ARE YOU READY FOR YOUR SCREEN TEST?

Lesbian, Gay and Bisexual Women in the North West:  
A Multi-Method Action Research Study of Cervical Screening Attitudes, Experiences and Uptake

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Executive Summary

The NHS Cervical Screening Programme is committed to reducing health inequalities for lesbian, gay and bisexual (LGB) women within cervical screening programmes, and has funded this project and research study in response to changes in NHS guidance regarding cervical screening in 2009.

This demonstration project, delivered by The Lesbian & Gay Foundation (LGF) in partnership with The University of Salford, builds on the findings of a comprehensive systematic review (Fish, 2009), which exposed the gaps in the current evidence base regarding cervical screening uptake and accessibility for LGB women, and evaluates methods to increase awareness and enhance participation in cervical screening programmes.

Women aged between 25-64 years are invited for regular cervical screening under a national Cervical Screening Programme. Current policy in England offers screening every three years for women aged 25-49 and every five years for those aged 50-64, although women outside such age ranges may be invited to be screened should a need be identified. Screening detects abnormalities within the cervix that if left untreated could develop into cancer.

The incidence of cervical cancer varies according to the area in which women reside, with higher than the national average rates being detected amongst women from more deprived areas. For example prevalence in the East and South of England has been found to be considerably lower for women compared to those living the North and the Midlands. Indeed, women living in less affluent areas (such as the North West) are not only at higher risk of developing cervical cancer but are more likely to die from the disease compared to women living in more affluent areas of England.

Despite new guidance regarding the need for LGB women to have regular cervical screening tests, there are still elements of confusion and contradiction.

“The incidence of cervical cancer varies according to the area in which women reside, with higher than the national average rates being detected amongst women in the more deprived areas.”

Barriers to accessing appropriate screening for LGB women have been exposed and confirmed across studies including: a reluctance to disclose sexual orientation to health care workers; fear of discrimination; and negative experiences of heterosexism through heteronormative questioning or assumptions of sexual orientation.

This project aimed to target LGB women who are less likely to access routine cervical screening than the general population of women, indicating the need to target specific health messages for LGB women specifically in order to ensure improved physical health and cancer outcomes in the longer term.

The project consisted of an awareness raising campaign, with research conducted both before and following the campaign, in order to better understand the experiences and behaviours of LGB women, and in order to measure the success of the campaign itself.
The number of women who had accessed cervical screening within the NHS recommended timescales (within three years for women aged 25-49, and within 5 years for women aged 50-64) was measured in both surveys. In survey one, this was 49%, and in survey two, this was 73%.

The percentage of women of an eligible screening age who accessed cervical screening within the past five years was 70.5% in survey one. In survey two this was 79%, which is significantly more in line with national NHS data which notes that 78.9% of the general population have been for a test within the past 5 years.

* It is notable that the post-campaign figure stood at 73%. Furthermore, if we adjust this figure to acknowledge the effect of the campaign (by treating those who went for a test because of the campaign as non-attendees rather than attendees) then the percentage of LGB women who had screened within the NHS timescales, had the campaign not occurred, would have been 51%, as opposed to 73%. This indicates the potential impact the campaign has had on screening uptake.

* Again, notably, if we adjust this survey two figure to acknowledge the effect of the campaign (by treating those who went for a test because of the campaign as non-attendees rather than attendees) then the percentage of LGB women who have accessed screened within the past 5 years, had the campaign not occurred, would have been 57%, as opposed to 79%. This similarly indicates the potential impact the campaign has had on screening uptake.

N.B. It is important to acknowledge that the pre and post samples of LGB women were opportunistic, rather than ideally controlled matched samples, which was impossible given the hidden and anonymous nature of the target population. Thus, although the campaign is reported by LGB women to have made a difference to their behaviour in survey two, we cannot compare this result with those figures regarding cervical screening uptake in survey one, although there is clear evidence that the campaign has influenced behaviour.
Cervical screening of women began in the UK in the 1960s. Since then, some lesbian, gay and bisexual women accessing screening have experienced homophobia, assumptions that they are heterosexual, inappropriate treatment and, most damaging of all, misinformation about their health when it comes to cervical screening.

As we move forward in the 21st century the needs of LGB women are starting to be examined and understood. In 2009 the NHS changed their guidance regarding cervical screening due to evidence being established that all women (with a cervix who are aged between 25 and 64) need regular cervical screening regardless of their sexual orientation or sexual history.

The Human Papilloma Virus (HPV), which causes cervical cancer, can be passed on during sexual activity between two women. The Lesbian & Gay Foundation and The University of Salford received funding in August 2010 from the NHS Cervical Screening Programme to deliver a 12 month project in three parts:

**PART ONE**

**INITIAL RESEARCH (SURVEY ONE)**

A baseline survey formed the first exploratory stage of the research. Survey one was conducted prior to the awareness raising campaign, and included exploring screening behaviour prior
to the project, along with capturing LGB women’s experiences and knowledge of screening.

Focus group interviews were used to situate the survey findings and generate a deeper understanding of individual and group experiences. In addition, LGB women were asked how the LGF could best provide information to the community. Strategies identified were then taken forward into the intervention action phase.

**PART TWO**

**AWARENESS RAISING CAMPAIGN**

The awareness raising campaign built on the work of NHS Cancer Screening Programmes and the recommendations from the systematic review by Fish (2009), in order to increase the awareness, confidence, knowledge and health-seeking behaviour of LGB women regarding cervical screening through targeted health information. The campaign centred around the theme of Hollywood movies to tie-in with the idea of ‘going for a screen test’. The campaign utilised a mixed method approach in order to target as many women as possible. Combined initiatives were implemented including:

- Campaign launch events
- Poster and postcard campaigns
- In-depth information booklet
- Print and online advertising
- Print and online editorial
- Viral videos
- Interactive web game
- Social media (Facebook, Twitter, YouTube)
- Radio adverts & interviews
- One-to-one targeted outreach work

Within the staff team of The Lesbian & Gay Foundation, the ‘Women’s Leadership Group’ (which develops the Women’s Programme work) provided specific organisational intelligence and advice regarding the LGB community and were used as a reference group for the campaign materials and implementation strategy.

**PART THREE POST-INTERVENTION EVALUATION (SURVEY TWO)**

A second survey was conducted after the awareness-raising campaign gathering information on LGB women’s screening behaviour, any changes in behaviour following the campaign, along with questions about the campaign, and the success of interventions used. The survey was grounded on survey one data and baseline findings. It is envisaged that the recommendations of this project will lead to greater understanding and further targeted work in this area.

For the full academic report, contact: women@lgf.org.uk or visit http://usir.salford.ac.uk/id/eprint/16596
The Lesbian & Gay Foundation’s knowledge of the lesbian, gay and bisexual (LGB) women’s community, along with nationally significant research and NHS changes in guidance, indicated a clear and pressing need to increase awareness of and participation in cervical screening within the LGB women’s community.

Research indicates that LGB women were up to 10 times less likely than heterosexual women to have had a test in the past three years (Fish 2009).

Further research has found that:

- Of those LGB women who have never been tested, one in five have been told by a health professional that they are not at risk.
- One in fifty LGB women have been refused a test, despite requesting one.
- One in five LGB women who have not attended a cervical screening test do not think that they are at risk of cervical cancer. This belief is not exclusively held by women who have never had sex with a man, as one in ten LGB women who have had sex with a man in the last 5 years have not attended a cervical screening test (Hunt & Fish 2008).

“The there is much evidence that LGB women are refused cervical screening, advised that it is not necessary, or are given inaccurate advice on the basis of their sexual orientation.”

The above research, along with other qualitative evidence the LGF has collected through engagement with LGB women, has indicated that there are several barriers to attending for cervical screening experienced by LGB women. These include:

**General Myths and Lack of Knowledge within the LGB Women’s Community about Risk Levels**

Research has found that lesbians often believe their risk of cervical cancer is lower than that of a heterosexual woman. Sex with men is often cited as a risk factor by health professionals, which could explain the non-attendance of LGB women who have never had sexual intercourse with a man, or who choose to put
emphasis on current rather than past sexual activity.

This myth is then perpetuated within the community, with inaccurate advice being passed from one generation of LGB women to the next.

A clearer awareness of the transmission routes of HPV is needed so that women are encouraged to accept their screening invitations.

LACK OF AWARENESS HELD BY HEALTH PROFESSIONALS ABOUT THE NEED TO SCREEN LGB WOMEN
Many LGB women have been refused cervical screening tests, advised that it is not necessary, or are given inaccurate advice on the basis of their sexual orientation.

Again, this may be due to the perception that HPV can only be transmitted through heterosexual sex, despite research showing it can be transmitted through same sex sexual activity.

HETEROSEXIST ATTITUDES OF HEALTH PROFESSIONALS
The types of questions asked by health professionals prior to a screening test are often not relevant to LGB women’s sexual orientation. Many of the questions asked assume heterosexuality, or indeed assume that women identifying as lesbians never have sex with men.

Such questioning does not take into account the diversity of those attending for screening.

“ A CLEARER AWARENESS OF THE TRANSMISSION ROUTES OF HPV IS NEEDED SO THAT WOMEN ARE ENCOURAGED TO ACCEPT THEIR SCREENING INVITATIONS.”

RELUCTANCE TO ‘COME OUT’, OR FEAR OF BEING FORCED TO ‘COME OUT’
Women may be deterred from attending for fear that their sexual orientation may be asked (more often than not inadvertently, through heteronormative questioning, as above). Whilst coming out to health professionals can often be a positive and empowering thing, it also poses a risk for many LGB women, through either actual or perceived homophobia.

PREVIOUS NEGATIVE EXPERIENCES OF HEALTHCARE
Many women have reported receiving hostile reactions or discriminatory practice when disclosing sexual orientation, resulting in disengagement from the health care system.
In a 2007 review, 1 in 5 health care professionals admitted to being homophobic (HMSO 2007).

All of the above elements not only impact negatively on patient experience and patient choice, but they also deter women from accessing routine and necessary cervical screening due to lack of awareness, or for fear of the ignorance and discrimination they may encounter.

Sexual orientation is not routinely monitored within the NHS, so it is impossible to know exact screening uptake within the LGB community, or the diagnosis rates of these women.

What we do know is that LGB women, including those who have not had sexual intercourse with a man, have been diagnosed with cervical abnormalities or cancer (Bailey, 2000).

This, along with the knowledge that HPV can be transmitted through non-heterosexual sex, indicates that sexual orientation should not be an indicator of screening eligibility. The NHS Cervical Screening Programme stated: ‘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’ (Fish 2009).

This specific risk is significantly more prevalent within the LGB women’s community as they are statistically less likely to attend screening.

Whilst an NHS information sheet was produced to reflect the new guidance and clarify the need for LGB women to attend screening, there were still elements of confusion and contradiction in practice.

This information can be difficult to relay to women who are often ‘hard to reach’ and are likely to have alienated and disengaged themselves from the healthcare system due to their invisibility within it, so it was important for more targeted work to be done with this community.

The NHS Constitution states ‘You have the right
to access NHS services. You will not be refused access on unreasonable grounds' and 'You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age'.

This policy is not being put into practice by many health care providers and professionals, resulting in LGB women not receiving the access they are constitutionally entitled to.

Misleading information, lack of knowledge, and myths surrounding this subject means that many LGB women are not receiving equal access to cervical screening — something that they are legally entitled to under the Equality Act 2010 and the NHS Constitution, and something that could significantly reduce their risk of cervical cancer and prevent devastating consequences on their health through early detection.

The aim of our project was to address these issues, ensuring greater equality of outcomes for LGB women.
AIMS AND OBJECTIVES

The overall project aim was to encourage greater equality of outcomes for LGB women, through increased uptake of cervical screening.

Five key project objectives were identified:

- Increase awareness within the LGB women's community about cervical cancer and the need to attend screening
- Increase LGB women's confidence in dealing with barriers to accessing screening
- Increase knowledge about LGB women's rights to access screening
- Develop a mixed-mode approach to intervention which takes account of the diversity of LGB women
- Develop solid evaluation mechanisms for interventions made to provide an evidence base for future action

Further to this, the primary research aim of the project was to generate an evidence base of LGB women's health behaviour and their attitudes towards and experiences of cervical screening, along with examining the influence of a multifaceted campaign to increase women's awareness, uptake and participation in cervical screening. The secondary aim was to analyse the effectiveness of interventions to provide an evidence base for the future.

The fundamental research purpose of this project was to provide insights that will inform future interventions and developments in this field.

METHOD

An initial survey of LGB women was undertaken in conjunction with focused group interviews to examine the attitudes and experiences of LGB women with respect to cervical screening, and to gather a deeper understanding as to the barriers LGB women can experience accessing screening.

An awareness raising campaign was then launched and a range of interventions were implemented to encourage greater awareness and screening uptake.

A second stage of research took place to measure the impact of the intensive campaign to influence LGB women's awareness and participation in cervical screening programmes.

"SURVEYS OF LGB WOMEN WERE UNDERTAKEN IN CONJUNCTION WITH FOCUSED GROUP INTERVIEWS TO EXAMINE THE ATTITUDES AND EXPERIENCES OF LGB WOMEN..."
IN SUPPORT

“We have been delighted to work with The Lesbian & Gay Foundation in Manchester and the University of Salford on a pilot programme of campaigning and information giving to see how this change of policy could be turned into real life action…I thank all those involved for their efforts and enthusiasm and commend this report to you.”

PROFESSOR JULIETTA PATNICK CBE
DIRECTOR
NHS CERVICAL SCREENING PROGRAMME

“Educating women about the importance of attending cervical screening to help to reduce their risk of cervical cancer is vitally important. Sadly we hear too often of women who have been diagnosed with cervical cancer because they didn’t attend screening, often due to ignorance and misinformation. The Lesbian & Gay Foundation are to be congratulated for their innovative ‘Are you ready for Screen Test?’ campaign. It is very well targeted, fun, relevant and provides that key message that all women should attend cervical screening regardless of sexual orientation. Quite simply by not attending screening they could be putting their life at risk”

ROBERT MUSIC
DIRECTOR
JO’S CERVICAL CANCER TRUST

“The Eve Appeal congratulates The Lesbian & Gay Foundation on their ‘Are You Ready For Your Screen Test?’ campaign. The information on the website is extremely comprehensive and helps to dispel the rumour that lesbian and bisexual women do not need to attend cervical screening. It is vitally important for all women to attend regular screening tests when invited which are estimated to save over 4,000 women’s lives each year in the UK.”

THE EVE APPEAL
In order to bust myths, raise awareness and increase the confidence in lesbian, gay and bisexual (LGB) women about their need and right to access cervical screening tests, we developed an awareness raising campaign centred around the theme of Hollywood movies, to tie in with the idea of ‘going for a screen test’. The campaign utilised a mixed method approach in order to target as many women as possible.

Campaign interventions included:
- Campaign launch events
- Poster and postcard campaigns
- In-depth information booklet
- Print and online advertising
- Print and online editorial
- Viral videos
- Interactive web game
- Social media (Facebook, Twitter, YouTube)
- Radio adverts & interviews
- One-to-one targeted outreach work

The campaign was developed during focused group sessions with members of the LGB community to ensure relevance and appropriateness, and in line with the action research methodology.

The campaign ran from October 2010 to June 2011 and was launched in October 2010 with three events in Manchester, Liverpool and Blackpool. During the launch events participants took part in a quiz and specifically designed board game (both of which contained relevant information regarding cervical screening) and were given information resources and promotional campaign items.

There were campaign experts on hand to utilise opportunities for one-to-one interventions and answer any questions attendees had. The event venues were dressed with posters and postcards advertising the campaign.

Following the launch events, the campaign was regularly promoted via print and online articles and adverts in outnorthwest (the North
West’s only free dedicated LGB community magazine) and other LGB press such as Diva, g3, Lebilicious, Gingerbeer, Pink Sofa and Pink News along with various other local press and media. Press releases and campaign updates were also send to health professionals, relevant health networks, health and equalities websites and newsletters, particularly to those working in cervical screening and the wider cancer screening field.

Radio adverts were produced and a dedicated radio advertising campaign ran on Gaydio (the UK’s first LGBT radio station), along with interviews and features about the campaign. Radio interviews also took place on local stations across the North West.

Posters, postcards and resources were distributed to over 640 targeted venues across the North West including LGB specific venues, GP surgeries, health clinics, community centres, libraries, etc. Posters and print adverts were updated and refreshed during the campaign to maintain interest, and engage with more women in the community.

A dedicated campaign web page was developed at www.lgf.org.uk/screening, which housed the videos and specific regularly updated information and news.

In January 2011 four viral videos were produced, each of which was a pastiche of a classic Hollywood movie, and were released on social networking sites including facebook, You Tube and Twitter.

Outreach workers targeted female specific and more generic LGB events in order to engage women with the campaign and its materials and messages via one-to-one interventions. In March 2011 The LGF hosted their annual health and wellbeing event for LGB women ‘Sugar & Spice’ for International Women’s Day. This hosted a dedicated campaign space where outreach workers were on hand to discuss the campaign and encourage women to engage in campaign materials. At ‘Sugar & Spice’ an interactive web game ‘Put Your Cervix in The Spotlight’ was launched. The idea of the game is to find as many women as possible using a mouse controlled ‘spotlight’ whilst facts, figures and campaign messages flash up throughout gameplay, and the final score page contains a link to the dedicated screening web page.
A mixed method action research methodology, combined with qualitative and quantitative approaches, alongside reflective intervention, was employed in order to comprehensively examine cervical screening for LGB women in the North West.

Surveys of LGB women were undertaken in conjunction with focused group interviews both before and following the awareness raising campaign interventions (attracting almost 1,000 combined responses). Both surveys was undertaken at Pride events and access to surveys were also available online.

The purpose of this research was to examine the attitudes, experiences and behaviours of LGB women with respect to cervical screening and to gather a deeper understanding of the barriers to access which LGB women experience. The purpose of the research element of this project was also to evaluate the interventions that were implemented in the awareness raising campaign, and measure the impact of this campaign in influencing LGB women’s awareness and participation in cervical screening programmes, and measure any differences between data-sets.

**PHASE 1**
Pre-campaign baseline survey

**PHASE 2**
Campaign/intervention/action

**PHASE 3**
Post-campaign evaluation

Action research requires an intervention to be made and reflected upon in order to develop understandings about the situation in question. In this research approach the process of reflective intervention generated study data within which to situate survey data.

What women told us before the campaign...

- 51% of LGB women of an eligible age had either never had a test, or not had one within the recommended NHS timescales (either 3 or 5 years depending on age), indicating the inequality of access to screening that this group experience.

- LGB women are significantly less likely to have accessed cervical screening within the last 5 years than heterosexual women. 70.5% of LGB women of an eligible age reported screening within the last 5 years compared to 78.9% of the general female population.

- A significantly high proportion of LGB women (19%) reported never having been for a cervical screening test, suggesting that the barriers faced by LGB women are not being addressed.

- 36% of all the LGB women in our study had been misinformed and told they did not require a test due to their sexual orientation. This directly resulted in over half of this group disengaging from screening systems.
Despite misinformation and a potential consequent disengagement from screening systems, the majority of LGB women perceived their risk of cervical cancer to be equal to that of heterosexual women. However, this perception of risk was clearly not the most important influencing factor affecting attitudes towards and behaviour surrounding regular screening, as over 50% of LGB women who knew they were at risk, still did not attend. Exploring this area further we found a range of significant barriers which influence screening avoidance. Along with the issues experienced by all women (regardless of sexual orientation) such as fear of the procedure being painful, the following barriers were explored:

LGB women were apprehensive about, and uncomfortable regarding, the line of heteronormative questioning often employed by health professionals when accessing screening. Concerns were raised regarding the relevance of this questioning, and the discomfort of feeling forced to ‘come out’ in order to answer these questions appropriately.

“When asking all the questions (about sex and contraception), I was forced to come out (in the past I’ve been forced to lie, and say ‘yes, I’m using condoms!’ even though I wasn’t even sleeping with a man). So, when I said I was gay, the nurse told me I didn’t need to be here. She was extremely homophobic and rude. I demanded that she go through with the procedure because I didn’t want me being there to be a waste of time, but she point blank refused. Looking back I should have complained about her, but didn’t feel confident enough - what if the person I complained to was just as homophobic”

LGB women feared being refused a test or receiving a sub-standard service as a result of their sexual orientation, and were therefore reluctant to disclose information to health care workers or fearful of experiencing homophobia. This was often based on previous negative experiences.

“When came out to my nurse - she kept asking about contraception and sex - I had no choice but to tell her. When I told her she was very rude and tried to get me out of the treatment room as soon as she could. I’m glad I don’t need a smear as I couldn’t go through that again.”

“Early on in my smear history I told a nurse that I had a female partner and she was completely taken back and said I don’t know what to do about that’… she was really confused as to what to do next clinically… she said ‘well you are here and we can do it anyway’ but she hadn’t been trained for that situation”

Health care professionals were shown, through LGB women’s recent experiences, to often lack the specific knowledge of LGB women’s needs, being unable to provide accurate and relevant health information.

“…for those 6 years (From 25 to being 31) I didn’t screen because I was told I didn’t need to have screening…Well actually it is not a very nice procedure so it is easy to say ‘well… yeah, fine won’t have one’… (other focus group participants agree)… but actually the reality is that you could have abnormal cells…”

“there is a real perception that we don’t need it like we are really safe… like they couldn’t catch an STI or anything…like you are not at risk of anything”

“Nurse and doctor have always said I don’t need one - lesbians cannot get cervical cancer, so of course, I won’t go through an embarrassing procedure I don’t need!”

“I put off going because at least three nurses over the years have said if you don’t have sex with men you don’t need a test - as I was really scared of going this just made me decide not to bother”

“I was told by a doctor because I was a lesbian and didn’t have sex with men I wouldn’t need one for a good ten years. It did affect me going for another - it was about 15 years to my next one”

“Nurse said I should not bother as I am a lesbian (even though I’ve slept with men) - she refused to give me one even though I asked”

“18 months ago it flashed up because I’d moved to Manchester and it identified I needed a cervical screen… and I said ‘well I’m gay’ and they said ‘you don’t need to go then’ and they cancelled the alert on the screen and the sending out of the reminder, that was about 18 months maybe 2 years ago...”

“I was declared ‘sexually inactive’ as my sexual practice apparently was ‘not applicable’"
RESEARCH

WHAT WOMEN TOLD US AFTER THE CAMPAIGN

79% of all LGB women of an eligible age have had a test within the last five years, which is in line with the general female population. Interestingly, this figure stood at 70.5% in the initial survey.

73% of LGB women of an eligible age have been for a cervical screening test within the recommended NHS timescales (either 3 or 5 years depending on age). Interestingly, this figure stood at 49% in the initial survey.

Specifically, it is notable that in this post-campaign survey 79% of women at an eligible screening age have had a test within the last five years, which compares favourably with national NHS data that also stands at 79% (The NHS Information Centre, 2010). In the survey one, this figure was much lower, at 70.5%.

It is important to acknowledge that the pre and post samples of LGB women were opportunistic, rather than ideally controlled matched samples, which was impossible given the hidden and anonymous nature of the target population. Thus, although the campaign is reported by LGB women to have made a difference to their behaviour in survey two, we cannot compare this result with those figures regarding cervical screening uptake in survey one, although there is clear evidence that the campaign has influenced behaviour.

Further research is necessary with a longitudinal and larger sample, although the plausibility of the findings are bolstered by the fact that this study resonates with earlier research with the same target population (R. Hunt and Dr J. Fish, Prescription for Change, 2008).

Two key overarching conclusions that can be made from the study are detailed here.

TARGETED LGB SPECIFIC CAMPAIGNS CAN BE EFFECTIVE IN INCREASING THE KNOWLEDGE AND CONFIDENCE OF LGB WOMEN TO ATTEND FOR CERVICAL SCREENING. FOLLOWING THE ‘ARE YOU READY FOR YOUR SCREEN TEST?’ CAMPAIGN WE FOUND THAT:

39% of women aged 16 and above felt that the campaign had increased their knowledge around the need to go for a cervical screening test.

33% of women aged 16 and above felt that the campaign had increased their confidence in going for a cervical screening test.

34% of women aged 16 and above felt that the campaign had increased their confidence in feeling able to be open about their sexuality with a health professional.

37% of women felt that the campaign had increased their confidence in challenging health professionals if they were to refuse or discourage them from having a cervical screening test because of their sexual orientation.

N.B. The samples for the above statistics include those who are already aware of their screening needs and confident in accessing screening.
Targeted LGB specific campaigns can be effective in positively influencing cervical screening behaviour. Following the ‘Are you ready for your screen test?’ campaign we found that:

- Of those aged 25-64, **25%** reported that they had actually been for a cervical screening test as a direct result of the campaign.
- Of those aged 25-64, **8%** reported that they had booked a cervical screening test as a result of the campaign.
- Of those aged 25-64, **8%** reported that they planned to book a cervical screening test in the near future as a result of the campaign.
- Overall **51%** of women aged 25-64 reported some form of positive behaviour change with respect to the uptake of cervical screening testing as a result of the campaign.
- Only **4%** of women aged 25-64 reported that they would still not go for a screening test.

Age, sexual orientation and domicile did not usually have any bearing upon participant responses and experiences (excepting the few areas we detail in the full academic report and acknowledging the geographically specific recruitment strategies deployed in survey one and survey two (Manchester and Blackpool Pride respectively).

**93%** of participants think more needs to be done to train health professionals regarding the needs of LGB women relating to cervical screening.

Following the ‘Are you ready for your screen test?’ campaign, there is much evidence to suggest its value. The campaign gained widespread recognition, with **73%** of participants reporting that they were aware of the campaign.

**99%** felt it would be worthwhile to run such a campaign nationally.

**96%** felt that the campaign was effective and the majority of participants rated the materials as either excellent or good.

Many people thought the design of the campaign was strong in terms of look and feel. One participant in particular reported that it was not immediately obvious what it is about - which given the potential unpleasantness of the subject matter was a good thing as this would ‘hook people in’. Participants thought the overall message was clear and well targeted at LGB women across a range of ages, and also noted that there was good use of humour, yet the materials were still informative and sensitive to the severity of the issue.

More information on the success of particular interventions can be found in the full academic report. For a copy, e-mail women@lgf.org.uk or visit www.lgf.org.uk.
CONCLUSIONS

The context for our work includes recognition of the evidence that LGB women have specific needs, experiences and difficulties with regard to accessing cervical screening, and the need for targeted work to address these issues.

Deploying an action research approach, this North West study focussed upon LGB women who are less likely to access cervical screening compared to the general population of women, in recognition of the need to target specific health messages to LGB women in order to ensure improved equality of cancer outcomes.

The experiences of LGB women were captured and the data strengthens current evidence regarding the screening behaviour of LGB women and exposes areas for further research and attention. The findings clearly indicate that the campaign was effective in changing the cervical screening behaviour of LGB women.

CONCLUSIONS FROM THE PRE-CAMPAIGN SURVEY AND FOCUS GROUPS

The baseline findings resonate with earlier studies and provide strong evidence that many LGB women continue to be misinformed regarding their need for cervical screening, despite there now being clear NHS guidance. LGB women reinforced the need for specific and targeted information regarding their need to attend cervical screening.

The most important outcome from this study, reinforced by the existing evidence base, is the need to continually provide LGB women with targeted, accurate and relevant information in order to encourage participation in national screening programmes. We found that:

- 51% of LGB women of an eligible age had either never had a test, or not had one within the recommended NHS timescales (either 3 or 5 years depending on age), indicating the inequality of access to screening that this group experience.

- LGB women are significantly less likely to have accessed cervical screening within the last 5 years than heterosexual women. 70.5% of LGB women of an eligible age reported screening within the last 5 years compared to 78.9% of the general female population.

- A significantly high proportion of LGB women (19%) reported never having been for a cervical screening test, suggesting that the barriers faced by LGB women are not being addressed.

- 36% of all the LGB women in our study had been misinformed and told they did not require a test due to their sexual orientation. This directly resulted in over half of them disengaging from screening systems, believing they were not at risk.

Despite misinformation and a potential consequent disengagement from screening systems, the majority of LGB women perceived their risk of cervical cancer to be equal to that of heterosexual women. However, this perception of risk was clearly not the most important influencing factor affecting attitudes towards and behaviour surrounding regular screening, as over 50% of LGB women still did not attend.

Examining this area further we found a range of significant barriers that influence screening avoidance, including apprehension regarding the heteronormative attitudes and questioning often employed by health professionals, the fear of being forced to ‘come out’ to health professionals.
due to such questioning, and the fear of experiencing homophobic attitudes or a sub-standard service due to sexual orientation. Indeed, our findings strongly indicate that there is a high degree of work needed to address the training needs of health care professionals to ensure equitable, non-discriminatory practice which ensures that LGB women are treated with dignity and respect.

**CONCLUSIONS FROM THE POST-CAMPAIGN SURVEY AND FOCUS GROUPS**

Customising uptake strategies has been shown to be particularly useful in low-uptake minority groups, and this was central to the campaign’s approach. Following the ‘Are You Ready for Your Screen Test?’ campaign there is much evidence to support its value. Of those that replied in survey two, 96% felt that the campaign was effective and the majority of participants rated the materials as either excellent or good. Moreover, in terms of screening behaviour, the results show that:

- 79% of all LGB women of an eligible age have had a test within the last five years, which is in line with the general female population. This figure stood at 70.5% in the initial survey.
- 73% of LGB women of an eligible age have been for a cervical screening test within the recommended NHS timescales (either 3 or 5 years depending on age). This figure stood at 49% in the initial survey.

Notably, if we adjust the two above statistics to acknowledge the effect of the campaign (by treating those who attended for screening because of the campaign as non-attendees), then these figures, had the campaign not occurred, would have been 57% and 51% respectively. This indicates the significant impact the campaign has had on screening uptake.

Specifically, it is notable that 79% of women of an eligible screening age have had a test within the last five years, which compares favourably with national NHS data that stands at 78.9% (The NHS Information Centre 2010). It is important to acknowledge that the pre and post samples of LGB women were opportunistic, rather than ideally controlled matched samples, which was impossible given the hidden and anonymous nature of the target population.

Thus, although the campaign is reported by LGB women to have made a difference to their behaviour in survey two, we cannot compare this result with those figures regarding cervical screening uptake in survey one, although there is clear evidence that the campaign has influenced behaviour. Further research is necessary with a longitudinal and larger sample, although the plausibility of the findings are bolstered by the fact that this study resonates with earlier research with the same target population (such as R. Hunt & J Fish, Prescription for Change, 2008).

Overarching conclusions that can be made from the study are that LGB specific campaigns can indeed be effective in increasing knowledge and confidence levels of LGB women with regard to cervical screening, and can positively influence cervical screening uptake.

We envisage that the evidence and recommendations provided in this report will inform and instigate further work in this area, in order to ensure equality of outcomes for lesbian, gay and bisexual women.

“**WE ENVISAGE THAT THE EVIDENCE AND RECOMMENDATIONS PROVIDED IN THIS REPORT WILL INFORM AND INSTIGATE FURTHER WORK IN THIS AREA IN ORDER TO ENSURE EQUALITY OF OUTCOMES FOR LESBIAN, GAY AND BISEXUAL WOMEN.”**
RECOMMENDATIONS

1. TARGETED, APPROPRIATE AND ACCURATE INFORMATION
   Sustained targeted, appropriate and accurate information is needed in order that those women who identify as LGB can make an informed choice as to whether to attend cervical screening programmes.

2. WIDESPREAD CAMPAIGN DELIVERY
   It is recommended that campaigns such as this are rolled out in all regions across the UK to ensure national coverage. 98% of survey 2 participants report that more campaigns such as the one detailed in this study are needed and 99% felt it would be worthwhile to run such a campaign nationally. The fact that the campaign was specifically targeted at LGB women was welcomed by our participants. Such work should be undertaken by organisations who have specific expertise and experience dealing with LGB people.

3. TARGETED CAMPAIGN APPROACHES
   Based on our experience and evidence we would recommend that campaigns:
   • Require strong design elements and clarity of message.
   • Are widely distributed, extending to areas beyond those places where LGB women might be assumed to frequent regularly.
   • Utilise targeted outreach opportunities within and with the LGB community for one-to-one engagement with LGB women.
   • Understand the target group in question and consider diversity issues beyond sexual orientation as appropriate.
   • Have integrated evaluation mechanisms – this requires a view of evaluation as an ongoing process, not an a-priori and/or after campaign event.
   • Engage with appropriate online spaces as these can be economical and effective, but also take account of the fact that they should not be the only media drawn upon.

4. LGB SPECIFIC TRAINING FOR HEALTH PROFESSIONALS
   We agree with Mitchell et al. (2009) in acknowledging that the pivotal role of medics and other health care professionals in facilitating screening cannot be underestimated and that as a consequence, awareness training and evidence of the effectiveness and impact of such training initiatives is essential. Research is required to assess the extent of health care professionals knowledge and practice in the area of cervical screening.

   Health care professionals require training to ensure that the structuring of the screening test avoids heteronormative assumptions – this should include areas such as the crafting and delivery of appropriate cervical screening questions, along with training around equality of access rights and non-discriminatory practice. It is notable that 93% of women in survey two felt that LGB specific training was necessary for this group.

   Here it is also helpful to note that working closely with expert outreach lay health workers and LGB advocacy groups to provide information and strategies that address unique barriers for low-uptake groups has been argued to be effective (Weller et al. 2009, Giordano et al. 2008).

5. LGB SPECIFIC CERVICAL SCREENING SERVICES
   There is demand for increased and dedicated cervical screening services for LGB women with knowledgeable and experienced LGB friendly staff. Consideration should be given to developing LGB specific cervical screening services, as a mechanism to break down barriers to uptake.

6. SEXUAL ORIENTATION MONITORING
   Health services should monitor sexual orientation in order to better understand the needs of LGB women and the health inequalities they experience.

   This includes generating better understanding for the need to monitor sexual orientation and the benefits of doing so within both the LGB women’s community, and with health professionals.

7. WORK WITH THE TRANS COMMUNITY
   Specific work needs to be undertaken with the trans community (both within the general and the LGB population) to understand and address the specific issues this community face.

   This was not within the remit of our study, but some participants raised it as an issue.

REFERENCES

- Fish J. Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods. Leicester: DeMontfort University. 2009
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Selected photography by Sarah Quinn and Paul Jones (Exposure)
We believe in a fair and equal society where all lesbian, gay and bisexual people can achieve their full potential.

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