave more information on this.

“Not necessarily that I don't need one, but they have explored prevalence and risk with me. A reasonable exploration of risk, but with the advice erring towards better safe than sorry.”

Others had thought they were at lower risk.

Evaluation of earlier work in Bradford and Airedale

They were asked where they had found information about cervical screening, whether these sources were specific to lesbians, whether they were local, and whether they were influenced by them. 63.3% said they had seen a leaflet intended for all women. Only 16.7% had seen any leaflet produced specifically for lesbians and bisexual women and another one had seen a poster. 30% said they had seen no leaflets or posters or other materials.

60% of those who had seen a leaflet, said they had seen the one produced by the NHS. Only 4 said they had seen one from Bradford or from an LGB organisation, 2 from each, and they were not the same people, so it can reasonably be presumed that they had seen the one produced as part of the earlier intervention.

One said she had seen the leaflet produced by Equity and thought it was good and was on open display at her GP practice, that she was “very pleased to see.”

The others who had seen a leaflet, and one a poster as well, for women who have sex with women had seen them in Bradford, apart from one who could not remember.

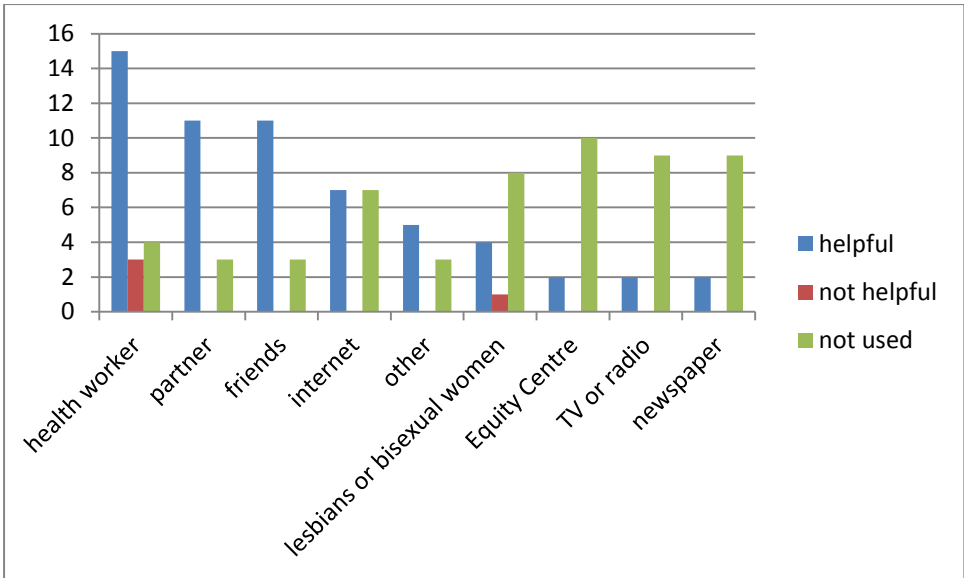
Those who had seen a leaflet or poster, 21 women altogether, were asked whether it had influenced their decision. Of the 5 women who had seen a specific leaflet for lesbians and bisexual women, 3 were planning to have the test anyway and one said it made no difference. The fifth said that it encouraged her to go and gave her enough information to make a decision. One of them also said that it helped to reassure her and said that it convinced her that lesbians and bisexual women do need a test. Another said 'I felt that I had enough information myself already, but I thought it would be very valuable for many lesbians and bisexual women'.

Of the 17 women who had seen a general NHS leaflet, only 4 said that they had been encouraged to have a test and that it gave them enough information to make a decision. Most said they were planning to have a test anyway or that it made no difference. On the negative side, one said that the general leaflet had led to her feeling 'guilty/cowardly that I hadn't had a test for some time, but didn't make me go and get one done'.

This leaves a question over what more can be done to encourage women to have a test, though it needs to be accepted that some women, however much knowledge they have, and however comfortable the test can be made, will decide not to have screening.

We also asked where they found most information about the test and whether it was helpful or not.

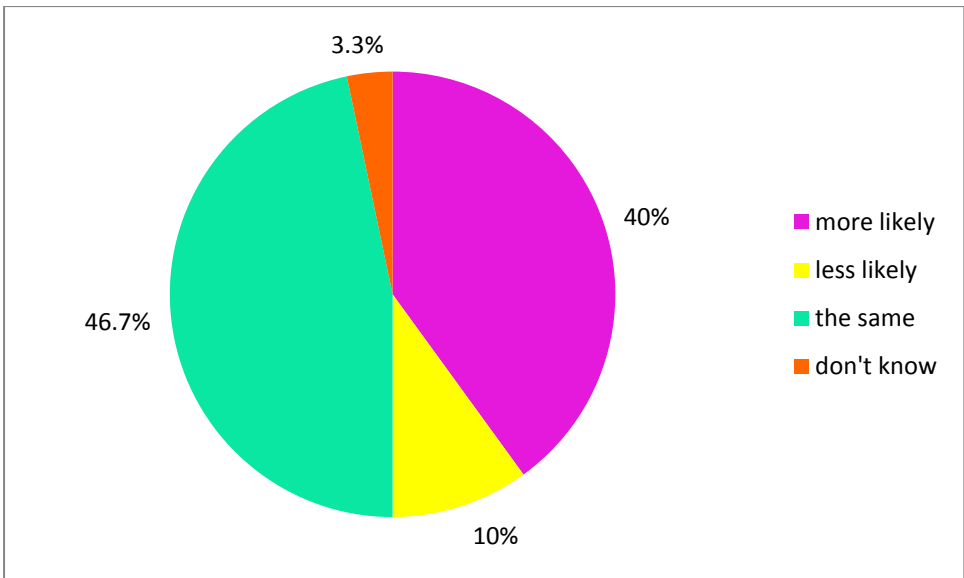
Figure 4: Sources of information



The source most found helpful was health workers though they were also listed (much less frequently) as not helpful. Partners, friends and the internet were also stated to be helpful in supplying information.

They were asked whether they were more or less likely to have a test now than they were 3 years ago. Most said the same, or more likely but some said less likely and a few gave reasons for this. Of those saying more likely, one said she had had breast cancer and so was more aware of the need for screening, and one said she felt more at risk following self-insemination. Also one said she was more at risk now she is older (she is in her early 40s). Of those who said 'less likely' the only explanation was 'It gets increasingly painful so I have stopped doing it'.

Figure 5: Likelihood of attendance for further tests



When asked what help they would like from their GP or from the clinic or hospital nearly one in five (78.6%) said that they would like staff to be trained in lesbian and bisexual health issues,

more than two thirds (67.9%) said they would like leaflets and other information specific to lesbians and bisexual women. Nearly two fifths said they would like clinics and other services provided specifically for lesbians and bisexual women and nearly a third (32.1%) would like lesbian and bisexual doctors and other staff.

Conclusion

Although the proportion of lesbian and bisexual women who attend for cervical screening is increasing, it is still unclear what is influencing this. Only a few of the respondents recalled seeing a leaflet or poster produced in Bradford and Airedale, although few recalled seeing any leaflet and these are sent out with the letter inviting them to a test.

While there is some evidence of improvements in healthcare some women reported apparent discomfort with their sexual preference from health staff. Very few had been on the receiving end of outright homophobia. However the effect of this treatment may have a more wide-reaching impact on lesbians and bisexual women. A bad experience is likely to be shared with friends.

Training for staff is clearly important. It appears that some staff are trying to approach lesbians and bisexual women sensitively and they could be supported with practical ways of doing this. Some specific needs that arose in the study could be met quickly within the existing screening programme. For women who wholly or mostly have sexual relationships with women, it appears that a smaller speculum may be less painful. This also appears to be particularly true for older women. These changes should not be overly difficult or costly.

Recommendations

- 1 All equality and diversity training should include information about the needs of lesbians and bisexual women.
- 2 Staff should be provided with practical skills in sensitive questioning and taking patient histories, in a way that supports them to develop confidence in approaching LGBT people.
- 3 Further training and information is needed for staff who administer the cervical screening programme. 6% of women who have sex with women are still hearing the false message that they do not need cervical screening, or that their risk is lower. If this has been heard in the past and is still believed, there is a need for more work to raise awareness of the facts among LB women, and possibly among staff.
- 4 Specific literature and other publicity material should be produced and/or purchased and made available in LGBT venues as well as outlets used by the general public.
- 5 Health and wellbeing strategies should make specific mention of the needs of lesbians and bisexual women.
- 6 Further health needs assessment should be conducted at regular intervals to monitor progress.
- 7 Practical steps to make the test more comfortable for all women would benefit LB women. This includes the acknowledgement that some women do find it painful and use of a smaller speculum.

8 Staff who administer the test should listen to women's concerns, experiences and suggestions.