LESBIAN, GAY & BISEXUAL WOMEN IN THE NORTH WEST:

A Multi-Method Study of Cervical Screening Attitudes, Experiences and Uptake

Professor Ben Light and Dr Paula Ormandy
University of Salford

with Rachel Bottomley and Annie Emery
The Lesbian & Gay Foundation

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Cervical Screening Programme

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Foreword

It has long been recognised that women who are not sexually active are at low risk of cervical cancer, and it was traditionally taken from this that women who had sex not with men but with women were therefore at low risk. Both virgins and lesbians were therefore often told they did not need cervical screening.

The cervical screening programme in the NHS has been organised for just over 20 years now. It has never enquired about sexual orientation, or indeed sexual activity, and has sent invitations to everyone. But the advice for those lesbians who identified themselves to their GP as lesbian, or who asked for advice as to whether they should be screened, was vague.

Knowledge about the origins of cervical cancer has advanced hugely. In 2008 Harald zur Hausen was awarded a share of the Nobel Prize in Medicine for his discovery of human papilloma viruses (HPV) causing cervical cancer. It seemed time for the NHS Cervical Screening Programme to revisit the issue of lesbians and cervical screening. We therefore commissioned a literature review from De Montfort University in Leicester which would examine what was known on this topic. This showed that lesbian, gay and bisexual women might be at lower risk, but were not at no risk and therefore should be screened.

But just changing advice is not good enough. We have to change practice and perceptions. 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. This report gives an account of that pilot; records what worked and what didn't, and allows other parts of the country to learn from this exercise. 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
July 2011

Preface

The NHS Cervical Screening Programme (NHSCSP), committed to reducing health inequalities for lesbian, gay and bisexual (LGB) women within cervical screening programmes, funded this research study in response to emerging evidence regarding the transmission rates of HPV. Within the Cancer Reform Strategy it is noted that there is a lack of evidence regarding what interventions might be most effective at addressing different forms of inequalities (DH 2007:85). Following this, in 2008, Cancer Research made a further call for an increase in government and health service commissioned research to better understand the needs of the LGB communities (CRUK 2008).

It was within this context that The Lesbian & Gay Foundation (LGF) approached us to work with them to secure the funding to undertake a project that aimed to develop understandings of, and interventions regarding, LGB women's attitudes towards, experiences of and uptake of cervical screening. Three key things motivated us to engage with the project. First, as Academics, we saw here an opportunity to engage with a local community organisation to affect change to people's lives directly and, potentially, through policy. Second, we knew that the LGF works closely with the local LGB population in the North West, and has considerable knowledge of the sexual minority group, providing outreach work and health education. Therefore, if this work was going to be done, this was the right partner. Third, this project resonated with work that we had begun together in 2009 in collaboration with Brook Advisory, a charity that provides sexual health services and advice for young people. This work focussed upon creating digital media based interventions to affect behaviour change, and the development of associated evaluation mechanisms, in the area of sexual health. We felt that this work on service user engagement and evaluation would feed in well to the project and that the knowledge and experience gained working with the LGF would feed back to our Brook project as this moved into its second and final year. Happily we were right on both counts.

We thus hope that the project as written up here underlines the importance of the need for women who identify as LGB to attend for screening and demonstrates that increasing uptake is possible. But also, we would like to think we point to the joint work between ourselves and the LGF which demonstrate the possibilities for modes of engagement that see evaluation as an ongoing process, embedded throughout methodologies of campaigns and formal research.

Professor Ben Light and Dr Paula Ormandy

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Acknowledgements

This report is one of the outputs of a year long collaborative project involving The Lesbian & Gay Foundation and the University of Salford, funded by the NHS Cervical Screening Programme. Without this funding, this project would not have come into existence and in this respect we are thankful to Professor Julietta Patnick CBE, Director of the NHS Cervical Screening Programmes.

We would sincerely like to thank Rob Cookson for his enthusiasm for the project, strategic guidance and ensuring that the LGF resources were made available. In particular, we would like to give tremendous thanks to Rachel Bottomley and Annie Emery of the LGF both have been a pleasure to work with throughout. Rachel has worked tirelessly to make us clear and accurate – the report you have here would not have been the same without her. Annie has achieved the impossible – making a project involving two academics run to time (almost all of the time).

Many staff at the LGF made this project work and helped to generate valuable publicity, materials and data for us to use here, including all those volunteers who conducted valuable outreach work and assisted at project events. We acknowledge the work of the following people:

- Kate Hardy for her travelling around the North West distributing posters and resource booklets.
- Joanne Dunning for helping to make the campaign, and project more generally, so visible.
- Mark Eastwood and Grahame Robertson for pulling together not only the report you see here but the summary report, and all the campaign materials.
- Eran Voisey and David Brown for developing the 'Put your cervix in the Spotlight' game and Marc Robinson for providing valuable data about web traffic.
- Samantha Days, Lucy Rolfe, Heather Williams, Kate Francis, Sian Payne, Sara Ashworth, and Claire Taylor; the members of the LGF's women's leadership group who devised the 'Screen Test' theme for the campaign which has proved so popular with LGB women.
- Emma Coleman of the University of Salford for engaging with the project throughout but specifically her role in the mundane, but important job of survey data entry.
- Dr Claire Hulme of the University of Leeds gave incredible support regarding the statistical significance tests we needed (errors of interpretation are ours not hers!).

Special thanks also needs to be given to the hundreds of women who took the time to engage with the campaign, the surveys and the focus groups. Unfortunately you won't have made it in if you didn't live in the North West, but your contributions from areas such as Birmingham, Edinburgh, Hull, Leeds, London and Wakefield didn't go unnoticed and only served to reinforce the point that LGB women need to get screened and can face challenges no matter where they live.

Glossary

Gay: This term is frequently used to describe men who are physically and/ or emotionally attracted to other men, however this term can be used for women also. For example; a gay man or a gay woman.

Lesbian: Women who are physically and/ or emotionally attracted to other women.

Bisexual: This can be a person of any gender who is physically and/or emotionally attracted to a person of any gender.

Equality of outcome: Regardless of any differences or regardless of where any inequalities exist; all will achieve the same result and be treated equally.

Google Analytics: A piece of Internet based software which enables the analysis of web traffic, such as the sources of visitors and number of visits to a web site.

Heterosexual: A person who is physically and/or emotionally attracted to people of a different gender to their own. A heterosexual person may be colloquially referred to as 'straight'.

Homophobia: Hatred or fear of those who do not identify as heterosexual. This term is often equated with gay men, but conceptually and practically applicable to LG women.

Heterosexism: This term applies to attitudes, bias, and discrimination in favour of solely opposite-sex sexuality and relationships.

Heteronormativity: This is a term to describe the marginalization of non- heterosexual lifestyles and the view that heterosexuality is the normal sexual orientation. It can also more broadly be engaged to refer to those lifestyles that do not conform to purported heterosexual norms for example, assumptions regarding the importance of marriage, conceptions of appropriate structures of relationships and those of family.

HPV: The human papilloma virus, a virus than can lead to the development of cervical cancer.

Protected characteristic: These are the grounds upon which discrimination is unlawful. The characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation.

Research methodology: The particular combination of philosophy, method/s and data gathering techniques that are used to investigate an area.

Research participant: A term used to describe someone who engages in a research study. This term is deployed in cognizance of the participatory role such people play and researchers using this term are signaling the problematic nature of downplaying such a role that the term 'research respondent' implies.

SPSS: Software package used to analyse quantitative data.

Sexual orientation: A way of describing someone's sexual preference. This can also be referred to as someone's sexuality depending upon the way one theorizes gender and sexuality. Some people see sexuality as something one 'has' and others see it as something one 'does' – a role performed. One can identify with a sexual orientation or sexuality.

Trans: This is a UK created term intended to be an umbrella inclusive of transgender, transsexual, transvestite, cross dresser and all others whose gender identity and/ or expression differ from the that they were assigned at birth.

Executive Summary

Context

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 in England are invited for regular cervical screening under a national Cervical Screening Programme. National policy 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.

It is important to note that the Human Papilloma Virus (HPV) vaccination programme of adolescent girls in the UK will lead to a substantial change in cervical cancer, which in the future will have an effect on cervical screening. Although it may reduce the frequency for cervical screening of those vaccinated, screening will still be required as the vaccine does not protect against all types of HPV and it is not guaranteed to prevent cervical 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 in the North and the Midlands. Indeed, women, living in less affluent areas (such as the North West) are not only at a higher risk of developing cervical cancer but more likely to die from the disease compared to women living in more affluent areas of the country.

Despite new guidance regarding the need for LGB women to have regular cervical screening tests, there are still elements of confusion and contradiction. 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 research study targets LGB women in the North West who are less likely to access health care compared to the general population of women, indicating the need to target specific health measures for LGB women specifically in order to ensure improved physical health and cancer outcomes in the longer term.

This pilot project consisted of an awareness raising campaign, and research was conducted both before and following this campaign, in order to better understand the experiences and behaviours of LGB women, and to measure the success of the campaign itself.

Pre-Campaign: Key Findings

Participants were asked whether they thought LGB women needed cervical screening. Out of 609 LGB women who responded, 91% agreed that LGB women need to have cervical screening tests. 4% did not know whether such a screening test was required, and 5% responded that screening was not necessary for LGB women.

Although the majority of participants were aware that LGB women needed cervical screening, 47 (8%) of LGB women sampled, aged between 25-64 years either did not know or perceived that LGB women did not need cervical screening tests. The majority of LGB women 77% (469) considered lesbian, gay and bisexual women to be at equal risk from cervical cancer compared to heterosexual/straight women. Despite holding this belief, 36% had not responded to a screening invitation and 28% had been told a screening test was not necessary.

From an eligible sample of 498 LGB women between the ages of 25-64 years, 70.5% accessed screening within the last five years.

Only 48% of LGB women aged between 25-49 years (461), accessed a screen test within the last three years, as recommended by the national screening programme, and only 73% of 50-64 years old had accessed screening within the last five years as recommended.

Overall 51% of LGB women had either never had a test, or not had one within the recommended timescales. The results in survey two show a marked difference to this figure.

Further to this, the survey data indicated that 50% of LGB women eligible for screening had at some point failed to respond to a routine invitation for a cervical screening test, and of these 35% considered themselves **less** at risk of cervical cancer than a heterosexual woman.

Reasons for non-response to a cervical screening invitation included not having the time to book a test, fear of a painful procedure, and embarrassment regarding the procedure. Along with these generic reasons, many reasons were cited that were specific to sexual orientation, such as previous negative experiences, and fear of negative attitudes of health workers.

There was clear evidence that LGB women have been misinformed for many years, particularly lesbian women, from both the survey and focus group data. The qualitative responses on the survey highlighted that 35 LGB women did not think they required a test because of their sexual orientation, 38 women didn't think it was important, and 61 had been told directly by a health professional, family or friends that because of their sexual orientation it was not necessary.

The myth of not needing a cervical screening test is being reinforced within the lesbian community. Although some perceived that awareness of cervical screening was increasing amongst LGB women there was recent contrasting evidence to suggest some LGB women lacked awareness and were misinformed. The survey uncovered 184 (37%) out of 505 LGB women had at some point been told that LGB women did not require a cervical screening test.

Evidence from the survey data indicated that 71 LGB women out of 500 (14%) had been actively refused or discouraged from having a cervical screening test by a health professional as a direct result of their sexual orientation.

Our research participants informed us that the style of questioning used by health care professionals was sometimes inappropriate and irrelevant for LGB women accessing screening services and that services were focused on heterosexual women.

LGB women described experiences of discrimination and feelings of apprehension at having to explain their sexual orientation when being asked heteronormative

questions. This prevented some LGB women from answering the questions honestly, worried about the response they would get from the health professional. It also deterred women from accessing future screening.

The most overwhelming finding from the focus groups was the consensus of opinion regarding the need for more realistic and accurate screening information for LGB women. This information included identifying clearly; that LGB women needed to attend for screening, why they need to attend whatever their sexual orientation, what is involved and what choices they have.

Post-Campaign: Key Findings

Overall 73% of participants reported that they were aware of the LGF's 'Are You Ready For Your Screen Test?' campaign (Figure 1, p 6). During the campaign, the campaign website was viewed 3348 times with over a 1000 further hits being generated by LGF news items. Ten sources of traffic accounted for 92% of website hits and of this 24% landed on the page as a result of directly typing in the URL of the page into their browser. This indicates that it is highly likely that these visitors had found the URL on a piece of promotional material.

Overall the campaign benefited from a steady flow of visitors as it progressed. However, we noticed peaks in the campaign and perhaps most striking is the role of the 'Screen Test' campaign videos in generating traffic.

Most participants thought the materials were either excellent or good with the design and message of the campaign, use of humour and deployment of videos being singled out by many.

Several people felt that the campaign deserved a wider coverage and should not be restricted to what they saw as places mainly frequented by LGB women.

Of those that replied 190 (96%) felt that the campaign was effective. This figure did not seem to be affected by the age, sexual orientation or domicile of participants.

Bearing in mind that these samples for the enclosed statistics include those who are already very aware of the need to attend screening and who access screening, overall 39% of women 25 years and over felt that the campaign had increased their knowledge around the need to get a test.

33% of women aged 25 and over felt that the campaign had increased their confidence in going for a test, and 34% of women felt that the campaign had increased their confidence in feeling able to be open about their sexuality with a health professional.

37% of women aged 25 and over 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.

Of those aged 25 and above 22% reported that they had *actually been* for a cervical screening test as a result of the LGF campaign. Of the 25-49 year old group – 84% had been influenced by the campaign and of the 50-64 year old group, 16% had been influenced.

Of those aged 25 and above 19 women (8%) reported that they had booked a cervical screening test (but not yet attended) as a result of the LGF campaign. Furthermore, of those aged 25 and above 19 women (8%) reported that they intended to book a cervical screening test in the near future as a result of the LGF screen test campaign.

If the figures for those who have gone for a test and those who have booked a test are combined, we see that 70 women (30%) have taken a direct positive action with respect to the maintenance of their health as a result of the LGF campaign. If those who plan to book a test in the near future are included, then this figure rises to 89 and 38%

respectively. **And finally, if those women (63) reporting no behaviour change because they already go for screening tests regularly are removed, then the overall behaviour change as a result of the campaign figure rises to 51%, meaning the campaign has directly impacted on the behaviour of those it hoped to target in particular (LGB women who are not currently accessing cervical screening).**

Focussing upon those aged 25 and above, and on the radar for cervical screening, 70 of 243 women (28%) reported not making any changes as a result of the campaign. Of this group, 61 women reported not making any changes because they already went for screening tests. Thus, in this group only 4% of women reported that they would still not go for a screening test.

Survey two data regarding screening behaviour showed marked differences in comparison to survey one data. Participants as a group reported that 86% of them had a cervical screening test at some point in their life meaning that 14% had not.

Survey two data also revealed that 70% of women aged 25-49 years old have had a test in the last three years as per NHS guidance, and 90% of women aged 50-64 years old have had a test in the last five years, as per NHS guidance.

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

79% of all LGB women of an eligible age have had a test within the last five years, in line with the general female population, which compares favourably with NHS data that stands at 78.9% (The NHS Information Centre 2010). Interestingly, this figure stood at 70.5% in the initial survey. 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.

Conclusions

The pre-campaign findings resonate with prior research and provide strong evidence that many LGB women continue to be misinformed regarding their need for cervical screening by health professionals, despite there now being clear guidance.

There is a high degree of work needed to address the training needs of health care professionals to ensure equitable, non-discriminatory practice that ensures that LGB women are treated with dignity and respect.

This study aims to provide evidence to inform and instigate further work in this area, including national coverage of this issue. Following the 'Are You Ready for Your Screen Test?' campaign there is much evidence to support its value.

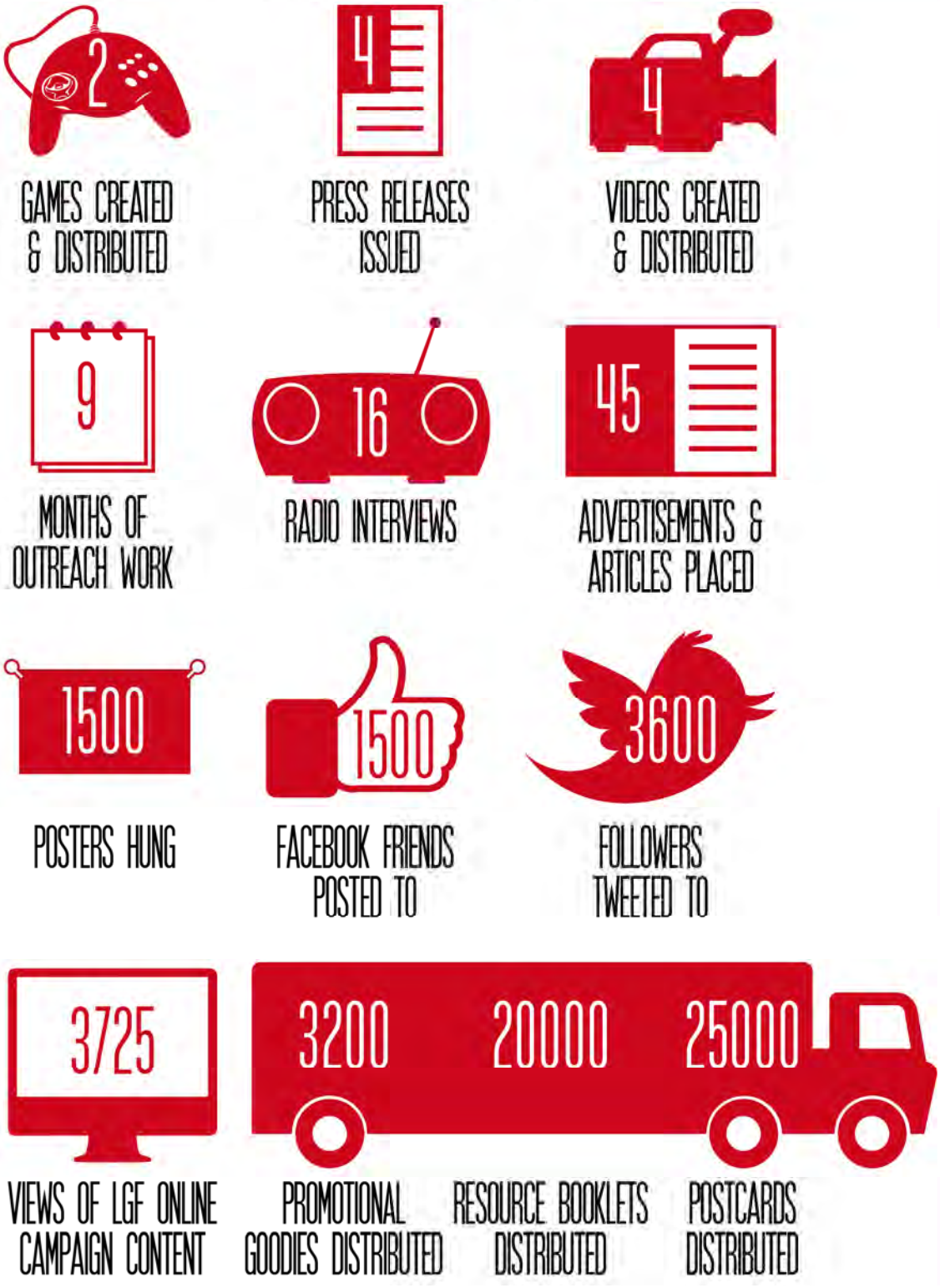
Targeted LGB specific campaigns can be effective in increasing the knowledge and confidence of LGB women to attend for cervical screening, and can be effective in positively influencing cervical screening behaviour.

Due to the size and distribution of the sample of our research components it was difficult to report with any certainty regarding any potential combined influences of sexual orientation, age and domicile. We thus leave conclusions open in this area.

Recommendations

1. 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. Campaigns such as this should be considered for roll out on a regional and national basis.
3. Campaigns should pay attention to strong design and clarity of message, distribution strategy, targeted outreach opportunities, integrated evaluation and enrol media of various forms as appropriate.
4. Research is required to assess the extent of health care professional's 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.
5. There is demand for increased and dedicated cervical screening services for LGB women with knowledgeable and experienced LGB friendly staff.
6. Health services should monitor sexual orientation in order to better understand the needs of LGB women and the health inequalities they experience.
7. 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 they face.

Figure 1: Summary of activity involved in the campaign



1. Context

The NHS Cervical Screening Programme (NHSCSP), which is committed to reducing health inequalities for lesbian, gay and bisexual (LGB) women within cancer screening programmes, funded this project in response to changes in NHS guidance regarding cervical screening in 2009. Prior to this change, the NHS advised that women might choose to decline their invitation for screening if they had never been sexually active with a man, but the latest guidance now recommends regular uptake of cervical screening tests between the ages of 25-64, regardless of sexual orientation or sexual history.

The Cancer Reform Strategy (DH 2007) highlighted that the challenge in reducing inequalities in cancer is 'the lack of evidence about the extent to which different forms of inequalities exist, what causes them and what interventions will be most effective in addressing them' (DH 2007:85). Further, Cancer Research UK in 2008 called for an increase in government and health service commissioned research to better understand the needs of the lesbian, gay and bisexual (LGB) communities (CRUK 2008). Indeed others have argued that most areas of LGB health and social care remain under-researched (Mitchell *et al.* 2009).

This demonstration project 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.

This collaborative pilot project between The Lesbian & Gay Foundation (LGF) and the University of Salford:

- Assesses attitudes towards, and experiences of, cervical screening.
- Delivers a campaign aimed at encouraging uptake of cervical screening.
- Determines the effectiveness of different strategies to engage LGB women with cervical screening.

Understanding the context surrounding research from the outset is essential to facilitate methodological enquiry and better interpret findings that emerge. This chapter summarises the complexities of researching LGB women, who are often considered a hidden population within health care, alongside discussing the prevalence of cervical cancer and screening programmes. Existing evidence of myths and barriers that are known to inhibit LGB women accessing screening are exposed, providing a platform from which to take forward the findings of this project.

1.1 LGB women: a hidden population

The evidence base of cancer inequalities and sexual orientation remains under-developed because information on sexual orientation is not routinely collected by the NHS (NCEI 2010), therefore the health of LGB women remains difficult to assess. Without sexual orientation monitoring, particularly within cervical screening programmes, it becomes impossible to conclude accurately how many LGB women are affected by cervical cancer (Hunt and Fish 2008a). That said, initiatives are being introduced, in an attempt to gather more accurate health data on sexual minority communities generally. For example, NHS North West in partnership with the LGF has recently launched a groundbreaking new sexual orientation monitoring resource (NHS North West 2011).

As sexual orientation is not monitored on the UK Census, there is no accurate record of the LGB population of the UK. Official government estimates of the size of the LGB population were made in a regulatory impact assessment document about the Civil Partnership Act in 2004 (Department of Trade & Industry 2004). It was estimated that between 5 and 7% of the adult population of the UK were LGB. This was based on figures gathered in 15 research reports from the UK, America and across Europe.

Research undertaken by ECOTEC in collaboration with the LGF, commissioned by the North West Development Agency (NWDA) estimated that there are 430,000 LGB people living in the North West (Hall and Panton 2010). This is roughly the same population as the City of Liverpool.

Currently there is no comprehensive data set of LGB women in the UK, which makes it extremely difficult conducting research regarding LGB issues where one might want to interrogate large quantities of survey data (Meads *et al.* 2007). Recently, the Office of National Statistics (ONS) has evaluated the initial testing of a sexual orientation measure within the Integrated Household Survey (IHS), viewed by some as a vital step forward, even though national and regional data on LGB communities may not be available for a number of years (Mitchell *et al.* 2009). The survey measured sexual orientation based on self perceived sexual identity; that is how individuals think of themselves, which excluded sexual attraction, behaviour or orientation. The results for April 2009 to March 2010 show that 1.4% of the population sampled (approximately 3345 out of 238,206) identify as LGB (Joloza *et al.* 2010). However, difficulties with this pilot test included grouping people who stated that they did not know their sexual identity together with those who did not answer the question. Therefore the ONS figures should be viewed as indicative and a starting point for considering the factors that inhibit people from identifying themselves as LGB in surveys where confidentiality cannot be absolutely guaranteed. There is no robust answer to the question, 'How many people are lesbian, gay or bisexual?', so at the moment we can only assert that 1.4% of people in the UK are willing to disclose their sexual identity.

Problems with random samples of population based studies (such as the IHS) include homogenous samples of well-educated, white women (Joloza *et al.* 2010, Fish 2009) or women reluctant to disclose their sexual orientation (Henderson 2009, Meads *et al.* 2007) resulting in data that still may not accurately represent those who identify as LGB. In addition, data gathered using convenience sampling methods (Hunt and Fish 2008, Meads *et al.* 2007, Bailey *et al.* 2003) recruited through community initiatives, groups, and local services, limit the ability to generalise findings to the whole population (Mitchell *et al.* 2008). Although an advantage of using this sampling method is that a larger and more diverse number of LGB women are often recruited as the surveys are more relevant to the target population (Fish 2009), a disadvantage again is the over representation of a select group of people (Roberts 2001).

Sexual orientation monitoring is outside the scope of this study, although recommendations suggest it should be introduced within health services, cancer screening programmes and population surveys to facilitate access to LGB women's health information (Mitchell *et al.* 2009). Without such monitoring the ability to target LGB women accessing cervical screening and monitor those who do not is limited. Until such a time, research into sexual minority populations in the UK will continue to rely on opportunistic, convenient and non-probability samples.

1.2 Incidence of cervical cancer and screening

Women aged between 25-64 years in England are invited for regular cervical screening under a national Cervical Screening Programme. National policy, changed in 2003, 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 cell abnormalities within the cervix that if untreated could develop into cancer (The NHS information Centre 2010). Prior to 2003 in the UK, women from the age of 20 were eligible for routine screening. However cervical screening of women aged 20-24 is considered less effective at preventing cancer (Sasieni *et al.* 2009). Thus the screening age was raised, with abnormal changes detected and treated from the age of 25 through the NHS Cervical Screening Programme (NHSCSP 2011).

It is important to note that the human papilloma virus (HPV) vaccination programme of adolescent girls in the UK will lead to a substantial change in cervical cancer, which in the future will have an effect on cervical screening (Weller *et al.* 2009). Although it may reduce the frequency for cervical screening, it will still be required as the vaccine does not protect against all types of HPV and it is not guaranteed to prevent cervical cancer.

Within the general population, screening uptake for women aged 25-49 (who are invited every three years) was shown to have increased to 74% (between 2009-2010) compared with 72.5% in the previous year, but for women aged 50-64 (who are invited every three years), uptake reduced slightly to 78.9% from 80% previously. Although the number of women invited for screening increased between 2009 and 2010 the number of women tested fell (The NHS information Centre 2010). In 2009-2010, a total of 3.3 million women between the target age range (25-64) were tested, compared with 3.6 million (2008-09) and 3.2 million (2007-08) (The NHS information Centre 2010). This equates to 78.9 % of eligible women (25-64 years) in the general female population having accessed a screen test within the last five years (The NHS Information Centre 2010).

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 in the North and the Midlands, varying from 6.5 to 10.4 per 100,000 female populations (Trent Cancer Registry 2011). Indeed, women living in less affluent areas (such as the North West or Yorkshire and Humber) are not only at a higher risk of developing cervical cancer but more likely to die from the disease compared to women living in the East of England (Trent Cancer Registry 2011).

One of the largest UK studies undertaken with LGB women in 2008 captured the health behaviour of over 6000 LGB women and highlighted that 15% of LGB women over the age of 25 had never had cervical screening test compared to 7% of women in the general population (Hunt and Fish 2008). Although, LGB women when compared to heterosexual women have shown comparable awareness of national cervical screening programmes (Gunstone 2010). Despite this, 14.3% LGB women aged between 25-64 years sampled from the North West (635) reported never having had cervical screening (Hunt and Fish 2008b). It is unclear whether these women were informed of screening but chose not to attend, or were misinformed.

The project outlined in this report targets LGB women in the North West who would appear to be less likely to access screening compared to the general population of women, indicating the need to target specific health messages to LGB women in order to ensure improved cancer outcomes for LGB women.

1.3 Myths regarding the risk of cervical cancer

There is evidence of differences in health and other behaviours among LGB women compared with the general population (NCEI 2010). LGB women experience increased risk factors in comparison to the general women's population such as higher smoking rates (Gruskin *et al.* 2001). There are also other risk factors such as early age of first intercourse with a man and the number of male partners, and it is important not to make assumptions about the sexual activity and sexual history of those identifying as LGB women (Hunt and Fish 2008a, Bailey *et al.* 2000). However, the greatest risk for all women including LGB women, is not being screened at all (NHSCSP 2009a).

The majority of LGB women see their perceived risk for cervical cancer to be the same as that of heterosexual women (Bailey *et al.* 2000). However, later evidence indicates that one in five LGB women who have not attended a cervical screening test did not think that they were at risk of cervical cancer (Hunt and Fish 2008a). This belief was not exclusively held by women who have never had sex with a man, as one in ten LGB women who have had sexual intercourse with a man in the last five years had not attended a cervical screening test (Hunt and fish 2008a).

Sex with men is often cited as a risk factor (Fish 2009) 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. LGB women, for many years, have been misinformed, lacking awareness and understanding regarding the transmission routes of HPV (Henderson 2009, Fish 2009).

Fish (2009) highlighted that reported rates of HPV infection amongst lesbians ranged from 3.3% to 30% with a prevalence of 19% for lesbians with no reported history of heterosexual sex. Indeed LGB women are at risk of contracting HPV through their own sexual activity with men, or though sexual activity with women, as HPV can be transmitted through vaginal penetration with fingers, skin to skin contact or through the use of sex toys (Fish 2009). Women who have sex with women exclusively are therefore still at risk of cervical cancer.

The myths and misinformation within the LGB women's community can be further perpetuated by health professionals through misleading LGB women regarding their risk of cervical cancer and providing inconsistent advice, as a result of their own lack of awareness and understanding of HPV transmission (Henderson 2009, McNair 2003). Of those LGB women who have never been for a cervical screening test, one in five have been told by a health professional that they are not at risk and one in fifty had been refused a test based on their sexual orientation (Hunt and Fish 2008a).

Only one in ten LGB women had received information from health care workers that was relevant to their sexual orientation (Hunt and Fish 2008a). LGB women themselves have demanded information to clarify their risks and whether they need to attend cervical screening, but there has been an inherent lack of relevant information and targeted promotional material available (Fish 2009). Even in general HPV leaflets, women's questions on HPV are inconsistently and often inadequately answered (Hall *et al.* 2008).

As a result of the Fish review a specific LGB women's advice sheet was developed in 2009 (NHSCSP 2009b) and revisions made to the pocket guide (NHSCSP 2009c) and cervical screening facts leaflet (NHSCSP 2009a) available on the NHSCSP website. The NHSCSP revised guidance indicates that LGB women who have had sex with either a man or a

woman should now attend screening, clarifying that even though women who have sex with women may have a reduced risk of developing HPV, they are still at risk due to the ability of HPV to be transmitted through same-sex sexual activity. Their own, or their sexual partners' previous sexual history may also increase their risk.

It is important that such updated advice and guidance is disseminated widely, through appropriate networks and target groups to prevent the perpetuation of myths.

"The most important outcome from the existing evidence base is the need to continually provide LGB women with targeted, accurate and relevant information and facilitate informed decisions regarding participation in national cervical screening programmes" **(Weller *et al.* 2009, Fish 2009).**

1.4 Barriers to accessing appropriate screening

Despite new guidance, there are still elements of confusion and contradiction, and 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 health care system due to their invisibility within it.

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 (Henderson 2009, Fish 2009, Hunt and Fish 2008a). Two in five LGB women indicated that health care practitioners had assumed they were heterosexual resulting in the provision of inappropriate advice (Hunt and Fish 2008a). Fish (2009) suggests that a health care practitioner's presumption of heterosexuality reinforces an association between cervical screening and sex with men for LGB women. Therefore, this type of discrimination influences patterns of health seeking behaviour, preventing appropriate health care and/or reducing openness during health consultations.

The information leaflet for LGB women generated by the NHSCSP encourages women to disclose their sexual orientation at the start of a health consultation for cervical screening to enable the health practitioner to provide more relevant information and ask pertinent questions. However, evidence suggests health care providers often lack specific knowledge of LGB women's needs, and are unable to provide relevant health information (McNair 2003). Health care workers have admitted to being homophobic and embarrassed when an LGB sexual orientation is disclosed (Hinchliff *et al.* 2005). As a result some LGB women are deterred from attending screening because of a reluctance to 'come out', or fear of being forced to 'come out', and face homophobic attitudes. Evidence reports LGB women often experience hostile reactions or discriminatory practice when disclosing sexual orientation (Hunt and Fish 2008a) resulting in disengagement with the health care system. Health care workers require increased training to expand their own knowledge and communication skills in managing the needs of LGB women effectively (Fish 2009, Giordano *et al.* 2008, Hinchliff *et al.* 2005).

These barriers alongside misinformation not only impact negatively on patient experience and patient choice, but they also deter LGB women from accessing routine and necessary cervical screening due to lack of awareness or for fear of encountering discrimination.

1.5 Cervical screening initiatives and campaigns

There is little or no evidence of what interventions are effective in addressing the inequality of access to screening and increasing the awareness of LGB women (NCEI 2010). Uptake of cervical screening has been shown to increase using direct invitation strategies rather than methods that rely on raising awareness (Jepson *et al.* 2000). However, Weller *et al.* (2009) indicate that customising uptake strategies is particularly useful in low-uptake minority groups, and using methods that are interactive and engaging provides higher rates of success. In addition, the development of culturally relevant and targeted information for minority communities is important (Fish 2009, Hall *et al.* 2008).

Information technology is being increasingly used, particularly web-based techniques with interactive decision-aid elements to determine whether screening is necessary (Weller *et al.* 2009). Also, media-based campaigns can produce short-term and geographically specific increases in uptake and awareness, but evidence of sustained impact is varied (Giordano *et al.* 2008, Meissner *et al.* 2004, Phillips-Angeles *et al.* 2004).

Successful strategies to enhance adherence to cancer screening guidelines have been directed towards multiple levels including individuals, health care providers, and organisations (Meissner *et al.* 2004). The pivotal role of medics and other health care professionals in facilitating screening cannot be underestimated therefore appropriate awareness training and evidence of the effectiveness and impact of such training initiatives is essential (Mitchell *et al.* 2009). In this vein, Fish (2009) recommends the inclusion of LGB women's health in medical education programmes.

Sharing examples of good practice is recommended to promote the equality agenda (Mitchell *et al.* 2009), such as reporting significant events to raise practice nurses awareness, to be sensitive to all women, and to never make assumptions (Edwards 2008). Working with outreach lay health workers or advocacy groups, such as dedicated organisations like the LGF, and utilising their expert knowledge of the specific community to provide information and strategies that address unique barriers for low-uptake groups are effective (Weller *et al.* 2009, Giordano *et al.* 2008).

This demonstration project builds on the recommendations from the comprehensive review of evidence by Fish (2009) taking forward a number of actions including developing targeted and relevant health information for LGB women , and collating data from LGB women regarding service uptake, satisfaction and health behaviour.

In addition, this study takes forward innovative research to generate an evidence base of what interventions are effective in addressing the differences and increasing the awareness of LGB women. The multi-method approach implements and evaluates a number of different digital and media campaigns that provide important evidence that will inform health campaigns within the LGB community and wider population in the future.

2. Research Methodology

This chapter provides an overview of the mixed method action research study, including details of how LGB women were identified and recruited using a variety of different sampling strategies. The innovative and responsive methods used to collect data through face-to-face and digitally mediated mechanisms enhanced the depth and breadth of the study data and provided additional data on how best to engage with this protected characteristic group. Maintaining confidentiality and anonymity were important to the success of the study. How this was achieved is described.

2.1 Aims and objectives

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

Five key objectives were identified:

- Increase the 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

2.2 Methods

A mixed method action research methodology, combined qualitative and quantitative data approaches, alongside reflective intervention to comprehensively examine cervical screening for LGB women in the North West. The project took place over an 11 month period, commencing in August 2010, completing at the end of June 2011 (Table 1).

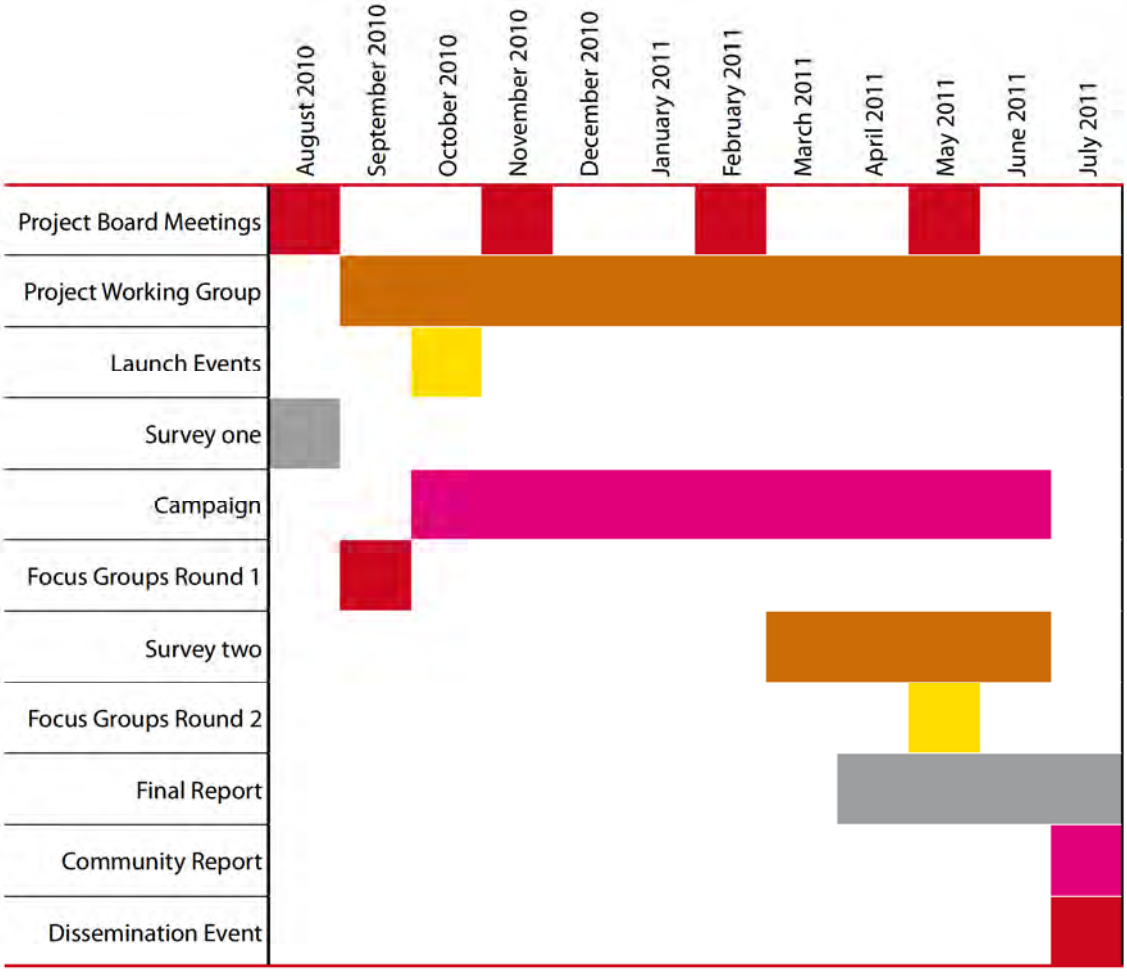
Surveys of LGB women were undertaken in conjunction with focused group interviews to examine the attitudes and experiences of LGB women with respect to cervical screening and gather a deeper understanding of the barriers to access which LGB women experience. Interventions were implemented and evaluated to measure the impact of an intensive campaign to directly influence LGB women's awareness and participation in cervical screening programmes.

A number of a-priori research constructs, exposed from the critical analysis of current evidence (chapter 1) underpinned the research approach and informed data items along with the focus of interventions (Fish 2009). These included that:

- LGB women lack awareness and accurate information regarding their need for cervical screening
- LGB women participate less in cervical screening compared to the general female population
- Lesbian women perceive they are less at risk of cervical cancer
- LGB women experience heterosexual assumptions from health care workers when attending screening

The fundamental purpose of the research was to develop evidence to further understand LGB women's screening behaviour, to take action to increase the number of LGB women attending for screening and to provide insights that will inform future interventions, developments and national policy.

Table 1: Project timeline



2.3 Action research

The research was conducted in three distinct action phases and data gathered sequentially informed each phase.

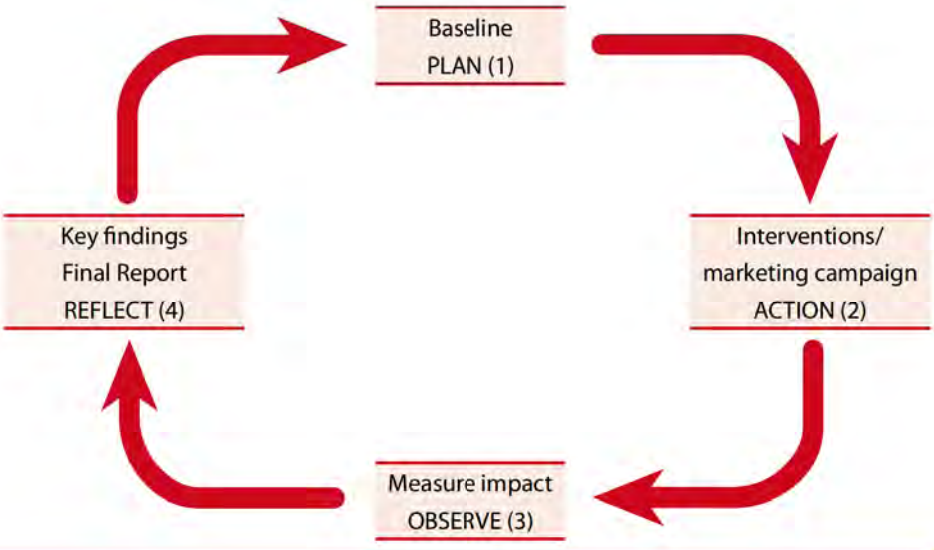
- Phase 1: Pre-campaign baseline survey
- Phase 2: Campaign/intervention/action
- Phase 3: Post-campaign evaluation

All three phases formed the overarching study action cycle, represented in its simplest form of; Plan, Act, Observe and Reflect (Lewin 1946) (Figure 2), with the fourth phase being dissemination of findings (described later). It is important to note that incorporated within each phase multiple sub-action cycles took place throughout the study approach; for example designing surveys, comparing baseline findings with what is already known, focus group feedback on campaign strategies, group analysis of interviews, and the progressive design, implementation and impact of interventions.

This methodology was suitable for the research in question, in that it facilitated an interactive inquiry that balanced problem solving actions and interventions with research to better understand theoretical constructs and ultimately influence behaviour change (Reason and Bradbury 2002).

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

Figure 2: The action research cycle



The research begins with an exploratory, intrinsic stance with the aim of developing a better understanding of the LGB women's experiences leading to the theorizing of LGB women's experiences of cervical screening. Through reflexivity, transparency, and critical examination of evidence in the light of relevant theory (Lincoln and Guba 1985) throughout the action cycle and sub-cycles with LGB women, theoretical constructs are confirmed or dismissed, explained and/or expanded (McNiff and Whitehead 2009).

The combination of qualitative and quantitative data generates a deeper understanding of the constructions of reality for LGB women, regarding their own risk of cervical cancer and experiences of accessing screening services. Involving LGB women in the progressive design of the study and appropriate campaign strategies, reflecting back findings and gathering opinions on how to engage better with the LGB population in the North West was an integral component of the participatory nature of the action research cycles.

2.3.1 Phase 1: Pre-campaign baseline survey

A pre-campaign survey formed the first exploratory stage of the research. Survey one was conducted prior to the awareness raising campaign, which included exploring how many women had been screened before the project, along with capturing women's experiences and knowledge of screening (appendix 1). This questionnaire provided a snapshot of LGB women's screening behaviour, along with their previous experiences relating to cervical screening.

The purpose of an exploratory questionnaire in the first instance was to expose data relevant to the research constructs and compare LGB women's experience in the North West with existing evidence, prior to intervention. 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 this information to the community and strategies identified were then taken forward into the intervention action phase.

2.3.2 Phase 2: Campaign/intervention/action

The intervention strategy built on the work of NHSCSP and in cognizance of the recommendations from the systematic review by Fish (2009), taking action on increasing the awareness, confidence and knowledge of LGB women of cervical screening in order to increase uptake of screening. Combined initiatives were implemented (described in detail in chapter four), including:

- Project launch events.
- Focus groups.
- Poster and postcard campaigns.
- Promotional goodies.
- Development of an information resource.
- Advertisements - in print and online.
- Creation of health website content.
- Production of video content and interactive games.
- Engagement with social media (Facebook, Twitter, YouTube).
- Radio advertising and interviews.
- Undertaking community outreach work.

The responsibility for the marketing and intervention campaign rested with the LGF, who have considerable experience in undertaking outreach work and communicating messages to an LGB audience. Within the staff team the 'Women's Leadership Group' who

lead the Women's Programme work stream provided specific organisational intelligence and advice regarding the LGB community and were used as a reference group for the study campaign materials and implementation strategy. Interventions identified above such as advertisements, focus groups, outreach work, social media and radio coverage form part of the everyday business activity for a variety of health awareness campaigns already in operation.

2.3.3 Phase 3: Post-campaign evaluation

A second survey was administered after the awareness raising campaign (appendix 2), investigating LGB women's screening behaviour and any changes in behaviour as a result of the campaign, along with questions about the campaign and the success of interventions used. The survey was grounded on survey one focus group data and baseline findings.

The second part of the survey was much more theoretically driven. The purpose of this was analytical – to focus on the interrelations between the a-priori theoretical constructs and inform the revision of these in combination with more detailed focus group data. For example, we were keen to understand if people in a particular geographical area or age group may react better to different interventions. In taking this approach, theoretically interesting cases could be identified from the survey population, and recommendations for full project roll-out informed. Again focus groups were used to explain, confirm and understand emerging findings.

Although intervention evaluation was integrated within each of the research data collection methods, additional mechanisms were utilised to provide direct feedback with respect to campaign interventions. For example readings of campaign materials and exchanges were monitored on various social media platforms (such as Facebook, Twitter, and LGB networking websites).

2.4 Ethics

Ethical approval was sought for the study from the University of Salford Research Governance and Ethics Committee and approved in August 2010, prior to the study commencing.

A number of different recruitment strategies were utilised within the study. Underpinning and embedded within each strategy was the need to respect individuals and their rights to privacy, anonymity and confidentiality, alongside ensuring participants recruited in the study were fully informed and aware of how the data they provided would be used to inform the study aims.

2.5 Survey sample and recruitment

It was difficult to estimate a representative sample for the study given that there was no definitive intelligence to indicate the size of the LGB target population nationally or within specific regions (Meads *et al.* 2007). Therefore, a multi-method sampling strategy was employed to target as many LGB women as possible within the time frame available. This included opportunistic sampling of LGB women at annual events, supported by access to the survey online from the website. Survey two also included the use of a LGB women's mailing list compiled through email collated from survey one responses. The aim of the study was to gather as many responses as possible within the time frame available.

It was estimated that between 300-500 surveys could be administered at each survey data point during two annual LGB community events (Manchester Pride/ Blackpool Pride) and via more general outreach work. It was estimated that 50-100 surveys could be completed on-line, but these figures were dependent upon if and how the LGB women's community engaged with the study and in turn the impact of the campaign.

2.5.1 Pride festival recruitment

An opportunistic/convenience sampling method was considered appropriate, in the first instance targeting LGB women at one of the most popular North West LGB annual events, Manchester Pride 2010 (27-30 August 2010). The LGF had numerous stands in different locations throughout the event, advertising the Foundation's activities. LGF staff asked women attending the event that approached the stands whether they would be interested in participating in a survey. Outreach workers also solicited participants by walking around the event space.

An initial screening question was used to recruit participants applicable to the study aims, for example '*This survey is for lesbian and bisexual women over 16 years old who live in the North West – does this apply to you?*' On providing a positive response the women were provided with a verbal explanation of the study, a copy of the information sheet (appendix 3), and time to ask questions, before agreement to complete the survey was sought.

The questionnaire took no more than 5-10 minutes to complete. Given the type of opportunistic sampling method being used, participants were recruited at the same time as being provided with the study information, although potential participants were offered the choice to come back and complete the survey at a later time, given that the data collection took place across the four days of the Manchester Pride festival. Over the course of the weekend it was anticipated that between 300-500 questionnaires would be administered.

A similar approach was used for the follow-up survey administered at Blackpool Pride Festival (11 June 2011) towards the end of the campaign. Although a smaller event than Manchester Pride it was considered theoretically important to sample outside Manchester to capture a wider geographical sample.

2.5.2 General outreach work and recruitment via the campaign

Participants were also recruited via the LGF's general outreach work. Outreach work specific to the campaign and campaign materials and process as described in chapter four were also engaged.

2.5.3 On-line recruitment

Both the pre and post surveys were available for completion online at two specified time periods of between 27 August 2010 – 5 October 2010 at the start (survey one) and 2 May 2011 – 12 June 2011 at the end of the campaign (survey two) on the LGF Website. Some initial surveys for round two were sourced at an event in March 2011. The survey purpose was advertised, an electronic version of the information sheet (appendix 3) was available for potential participants to read, and an email contact was available to ask questions if necessary prior to completing the on-line version of the questionnaire.

Consent was presumed on completion of an online survey, and responses were completely anonymous. Lime Survey™ an open source online survey application was

used to gather responses, stored in a password protected on-line facility until downloaded to a password protected computer within the LGF. The database was only accessed by the project lead and research team. This survey facility automatically collated data items within an excel database to facilitate statistical analysis (in addition to enabling data import to SPSS where appropriate).

2.5.4 Email sample database

With the completion of each baseline survey LGB women were asked to volunteer their email contact address if they were willing to be contacted further regarding the research study. All email addresses collected throughout the course of the study were managed on a password protected database based at the LGF, accessed by the project lead.

Email contact information was used only for the study purpose, (where the participant had requested to be added to other LGF mailing lists this information was held and accessed on a different password protected database). This ensured that all email addresses remained confidential and were not shared outside the LGF. All contacts within the database were invited by email to participate in the follow-up survey (2), and sent a link to the online survey and study information sheet. A follow-up email was sent after 14 days to remind those participants who had not returned a completed survey after which if there had been no response, no further contact was made regarding the survey. Completed surveys returned on email were downloaded to a password protected computer, coded and stored separately to the email identifier to ensure anonymity.

2.6 Focus groups

The purpose of group and individual interviews was to explore and gain a deeper understanding of behaviour and experiences of cervical screening, knowledge and in turn the impact of the campaign on their behaviour.

Sixty participants were targeted to take part in six focus groups. Between 8-10 participants per group was considered a maximum number to manage within a group discussion at any one time to enable effective facilitation of group discussion. Discussions were guided by semi-structured topics (appendix 4) but not restrictive, enabling women to discuss issues that were important to them. Participants who agreed to take part in the initial focus groups were invited in the first instance to be involved in the second focus groups taking place later in the study.

Six focus groups were considered manageable and appropriate in the time frame available, three at the start (month 2/3) to explore and enhance baseline findings and three were to take place later in the 12 month project (month 9/10) to further evaluate the impact of the interventions on cervical screening experiences, behaviour and knowledge. LGB women's groups known to the LGF were approached, and permission to address the group negotiated, accessing a scheduled meeting to explain the study and providing copies of the study information sheet (similar to appendix 3) for all group members. Group members who were interested in volunteering to take part in a focus group were asked to reply using email or telephone contact. A focus group meeting was then organised at a time and place that suited participants.

Given that this was a North West study focus groups were located where the women normally meet if preferred, or a room booked within the geographical area to minimise travel time for participants. Each focus group involved no more than ten participants,

the discussion was facilitated by a member of the research team and/or the project lead, lasted between 1-2 hours, and was digitally recorded with the consent of all participants.

Prior to the start of each focus group participants were provided time to ask questions about the study and their agreement to be involved confirmed, then each participant was asked to provide written consent (appendix 5), taken by the group facilitator. Ground rules for each group included ensuring they understood the need to respect confidentiality and anonymity regarding topics discussed, allowing people time to speak, and only sharing experiences that they felt comfortable discussing. Participants were invited to complete a follow-up survey and take part in a second focus group at a later date, but were not committed to take part, and could withdraw their consent to be involved at anytime.

2.7 Intervention feedback

It was impossible at the outset to determine the level and amount of feedback gained using on-line evaluation strategies for interventions, for example a video posted on a LGF website may get 30 anonymous comments from service users, whereas a poll deployed via the website which rates the same video might get 200 anonymous responses. However this feedback mechanism was the safest and least intrusive given the nature of the service in question and LGB women's right to privacy.

Data occurring in the public domain posted as comments on websites was thematically analysed for content relevant to the LGF's campaign and if quotations were used, the consent of those individuals who posted the comments was sought.

Any comments posted were cleaned with respect to identifiable names, places and groups to ensure the anonymity of participants was maintained. Phrases used from transcripts in this final report or later in peer review papers were only selected if the source of the data could not be recognised.

2.8 Data protection and storage

Data protection was an important focus throughout the study and campaign and the operating guidelines of the LGF were followed with respect to maintaining client confidentiality and anonymity. All data collected was kept in a locked cabinet either in hand written/typed up/printed out hard copy form, or were electronically stored as encrypted files on a hard disk.

Interview transcripts were anonymous using research codes, non-identifiable to an individual or group. Data was cleaned with respect to identifiable names, places and groups to ensure anonymity of participants was maintained. Phrases used from transcripts in final reports or peer review papers will only be selected if the source of the data cannot be recognised.

An email address contact database generated as part of the study was only used for the purpose of the research study, and was password protected and accessed only by the project lead. At the end of the study participants were asked if they wished to be added to a LGF confidential mailing list prior to their details being erased.

Research data separate to the LGF campaign will be kept for a period of three years on completion of the study, allowing sufficient time post-peer reviewed publication for data to be challenged.

2.9 Research governance and delivery

The study was delivered by the project delivery team made up of LGF staff including Project Manager Annie Emery and Rachel Bottomley, with Professor Light, Dr Ormandy and Emma Coleman from the University of Salford, who met every month to monitor and review progress. However, beyond this initial project team, several other staff teams within the LGF were involved (for example Policy and Research, Finance, Communications, Design, and Distribution). The LGF Women's Leadership Group acted as an advisory group for the project.

In addition, quarterly governance meetings took place with the Project Board whose wider membership involved Rob Cookson, the Director of Programmes and Performance at the LGF and expertise from NHS Salford. Quarterly monitoring reports were generated for the funders (NHSCSP) to provide feedback on the developing study and emerging findings.

2.10 Data analysis

Data was collated from a number of sources, (for example surveys, focus groups and Google Analytics) and either imported electronically into SPSS databases, manual data entry or transcribed text from qualitative group interviews. Quantitative data was coded and interrogated using appropriate applications, predominantly focusing on the use of descriptive statistics and where appropriate inferential statistics were used to explore sub-group characteristics (such as age, geographical location) where data allowed. We have excluded details of inferential statistics within this report for brevity but these are available from the authors upon request.

Focus group interviews and qualitative survey data items were transcribed verbatim then combined as appropriate. Findings from successive focus groups were fed back into group discussions to explore and confirm similar or different experiences (Strauss and Corbin 1998). Qualitative data was analysed using thematic analysis grounded on an emerging theoretical framework where data was compared and contrasted within coded matrices (Miles and Huberman 1994).

Whilst individual cases are used as explanatory exemplars of extreme or comparable experience, the majority opinion through survey analysis reinforces prevalence and relationships between constructs, increasing the authenticity and credibility of data generated (Lincoln and Guba 1985).

2.11 Dissemination

Integral to the action research study was a continual flow of information between the research team, the LGB population, funders and local health care providers. The findings of the pre-campaign survey and the prospective study were communicated and disseminated back to the LGB population using opportunistic feedback mechanisms to inform and promote health (for example outreach and targeted community literature).

More formal dissemination included conference presentations (Making Diversity Interventions Count in Organisational Performance and Service Delivery, June 2011), a one day seminar and workshop for health practitioners and dissemination of the research findings within LGB networks, groups and press. This study will also be disseminated in peer reviewed academic journals – please contact the authors should you require copies of papers.

Access to an electronic copy of the whole report will be advertised and available through a variety of digital/electronic forums and websites – please contact the authors if you would like to request a copy. A community report has also been developed that summarises the key findings and messages of the study to continue to raise awareness of the need for LGB screening and health promotion – this is available from the LGF. An emailed electronic copy of this report and a URL link to the whole report will be sent to each participant who provided their email address contact.

3. Pre-campaign Evaluation & Findings

This chapter presents the pre-campaign baseline findings of the study. The purpose of this baseline phase in the research was twofold; to generate deeper intelligence of the knowledge, attitudes, experiences and behaviour of LGB women in the North West relating to cervical screening, and identify ways of how best to engage and recruit the hidden study population. Without such a baseline it was impossible to fully understand and explore the barriers LGB women face, and measure the impact of the subsequent intervention campaign. Indeed this survey is only the second of its kind to expose and gather regional intelligence within the North West of LGB women's health behaviour, the first being Hunt and Fish (2008), a national survey, where 638 LGB women participated from the North West region.

3.1 Survey one sample characteristics

An opportunistic/convenience sampling method was adopted, which in the first instance targeted LGB women at one of the most popular North West LGB annual events – Manchester Pride 2010 (27-30 August 2010). In addition an electronic copy of the survey was placed on-line and access links advertised widely throughout LGB women's networks from 27 August 2010 – 5 October 2010 at the start of the survey.

Survey one obtained 647 responses overall. Of these, 82 were via an online survey tool and 565 via a print based survey. Of these responses 36 responses were removed from the sample as they either provided no age information and/or were not based in the North West of England, leaving an overall valid sample of 611.

The majority of LGB women who participated in this survey, 475 (78%), were not aware of any campaigns targeting LGB women about cervical screening. 117 LGB women had seen some cervical screening campaigns, of which 55% were Manchester residents.

3.1.1 Age and sexual orientation

Analysis of sample characteristics indicate that the majority (79%, 483) identified their sexual orientation as lesbian, with a considerably lower number of bisexual (13%, 80), and gay (8%, 47) women represented, with one person choosing not to identify their specific sexual orientation from the list provided, however they did state that they identified as either lesbian, gay or bisexual in a previous question. Indeed lesbian women were the highest participants across all age groups (16 to 64) (Table 2, Figure 3).

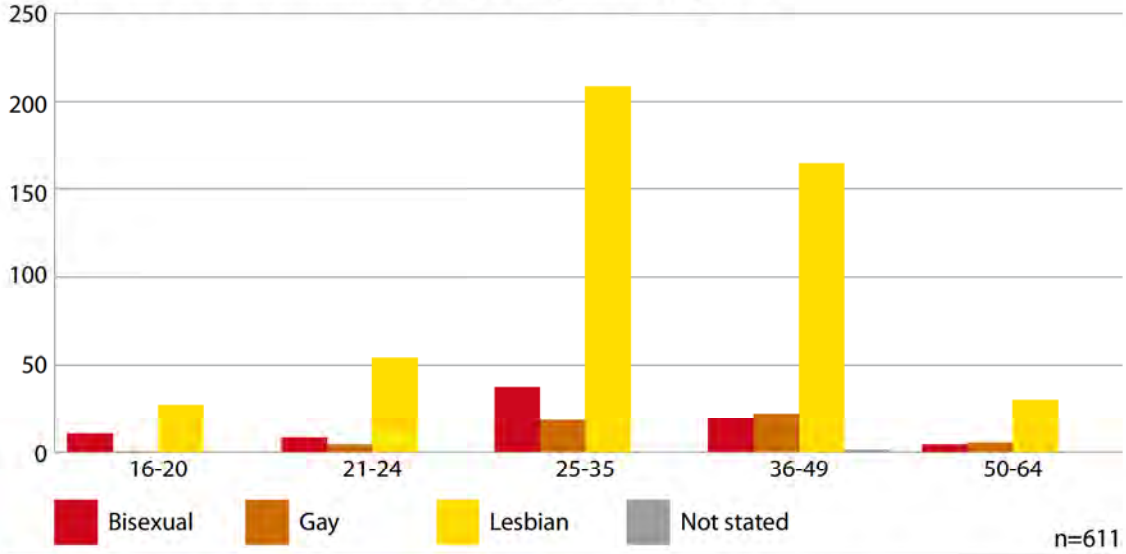
Table 2: Sexual orientation (by age range - survey one)

	16-20	21-24	25-35	36-49	50-64	Total
Bisexual	10	8	37	19	4	78
Gay	0	4	18	22	5	49
Lesbian	27	54	208	164	30	483
Not stated	0	0	0	1	0	1
Total	37	66	263	206	39	611

n=611

The majority of women 77% were aged between 25-35 (263) and 36-49 (206), 43% and 34% respectively. Younger LGB women (aged less than 24 years) represented 16.9% (103) of the sample and older LGB women (aged over 50 years) represented only 6% (39). Therefore the sexual orientation of those aged between 25-49 years (469) was mostly lesbian (372) compared with a lower number of bisexual (56) and gay (40) women.

Figure 3: Sexual orientation (by age range - survey one)

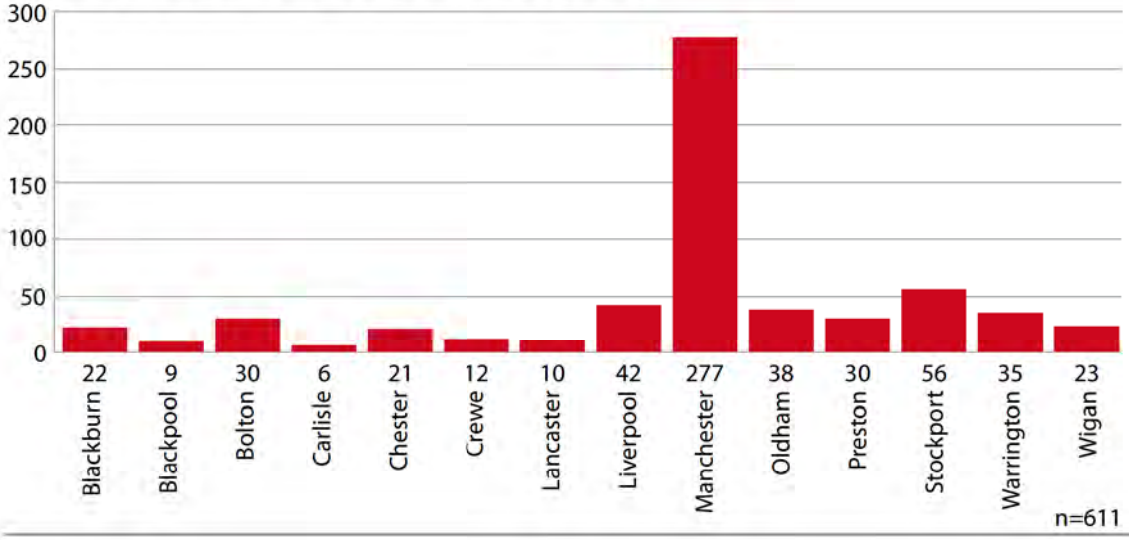


It is important to note that not all age groups will be included in the analysis and that we will group certain age ranges together on a question by question basis. Specifically, for example, questions regarding such things as awareness would include the whole sample, whereas the specifics of having undertaken screening would be reserved for those aged 25 years of age and over, as this is the age from which women are currently invited to attend cervical screening in England. Moreover, within this group, it is at times necessary to create two groups 25-49 and 50-64 in order to analyse areas such as the timeliness of cervical screening attendance in the light of NHS guidance.

3.1.2 Location

LGB women who responded to the survey originated from 14 different areas across the North West region, which was captured by recording women's post codes. Understandably given that the survey was distributed at Manchester Pride the majority of LGB women originated from within Manchester, 277 (45%) compared with the other 13 regions where responses ranged between 6-56 and 1-9% (Figure 4).

Figure 4: Domicile of participants (survey one)

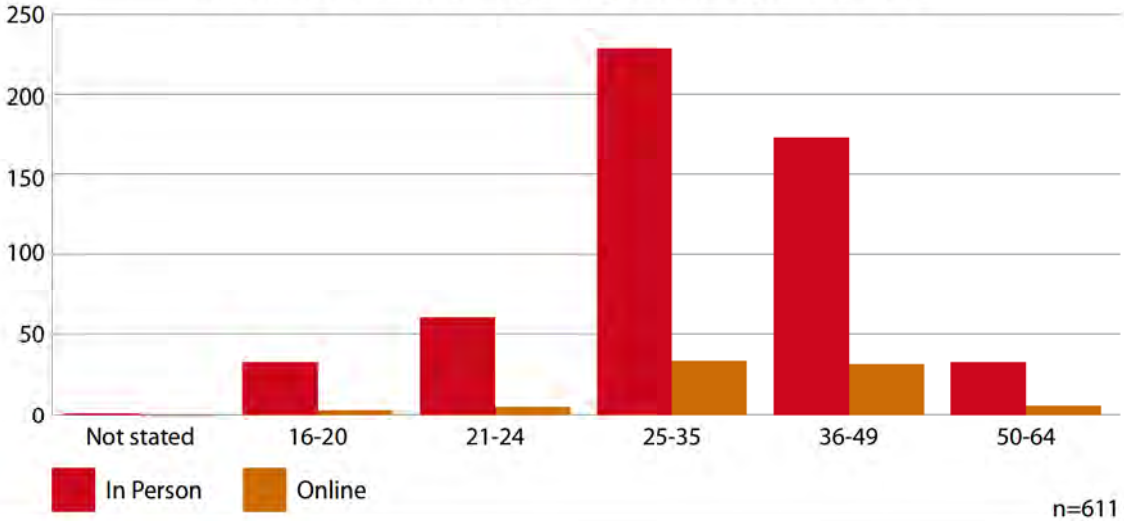


The three highest regions represented by the sample included: Manchester (277, 45%), Stockport (56, 9.2%) and Liverpool (42, 7%). The three lowest represented areas included: Carlisle (6, 1%), Blackpool (9, 2%) and Lancaster (10, 2%).

3.1.3 Mode of survey completion

Face-to-face survey completion at Manchester Pride Festival was successful in targeting a large number of LGB women with 531 (87%) surveys completed over the four day period. A further 80 (13%) surveys were completed on-line, reflecting initial response estimations (Figure 5). The majority of LGB women who completed the on-line survey (75%) and those who completed the in-person questionnaire (76%) originated from Manchester and were aged between 25-49 years.

Figure 5: Mode of survey completion (by age range)



The different methods of survey administration showed no clear advantage over the other with respect to attracting LGB women from specific age groups or different regions.

3.1.4 Focus groups

It was envisaged that three focus groups would take place prior to the intervention phase. These would be in different geographical locations to facilitate wider regional access for those women interested in participating. Only two focus groups came to fruition (one in both Manchester and Liverpool) with the group being planned to take place in Blackpool being cancelled (Table 3). Unfortunately researchers were unable to recruit LGB women from Blackpool in the time frame available, despite using four email contacts provided on survey one by participants and using LGB women's networks in Blackpool to advertise the event to a wider audience.

Table 3: Focus group participants

Location	Date	No. invited	Duration of nterview (mins)	No. attended
Blackpool	Cancelled	4	0	0
Liverpool	29/09/10 (6-8pm)	5	26	3
Manchester	30/09/10 (7-9pm)	21	85	9

The purpose of the focus group was to explore in detail LGB women's attitudes and experiences regarding cervical screening. All participants identified themselves as LGB women, over the age of 16 years, and living in the North West. More specific characteristics such as ages of individual participants were not recorded. In addition one participant who was unable to attend a group meeting wrote down her experiences in email and gave verbal consent that they should be used to inform the study.

3.1.5 Analysis

Survey data was analysed using SPSS and predominantly descriptive statistics. Qualitative thematic analysis of focus group interviews are presented alongside statistical findings, as exemplars individual experiences to situate, corroborate, and explain key issues highlighting LGB women's experiences of cervical screening. Two narrative excerpts have been drawn out from the group interview text to highlight the experiences of two different LGB women. These are referred to as the pseudonyms of Jane and Karen.

Eight key themes emerge from the findings:

- Is cervical screening necessary?
- Do LGB women think they are at risk of cervical cancer?
- Cervical screening test behaviour.
- Not attending/avoiding screening.
- Misinformed due to sexual orientation.
- Heteronormative assumptions and discrimination.
- What has encouraged LGB women to attend for screening?
- What would improve services and screening?

3.2 Is cervical screening necessary?

Participants were asked whether they thought LGB women needed cervical screening. Out of 609 LGB women who responded, 91% (556) agreed that LGB women need to have cervical screening tests, 4% (24) did not know whether such a screening test was required, and 5% (29) responded that screening was not necessary for LGB women (Table 4).

Table 4: Do LGB women need cervical screening?

		Yes	No	Don't know	Total
Age Range	16-20	35	0	2	37
	21-24	62	1	3	66
	25-35	238	13	11	262
	36-49	186	13	6	205
	50-64	35	2	2	39
	Total	556	29	24	609

n=609

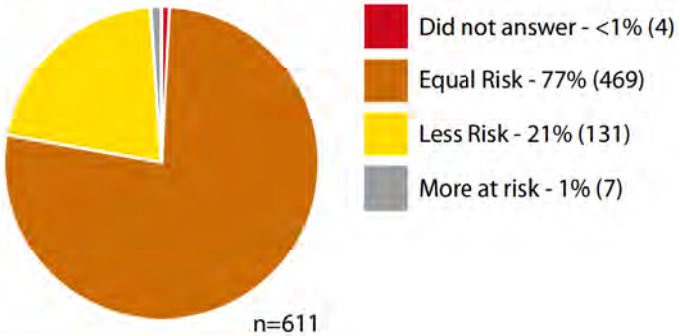
Although the majority of participants were aware that LGB women needed cervical screening, 47 (8%) of LGB women sampled, aged between 25-64 years either **did not know** (19) or **perceived that LGB women did not need** cervical screening tests (28). A closer examination of these 47 LGB participants' who were eligible to access the national

screening programme, revealed that 44 perceived themselves to be at less risk than heterosexual women, 37 had been told they did not require a test and as a result 28 LGB women had never been screened. This is explored in more detail in later sections.

3.3 Do LGB women think they are at risk of cervical cancer?

The majority of LGB women 77% (469) considered lesbian, gay and bisexual women to be at equal risk from cervical cancer compared to heterosexual/straight women, of these the majority were aged between 25-64 years (80%) (Figure 6).

Figure 6: Perceived risk of cervical cancer for LGB women as compared to heterosexual women



n=611

Interestingly, of those 469 LGB women who considered lesbian, gay and bisexual women to be at equal risk from cervical cancer, 169 (36%) had not responded to a screening invitation and 129 (27.5%) had been told a screening test was not necessary.

LGB women were considered to be at less risk from cervical cancer compared to heterosexual/straight women by 131 (21%) participants. The majority of these, 93% (122) were aged between 25-64 years, of which **53% had been told a screen test was not necessary** (Table 5), and a further 91 (70%) had failed to respond to a screening invitation. 40 LGB women eligible for screening who thought they were at less risk had never had a cervical screening test and 27 believed LGB women did not need a cervical screening test.

Table 5: Perception of LGB women at less risk - told a test was not needed

	16-20	21-24	25-35	36-49	50-64	Total
Did not answer	0	0	1	0	0	1
Yes	1	2	32	30	5	70
No	3	3	26	24	4	60
Total	4	5	59	54	9	131

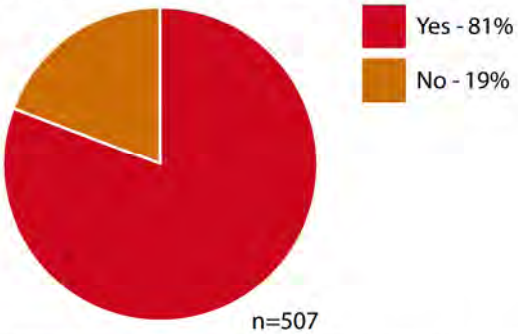
n=131

Only seven LGB women (1%) considered themselves to be **more** at risk from cervical cancer compared to heterosexual/straight women.

3.4 Cervical screening test behaviour

Survey responses regarding cervical screening behaviour were analysed for LGB women aged 25 years or over, as women below this age would not routinely be called for a test, following NHS guidance. From a sample of 507 LGB women aged between 25-64 years old, 81% (411) indicated that they had at sometime in their life attended for a cervical screening test, with **19% indicating they had never been for a test** (Figure 7).

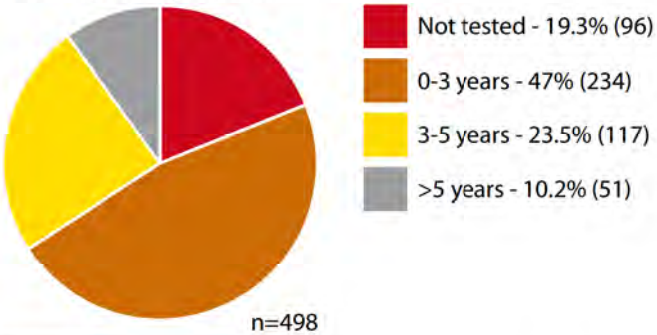
Figure 7: Have you ever had a cervical screening test? (survey one)



n=507

LGB women were asked to identify a time frame of when they last attended for screening. From an eligible sample of 498 LGB women between the ages of 25-64 years, **70.5% accessed screening within the last five years**, 96 indicated that they had never been tested (Figure 8).

Figure 8: Frequency of screening tests for LGB women aged 25+ years (survey one)



n=498

On closer examination of the screening uptake and age it was highlighted that only 48% of LGB women aged between 25-49 years (461) had accessed a screen test within the last three years, as recommended by the national screening programme, although 70.5% had accessed a screen test within the last five years. Of these women aged between 50-64 years, 73% had accessed screening within the last five years as recommended (Table 6).

Table 6: Timescales of last cervical screening test (by age group)

	25-49	50-64	Total
Not Tested	93	3	96
0-3 years	219	15	234
3-5 years	105	12	117
>5 years	44	7	51
Total	461	37	498

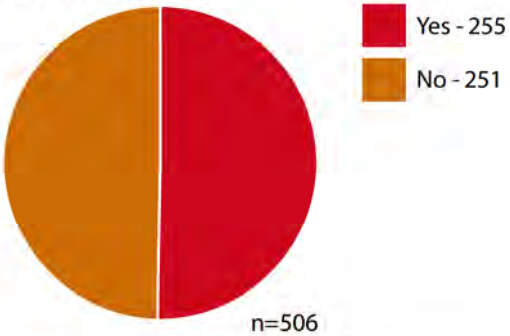
n=498

Overall the data exposes that only 49% of LGB women tested within the recommended timescales. More importantly, this indicates that 51% of LGB women had either never had a test, or not had one within the recommended timescales.

3.5 Not attending/avoiding screening

The survey data indicated that 255 out of 506 LGB women (approximately 50%) eligible for screening had failed to respond to an invitation for a cervical screening test (Figure 9) at some point. Of these 90 (35%) women considered themselves **less** at risk of cervical cancer than a heterosexual/straight women.

Figure 9: Have you ever not responded to a cervical screening invitation?



A number of reasons why LGB women don't respond to cervical screening were exposed through qualitative responses within the survey and reinforced within the focus groups interviews. Not getting around to booking a test and the fear, pain, discomfort and embarrassment of an invasive procedure were reasons put forward by women as to why they may not engage in cervical screening programmes. In addition, reasons which relate to sexual orientation such as being told you do not need to access screening if not engaging in sexual activity with a man were also cited.

The most common reason for not attending screening identified from 101 LGB women (17%) in the survey was that many women just hadn't got round to organising a test. A reason for this was being too busy with work, especially making an appointment during work hours, creating a barrier to booking a test. A further 39 women indicated that they had not yet organised their cervical screening because they had moved area.

A number of women across the focus groups indicated that the fear of what to expect, whether it would be embarrassing, and the possible response of a health care professional, put many LGB women off booking an appointment. Data suggests that the more a woman put off having a screening test the more difficult it became to book an appointment as the fear of what to expect increased.

> *'I think there is fear as well as embarrassment... fear of what is going to happen, is it going to hurt, will it be embarrassing, will I make a fool of myself because you are never quite sure what sort of response you might get, what level of care you might get and that was a factor for me being too scared to go really. Cervical screening it is also about sex... you might be asked questions about your sex life and the added apprehension of what you might be asked questions'*

> *'Sometimes it's the fear of it and when you get there it's not as bad, everyone builds it up'*

Pain experienced by women during the test was evident in some of their narratives (Box 1). We were told by some that they thought the size of the speculum used within the test related to the level of pain women experienced, and as Jane's experience tells us, stress

can also be a factor. Some LGB women, like women in the general population, recounted negative experiences of the procedure, with respect to it being very painful, but also regarding the manner of the health care professionals. Issues were also raised around privacy and maintaining a person's dignity during the procedure.

> *'She was really awful this first woman I had and she was rooting around saying 'I can't see it, I can't find it' and I was 'Ow, Ow', then she said I really can't find it and she was getting quite cross about it and she left the room and left me there with my little piece of paper towel over me with my legs akimbo. Then this chap comes in and he couldn't find it then someone else comes in they did find it (my cervix) and she said next time you have it done remember it is down to the right... It was really horrible being left there though on the examination couch and having three different people come in...That was really bad'*

Box 1: Jane's experience

'For my whole life I was told by my GPs that I didn't need to have a smear test because I am a lesbian. Even certain counter-information from gay organisations would say that lesbians need a smear because they may have had sex with men or shared sex toys. As I had never done either of those things I decided I didn't need a smear test. Something at the back of my mind niggled at me and told me I should still go, but as the thought of it terrified me, I clung onto the fact that I was told I didn't need to go for one. I would always get regular letters from my GP asking me to have smear tests or saying my smear tests were well overdue, but I ignored them, and whenever the GP asked me I would say I didn't want one, and they sometimes asked me to sign a waiver to say they had recommended it and I had refused it

I feel like my decision to have the smear test was a huge mistake. The nurse understood my situation, and I was completely honest with her, and she tried to set my mind at rest. But when she carried out the procedure I was in complete and utter agony! I am embarrassed to say I screamed in pain, and the nurse had to stop and remove the instrument, and went to fetch another nurse to help stay down by my head and coach me through it. They did it a second time and it was still agony but they managed to get a swab. As I stood up from the bed there was a lot of blood. It hurt when I walked or even sat up... I was off work for a few days. Eventually everything went back to normal. But I felt violated and traumatised by the experience. I don't know if I am over-sensitive 'down there', or if they should have used a smaller instrument with my being a virgin.

I do not ever want to go back for a smear test. It has scared me off.'

LGB Women reinforced the need for more accurate information, to be more aware of what the test involves and what to expect to allay fears.

> *'They invite you for your first smear test and they tell you nothing - they don't tell you what to expect, whether it would be painful you just don't know what to expect'*
>
> *'They think you know so much and you know so little'*
>
> *'She just assumed I knew what would happen but I didn't have a clue'*

3.6 Misinformed due to sexual orientation

From the survey and interview data there was clear evidence that LGB women have been misinformed for many years, particularly those identifying as lesbian. The qualitative responses on the survey highlighted that 35 LGB women did not think they required a test because of their sexual orientation, 38 women didn't think it was important, and 61 had been told directly by a health professional, family or friends that because of their sexual orientation it was not necessary.

The myth of not needing a cervical screening test is being reinforced within the lesbian community. Although it was perceived by some that awareness of cervical screening was increasing amongst LGB women there was recent evidence to suggest some LGB women lacked awareness and were misinformed.

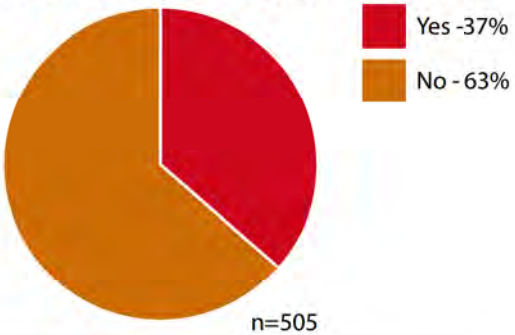
> *'A few years ago I was involved in a project, a LGB women's health project and we went on a camp and I'd read all the leaflets and I heard these two girls talking and saying you don't need to go and we had this massive debate on whether you did need to go'*

> *'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'*

> *'When I was younger in my 20s the lesbian community then was definitely (thinking) that you didn't have to go but now it has filtered through with the people I associate with is that you do need to go and that has filtered through I would say over the last ten years really but prior to that you didn't need to bother...'*

Indeed the survey uncovered 184 (37%) out of 505 LGB women had at some point been told that LGB women did not require a cervical screening test (Figure 10).

Figure 10: Have you ever been told that you do not need a test because of your sexual orientation?



n=505

Being told that LGB women did not require a screening test negatively influenced the behaviour of 37% in terms of these women accessing routine testing. LGB women within the group interview provided experience of having been told a test was not necessary by health care professionals and more importantly how this delayed their access to screening for a number of years. Women agreed that because of the invasive nature of the test, sometimes being told that screening was not necessary was seen as a 'good' thing, as it is not a test you would want to have performed if it was unnecessary. Therefore this misinformation was often not challenged.

> *'…for those six 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...'

'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 didn't have sex with men I wouldn't need one for a good ten years. It did affect me going for another - she hurt and it was about 15 years to my next one'

'I was told by my (former) GP that as a lesbian it was unnecessary!'

Sexual orientation was clearly the reason health care professional's discouraged LGB women from accessing national screening programmes, and in many cases directly refused access to women, despite their requests to be screened.

'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 two years ago...'

'My Dr did not approve of me having one due to the fact I was gay'

'My nurse told me I didn't need a cervical screening test because I was a lesbian even though I explained I've slept with men. Also, all the info was very heteronormative'

'When pressed about what contraception I used I told them I was gay and the nurse then proceeded to go to all doctors in the centre and ask to see if I needed one. She said I didn't need one but I requested one anyway'.

'Negative experience was being told I was wasting nurses time for going for a test because I was a lesbian and 'of course' I didn't need one'

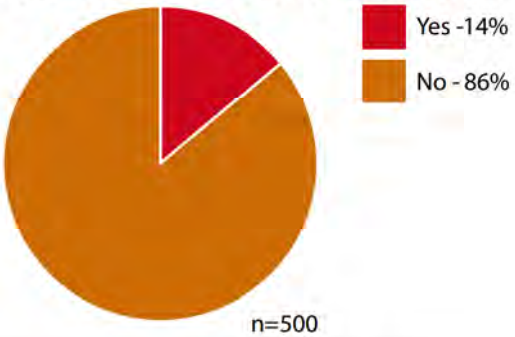
The evidence indicates that the perception by some health care professionals was that if you were not having heterosexual sex then you would not require a screening test, and indeed this was the advice for many years from national bodies. However the discriminatory refusal of LGB women to access services was upsetting for many and LGB women often lacked the confidence to fight for what they perceived to be their right.

'She said 'have you ever had one?', 'No' I said and she said that's because I was not sexually active...the line of questioning was basically if you don't have penetrative sex you don't need anything and I felt really upset as well because I thought what if...I could still have abnormal cells and I thought I should really push for it, but then I thought I can't be bothered ...can't be bothered, I can't face that, you know?'

'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'

Evidence from the survey data indicated that 71 LGB women out of 500 (14%) had been actively refused or discouraged from having a cervical screening test as a result of their sexual orientation by a health professional (Figure 11).

Figure 11: Have you have been discouraged or refused a test because of your sexual orientation?



Misinformation on the part of health care professionals and health services has reinforced and contributed to the lack of awareness by LGB women for the need to be tested. This has clearly contributed to the reduced response of LGB women attending for screening. Further analysis of the 96 LGB women (aged 25-64 years) who had not attended for screening highlighted that 22% perceived screening to not be necessary, **42% perceived they were less at risk, and 43% were told the test was not required because of their sexual orientation.**

3.7 Heteronormative assumptions and discrimination

The style of questioning used by health care professionals was considered to be inappropriate and irrelevant for LGB women accessing screening services. Indeed services were inherently heteronormative and did not appear to accommodate the needs of LGB women. Many LGB women described a standard line of questioning when attending screening regarding sexual activity and contraception.

'It is like that person has had their training and they are going to ask those questions regardless and they don't even listen to the answers and even if you register at the same practice for a while they still go down the line of are you sexually active and then are you using contraception… they get all the way down and you can almost see the confusion on their face and their brain ticking and you can turn it around and make them feel embarrassed and if they had read their notes then they wouldn't have to feel like that...'

'When they ask what contraception are you using and you say 'nothing', you can't leave it like that, so you have to explain yourself and that is the only negative side - that you have to kind of explain yourself'

'All women need a smear whoever you sleep with so there is no real point asking, sexuality is irrelevant'

LGB women described experiences of discrimination and feelings of apprehension at having to explain their sexual orientation when being asked heteronormative questions. This prevented some LGB women from answering the questions honestly, worried about the response they would get from the health professional, while others experienced negative attitudes and homophobic prejudice (see Karen's experience, Box 2).

Box 2: Karen's experience

'Well I got a lecture basically... the first time I went I was trying to be all responsible about my health and I thought I would respond to this and the first question was are you sexually active and I said YES, then they asked what contraception are you using and I'm said I'm not using any and they said oh are you trying to get pregnant then NO... then it was a tirade and I was only 25, about 'do you know how irresponsible you are being and how at risk you are of all sorts of disease and if you're not trying for a baby then you really need to be using contraception' and she went on and on like that... and I was actually really frightened.. and in the end I said I don't sleep with men I only sleep with women and she physically recoiled and was shocked and she said you well you don't need a test... and they packed me off'

Of the LGB women who completed the survey, 78 (12.7%) indicated that they had previously had a negative experience relating to their sexual orientation. Whilst some women reported positive experiences, there was clear evidence that some health professionals had not received appropriate training in managing situations and understanding the needs of LGB women and needed improved skills.

'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'

'When I first went for one…I was told I didn't need one. It was her face, I'll never forget it but she was physically repulsed, and that is how it felt, she was absolutely appalled… but I do think it is getting easier and we are a bit more visible than we used to be'

'Health professional training is definitely a good idea - not just what they say but how they say it, and pre-warn them that they do have some gay patients'

'I was screened when I came out and it was more me worrying about what she might think… she was the most non-judgemental nurse you could meet so I told her and she said oh fair enough and just carried on as normal'

'I was declared 'sexually inactive' as my sexual practice apparently was 'not applicable"

'A nurse at my local surgery was clearly uncomfortable with my sexuality making me feel very uncomfortable and hinted she wasn't happy to do the test'

'Nurse said I didn't need a test, so I didn't have one. I later went to my doctor to ask about this, to double check. My doctor confirmed I didn't need one. I wouldn't mind, but I didn't really want to 'come 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'

Coming out to a health professional was an issue discussed at length, and opinions were mixed with no consensus between women as to whether LGB women should or shouldn't inform the health professional regarding their sexuality during cervical screening.

'I'd rather they didn't know…'

'I think it is very tricky and I don't think they are able to ask you the right questions or provide the right health care if they don't know.. It's such a personal thing to do, coming out'

'I wouldn't tell my GP unless it was relevant. If I was going for sexually related problem then I would tell him but if I was going for a cough I wouldn't - it has nothing to do with it …I would come out to anyone else but only to my GP if it is relevant'

There were mixed views from LGB women regarding sexual orientation monitoring, some advocated that it should be recorded to ensure more relevant health care provision in the future (so questions would be tailored to their needs, for example), whilst others feared worse discrimination and would refuse to disclose the information. This is a common issue when collecting demographic information however it is widely thought by equalities organisations that if demographic information is collected, this should include sexual orientation monitoring.

'Don't think it is relevant I would fear assumptions were being made'

'Well questions about contraception don't bother me as much because I'm bi, but the thought of it being marked down somewhere does fill me with a feeling of dread'

'I would totally fill it in… people should fill it in and then they would get a better service'

'Last week I said I was gay and things and if she had marked that down then that would have been better for me so the next time I go no-one will ask me about contraception and stuff'

'Well it's about confidentiality and they shouldn't really tell anyone anyway so they shouldn't share that information with anyone, and it would give them a better understanding of you especially if you go in with other problems - emotional or whatever - they would be better able to help you, wouldn't they?'

3.8 What has encouraged LGB women to attend for screening?

The national recall system was seen to be an effective way of sending out reminders to women and vigilant GP practices follow up women on their databases.

> *'When I moved to Manchester just over a year ago and I got a letter then a reminder, reminder, reminder every month and I just thought I would just do it so it works…'*

> *'I got a couple of letters through the door, then they started stalking me and I thought 'Jesus I better go!'…'*

LGB women reported that having the option to take the screening tests in places other than your GP surgery gave women a positive choice on where best to attend, with some preferring the anonymity of a specific clinic with more experienced staff.

> *'I think the option of having it somewhere other than your GP surgery worked better for me. I went to a sexual health clinic and had it there because then I just knew they were used to dealing with that sort of thing'*

> *'In my GP's there are people outside and it is not somewhere you can relax but knowing that I could go somewhere faceless would be better…'*

> *'Even though I go to these clinics and they are good at doing them I don't think any other lesbians go because I still get the same assumptions made that I am heterosexual… surely you must have met other lesbians but it feels that they haven't'*

The awareness of cervical cancer was raised nationally with the death of Jade Goody and this was seen by many within the groups as a reminder that women were at risk of the disease which prompted some LGB women to attend for a test. This was in line with national reports of increased screening due to the effect of this high profile case.

3.9 What would improve services and screening

The most overwhelming finding from the groups was the consensus of opinion regarding the need for more realistic and accurate screening information specifically for LGB women to identify clearly that LGB women need to attend screening regardless of who they sleep with, along with providing more general awareness of what testing involves and what the results mean.

> *'My situation was complicated because my girlfriend was a pre-op transwoman. Therefore I didn't know if this made me more susceptible to cervical cancer, even though we didn't have penetrative sex'*

> *'Telling them they have a right to go, you are eligible to go if you have a cervix, and someone telling you what is involved clearly, … but there is also knowing that there is a complaints procedure if you have a bad experience and there are ways to deal with homophobia and that it is illegal to provide a bad service to LGB women…'*

> *'People assume others have already told you, and they don't always have time'*

> *'It would be useful to have flyers and things'*

> *'If you weren't out and you spied the poster then it's a subtle reminder but not in your face, not too obvious'*

'I had a friend who was asked to come back in three months apparently because it gives the cells time to re-grow but she had absolutely no idea why and she spent the three months worrying and nobody told her anything'

'I had an abnormal smear but then was just told 'here is your hospital appointment' and I thought my days were numbered but again with no supporting information. It was within the month but just some clearer information would be better'

Developing dedicated women's health services were discussed and all the participants in one group agreed enthusiastically to the idea, particularly services that were specifically for LGB women, overcoming the majority of barriers faced in other mainstream health services.

'I always feel short-changed as a gay women, compared to gay men. They have access to many different rapid clinics and a choice of sexual health services and as a gay women you just have to slot in to mainstream… I think that also reinforces the view that gay men have clinic for everything and there is nothing for women and then there must be nothing wrong with women, otherwise there would be a clinic for it'

3.10 Summary of key baseline findings

The baseline survey highlights a number of significant findings that reinforce the notion that LGB women are and have for many years been excluded from cervical screening. This has had a direct impact on the number of LGB women (aged 25 to 64) who attend regular screening, which can be observed by a lower number of LGB women being screened when compared the general population.

- **Only 70.5% of LGB women reported screening within the last five years compared to 78.9% of the general female population.**
- **Just 49% of LGB women tested within the recommended NHSCSP timescales.**
- **51% of LGB women had either never had a test, or not had one within the recommended timescales.**
- **19% of all LGB women had never been for a cervical screening test.**
- **Over 50% of LGB women fail to respond to an invitation for a cervical screening test at some point.**
- **36% of LGB women had been told they did not require a cervical screening test. This influenced the screening behaviour of 66 of these women.**
- **14% of women surveyed had been refused or discouraged from having a test by a health professional because of their sexual orientation.**

This baseline study shows a higher number of LGB women (19%) who had never had a screening test compared to 14.3% of those sampled in the North West, and 15% of the 6000 LGB women sampled nationally in the 2008 study by Hunt and Fish (2008).

Despite this overall poor uptake of screening services, there was evidence that the majority of LGB women were aware of the risk of cervical cancer and considered LGB women to be at equal risk compared to a heterosexual/straight woman. This awareness of risk does not seem to be translated into screening attendance, which indicates that there are alternative reasons for non-attendance.

Many barriers were identified through the qualitative findings of this study that confirmed earlier studies. Inaccurate information has and is still being perpetuated throughout the LGB community, heteronormative questioning often occurs at screening tests and LGB women are apprehensive regarding coming out because of fear of discrimination and the homophobic attitudes of health care professionals and therefore avoid health services. There are clear experiences of LGB women being discouraged and refused access to screening despite the guidance as to who is eligible to access screening being widened and clarified in 2009. Whilst many women have had positive experiences, health care professionals are still misinforming LGB women and there is a lack of relevant routine training to enable health professionals to better understand and meet the needs of LGB women. Appropriate training for health care professionals would facilitate an improved service for LGB women and in turn influence the response and attendance at screening test, and therefore the equality of health outcomes for LGB women.

4. The Campaign

The 'Are You Ready For Your Screen Test?' campaign was devised by staff at the LGF, based on the theme of screen tests as undertaken by actors in the movie industry. The LGF are experienced in delivering innovative health campaigns for the LGB community, and the aim was to communicate messages regarding the necessity for LGB women to have a cervical screening test, in an engaging way that captured the imagination. This was to differentiate the campaign from generic health information which is historically more formal in nature, and which many LGB women may have disengaged from due to negative experiences of accessing health care. Further this allowed the team to draw upon the strength of the LGF more generally as an organisation that aims to engage people in health messages by 'making scary stuff not as scary'. The theme also facilitated engagement in different ways – for example, the use of promotional videos (going to the cinema) and torches (referencing usherettes). The campaign was also tied to the theme of events such as the Oscars as a result.

There were launch events in Manchester, Blackpool and Liverpool. The launch events involved a short presentation about the project and the need for LGB women to go for a screening test. The events also involved the playing of a specifically designed 'snakes and ladders' game and a general quiz (including questions and messages about cervical screening), and campaign resources were shared. Opportunities were given for attendees to speak to outreach workers about any questions or comments they had.

4.1 Press releases

The campaign was underpinned by a series of press releases. Throughout the campaign press releases were sent to over 250 targeted organisations including local, national and gay media, lesbian and bisexual women's specific magazines and web sites, health publications and cancer specific organisations. These were released on four occasions. In October 2010 a release regarding the launch of the campaign was undertaken, following the closure of survey one. In February 2011, a further round of releases related to publicising the headlines of survey one and the launch of the campaigns publicity videos. April 2011 saw a release associated with the launch of the 'Put your cervix in the spotlight" game, and in May 2011 a final release called for participation in survey two and post-campaign focus groups.

4.2 Campaign materials

Campaign materials were distributed through a variety of channels as shown in tables 7-10. In total, 25,000 postcards, 1,500 posters, 3,000 torches and 20,000 resource booklets were distributed.

In January 2011 a series of promotional videos were introduced (Figure 12). These videos parodied famous movie scenes from Dirty Dancing, Gone with the Wind, Pretty Woman and Star Wars. These videos were made accessible via the campaign's section of the LGF website, via the LGF's YouTube channel 'lgfonline' and via the LGF's Facebook page. To date they have received over 1,200 views. It is important to note that these videos were also screened to several groups of people at events thereby increasing the audience. Other film titles were also enrolled more generally – for example around Valentines Day a poster which played on the film 'Love Actually' was released (Figure 13).

Table 7: Examples of outreach events and locations

October 2010	Launch Events (Blackpool, Liverpool, Manchester), Blackpool outreach in LGB venues, Liverpool outreach in LGB venues, The LGF's monthly event for women, Manchester outreach in LGB venues.
November 2010	'Lesbian Community Project' drop in group, Blackpool outreach in LGB venues, The LGF's monthly event for women, Manchester outreach in LGB venues.
December 2010	University of Bolton Freshers' Fair, Women MATTA (a partnership between the Pankhurst Centre and Women in Prison), Liverpool outreach in LGB venues, The LGF's monthly event for women, Manchester outreach in LGB venues, Stepping Stones - an LB women's Social Group.
January 2011	Manchester outreach in LGB venues, Chorlton outreach in LGB venues, Todmorden/ Hebden Bridge outreach in LGB venues, Manchester City Council's lesbian, gay and bisexual (LGB) Mail Out, Co-op Diveristy event, Outreach at all venues on outnorthwest distribution list (across NW), 'Chew Disco' Liverpool, Blackpool outreach in LGB venues, The LGF's monthly event for women.
February 2011	Knowsley Healthcare centre outreach, Stockport College, Bolton womens' Disco, LGBT Centre event in Preston, Carousel LB Women's social group, The LGF's monthly event for women, Manchester outreach in LGB venues, Blackpool outreach in LGB venues.
March 2011	'Sugar & Spice' LGB women's event, Bolton Health Mela event, 'Pankhurst Women's Centre' event, The University of Salford equality event, Manchester Town Hall International Women's Day Event, Knowsley College, Liverpool outreach in LGB venues, Manchester outreach in LGB venues.
April 2011	Heather Peace gig, Stockport Health fair, Blackpool outreach in LGB venues, Manchester outreach in LGB venues.
May 2011	Salford Salix Homes event, Castlefield Gay Beach party, Bolton International Day Against Homophobia (IDAHO) event, Sackville Gardens IDAHO event, SM Dykes Conference, Blackpool outreach in LGB venues, Manchester outreach in LGB venues.
June 2011	Blackpool Pride, Salford equality event, Manchester outreach in LGB venues.

Table 8: Campaign material dissemination

	October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011	June 2011
Postcards	✓	✓	✓	✓	✓	✓	✓	✓	✓
Posters	✓	✓	✓	✓	✓	✓	✓	✓	✓
Torches	✓	✓	✓	✓	✓	✓	✓	✓	✓
Resource	✓	✓	✓	✓	✓	✓	✓	✓	✓
Videos				✓	✓	✓	✓	✓	✓

Table 9: Example of campaign presence in online and print health matter

October 2010	NHS North West HELP Portal
November 2010	Women's Grid Stockport NHS 'Diversity Matters' Lancashire & South Cumbria Cancer Network
December 2010	Blackpool Link
January 2011	Equality Cumbria
February 2011	Barnsley NHS Foundation
March 2011	Lancashire LINK bulletin Jo's Cervical Cancer Trust website
April 2011	Liverpool Link
May 2011	healthcarepromotions.co.uk Eve Appeal Website

Table 10: Examples of venues for distribution of materials at health sites and related events

October 2010	Merseyside Hospitals, Liverpool Womens' Hospital, Blackburn Hospitals/GP surgeries, St Helens surgeries, Warrington Hospital, Macmillan Services.
November 2010	mail out to GM GP surgeries, Oldham NHS venues, Wigan PCT, Wigan Healthcare venues, presentation to Blackpool GP Practice managers and at Bolton Practice Managers meeting.
December 2010	Cumbria GP surgeries, Christie Centre.
January 2011	Chorlton Health Centre, Oldham Community Health Services, Urban village medical practice, distributed across GM GP surgeries.
February 2011	Terence Higgins Trust, SHIVER Blackpool, Alexandra Practice (Chorlton), Cheshire Central PCT venues, distributed across GM GP surgeries.
March 2011	Jo's Cervical Cancer Trust, distributed across GM GP surgeries.
April 2011	Westmorland Hospitals, distributed across GM GP surgeries.
May 2011	Eve Appeal Gynocological Cancer Organisation, Cumbria PCT venues.
June 2011	University of Bradford Diversity conference.

Figure 12: Series of promotional videos

Gone with the Wind: released 25 January 2011.
Total views: 471

Star Wars: released 3 February 2011.
Total views: 214

Dirty Dancing: released 10 February 2011.
Total views: 277

Pretty Woman: released, 18 February 2011.
Total views: 306

Figure 13: Valentine's poster

In March 2011, a game was released as a further promotional and educational vehicle (Figure 14). The 'Put your cervix in the spotlight' game challenged people to use a 'spotlight' to find as many women as they could within 60 seconds. During the course of finding women, headlines regarding the findings of the pre-campaign survey were displayed to the player and at the end of the game a link back to the campaign site is provided. This game was used at events such as Sugar and Spice in addition to it being released for anyone to play at a time and in a place of their choosing. Interest in the game was generated, beyond the press release and the LGF's online spaces, via the use of social media such as Facebook and Twitter.

Figure 14: 'Put your cervix in the spotlight' Flash game

All campaign materials were distributed throughout a range of community outreach events across the region, to ensure that one-to-one meaningful engagement took place with individuals.

4.3 Print and online coverage

Along with campaign-specific printed resources such as posters, postcards and the information booklet, online and print magazine media coverage took the form of advertisements and educational articles regarding the campaign and the need for LGB women to engage with cervical screening. As can be seen in table 11 such content appeared at various points throughout the campaign, in various sources.

Table 11: Campaign print coverage

	October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011	June 2011
outnorthwest	✓	✓	✓	✓	✓	✓	✓	✓	✓
DIVA Advert			✓	✓	✓				
DIVA Article				✓					
G3 Advert			✓	✓	✓	✓			
G3 Article				✓					

In relation to printed media coverage:

- outnorthwest, a bimonthly publication, has a reported readership of in the region of 45,000: five advertisements and five pieces of editorial were inserted during the campaign. Further, the project findings will be inserted into the August/September 2011 issue.
- DIVA magazine, a monthly publication, has a reported readership of 150,000: three advertisements were placed in different issues and an article was produced regarding the campaign.
- G3 magazine, a monthly publication, has a reported readership of 140,000: four advertisements were placed in different issues and an article was produced regarding the campaign.

In relation to online magazine type media coverage:

- DIVA online is reported to attract 65,000 unique monthly visitors: three advertisements were placed in different issues and two articles were produced regarding the campaign.
- G3 online is reported to attract 12,000 unique monthly visitors: six advertisements were placed and an article was produced regarding the campaign.
- Lesbilicious is report to attract 30,000 unique monthly visitors: five advertisements were placed in different issues and four articles were produced regarding the campaign.
- A range of other articles regarding the campaign also appeared on sites such as Canal St News and Pink News.

Beyond magazine type coverage other digital media were engaged with to promote the campaign, including a range of health oriented outlets (Table 12), the LGF's eBulletin, their website, the campaign micro-site and the LGF's presences on Facebook, Twitter and YouTube.

Table 12: Campaign online coverage

	October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011	June 2011
LGF eBulletin	✓	✓	✓	✓	✓	✓	✓	✓	✓
LGF Online	✓	✓	✓	✓	✓	✓	✓	✓	✓
Facebook	✓	✓	✓	✓	✓	✓	✓	✓	✓
Twitter	✓	✓	✓	✓	✓	✓	✓	✓	✓
YouTube				✓	✓	✓	✓	✓	✓
DIVA Advert			✓	✓	✓				
DIVA Article				✓				✓	
G3 Advert			✓	✓	✓	✓	✓	✓	
G3 Article			✓						
Lesbilicious Advert				✓	✓	✓	✓	✓	
Lesbilicious Article				✓	✓	✓		✓	
Other	✓	✓		✓	✓		✓	✓	

- The LGF's eBulletin carried details of the campaign from October 2010 through to June 2011. This bulletin information changed in line with the needs of the campaign. From October through to January an emphasis was upon the promotion of the campaign website and resource booklets, February added details of the promotional videos, April the 'Put your cervix in the spotlight' game, and in May a call for participation in survey two and post-campaign focus groups.
- The LGF's website garners 175,000 unique users every month. A dedicated micro-site was created for the campaign at www.lgf.org.uk/screening. This contains details of the project's aims, links to resources, promotional videos and the campaign game. The Facebook page of the LGF has nearly 1,500 members and the Twitter account of the LGF (@lgfoundation) has over 3,600 followers.
- The YouTube account of the LGF has 148 subscribers and was used to host four promotional videos for the campaign.
- A range of other articles regarding the campaign also appeared on sites such as: Queer UK, Pink News, Outreach Cumbria and Manchester Pride.

4.4 Radio coverage

Over the campaign at least five radio stations have been used to promote the campaign – one specifically aimed at the LGB&T community (Gaydio), and others that carry regional programming for a wider audience (Table 13). Throughout the campaign a total of 16 interviews have been undertaken and five months of advertisements have been placed. There was also one instance of sponsorship. The project sponsored International Women's Day on Gaydio and received regular 'adverts and plugs' as a result.

Table 13: Campaign radio coverage

	October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011
Gaydio Advert				✓	✓	✓	✓	✓
Gaydio Interview	✓		✓		✓	✓	✓	
BBC Manchester Interview	✓		✓					✓
Pure FM Interview	✓		✓			✓		✓
North Manchester Interview	✓	✓	✓					
Chorley FM Interview	✓							
Gaydio IWD Sponsor						✓		

5. Post-Campaign Evaluation & Findings

This chapter presents the post campaign evaluation and findings of the study. This involves an analysis and evaluation of the campaign content and approach and an analysis of the impact of the campaign in terms of the uptake of cervical screening by LGB women in the North West of England. This chapter is thus informed by an analysis of campaign materials and of the data collected via survey two.

5.1 Summary comparison: Between survey one and survey two

Whilst the two surveys we deployed during the study served differing purposes, there were certain aspects that were comparable. Specifically these areas related to: i) mode of survey completion, ii) age, sexual orientation and domiciliary information.

- Survey one obtained 647 responses overall. Of these, 82 were via an online survey tool and 565 via a print based survey. Of these responses 36 responses were removed from the sample as they either provided no age information and/or were not based in the North West of England, leaving an overall valid sample of 611.
- Survey two obtained 345 responses overall. Of these, 185 were via an online survey tool and 160 via a print based survey. Of these responses 52 responses were removed from the sample as they either provided no age information and/or were not based in the North West of England, leaving an overall valid sample of 293.
- The overall valid sample of the combined studies was 904. The reported sexual orientation and domiciles of our participants are shown in figures 15 and 16. The breakdown of the sample by age and sexual orientation is provided figure 17.

Figure 15: Overall reported sexual orientation of survey one and survey two participants

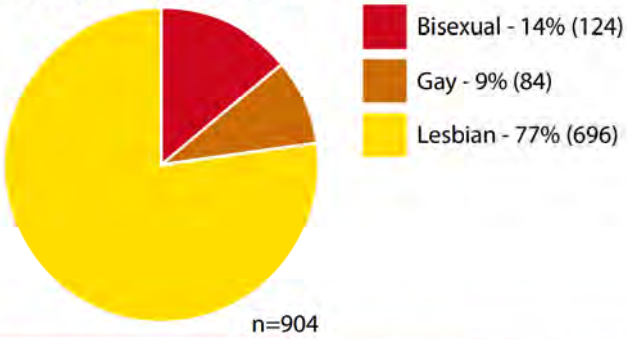


Figure 16: Overall reported domiciles of survey one and survey two participants

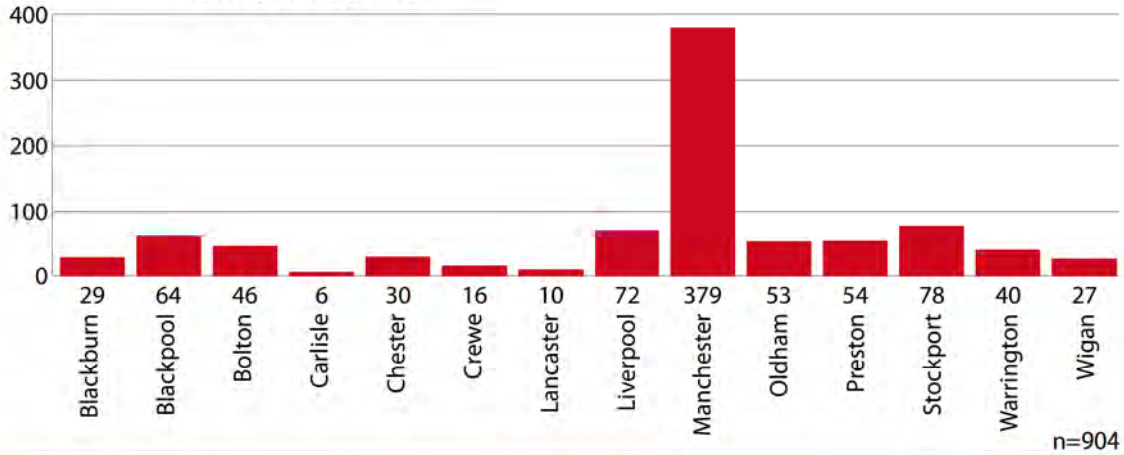
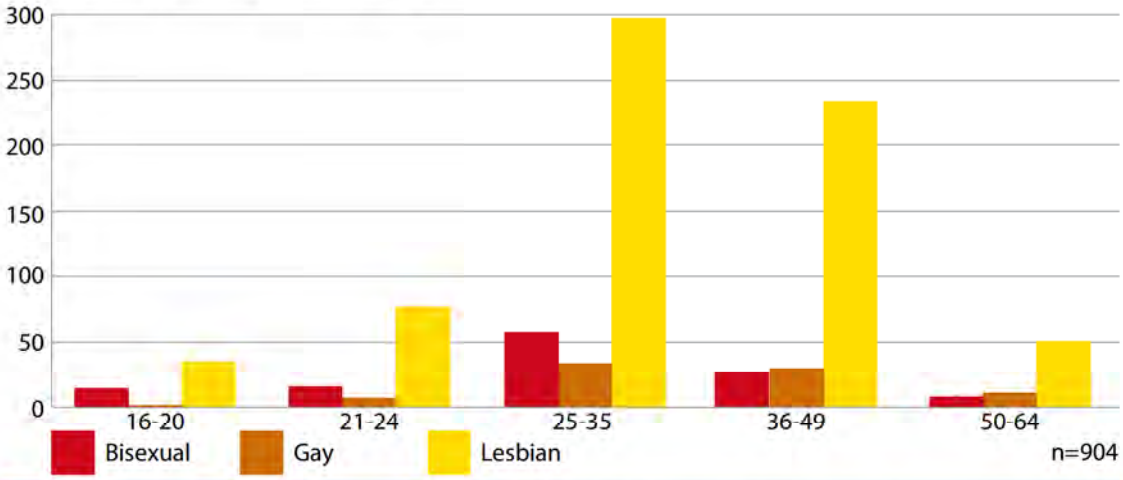
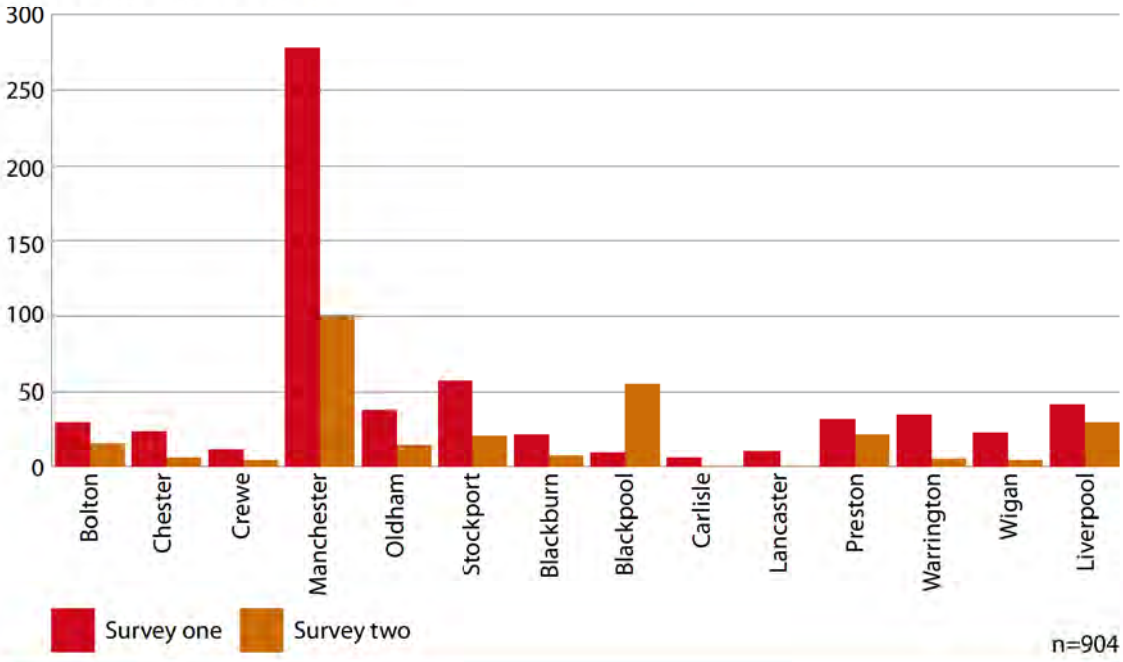


Figure 17: Overall reported sexual orientation of survey one and survey two participants (by age range)



- It does not appear that the choice of the mode by which the survey was completed (online or in person) was affected by the age of the survey participant. We were keen to understand this in the light of discourses that can position people of different ages as having greater access to, and being more capable of engaging with the Internet (Dutton *et al.* 2009). As we had used an online approach we needed to consider the extent to which this might affect the uptake of the survey.
- The spread of ages and sexual orientations across survey one and survey two showed no significant differences.
- Participation in each survey was affected by location in different ways but this is generally explainable by the fact that survey one was based heavily on the recruitment of participants at the 2010 Manchester Pride event and survey two involved recruitment at the 2011 Blackpool Pride Event (Figure 18).

Figure 18: Comparison of participation levels for survey one and survey two (by domicile)



5.2 Survey two sample characteristics

An opportunistic/convenience sampling method was adopted, as with survey one. This largely targeted LGB women at Blackpool Pride event (11 June 2011), and in addition, an online survey was placed on the LGF's website, which was promoted widely throughout a range of LGB women's networks, online spaces and print matter. Survey two was accessible 2 May 2011 - 12 June 2011 (with some initial surveys being sourced at an event in March 2011).

5.2.1 Age and sexual orientation

A total of 293 surveys were completed by women who identified as LGB. Analysis of sample characteristics indicates the majority identified as lesbian, with a considerably lower number of gay and bisexual women represented (Figure 19). Indeed, lesbian women were the highest participants across all age groups (16-64) (Figure 20). The majority of women fell into the age group who are required to undergo cervical screening (83%, 243).

Figure 19: Overall reported sexual orientation of survey two participants

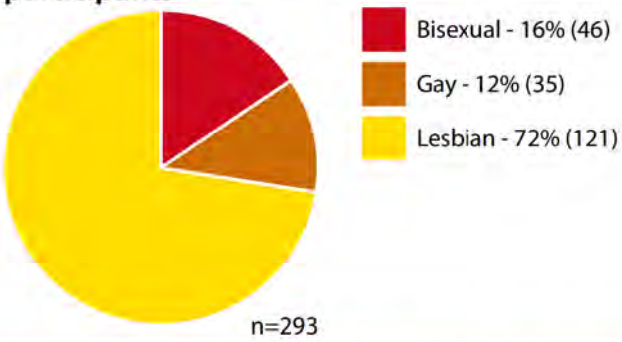
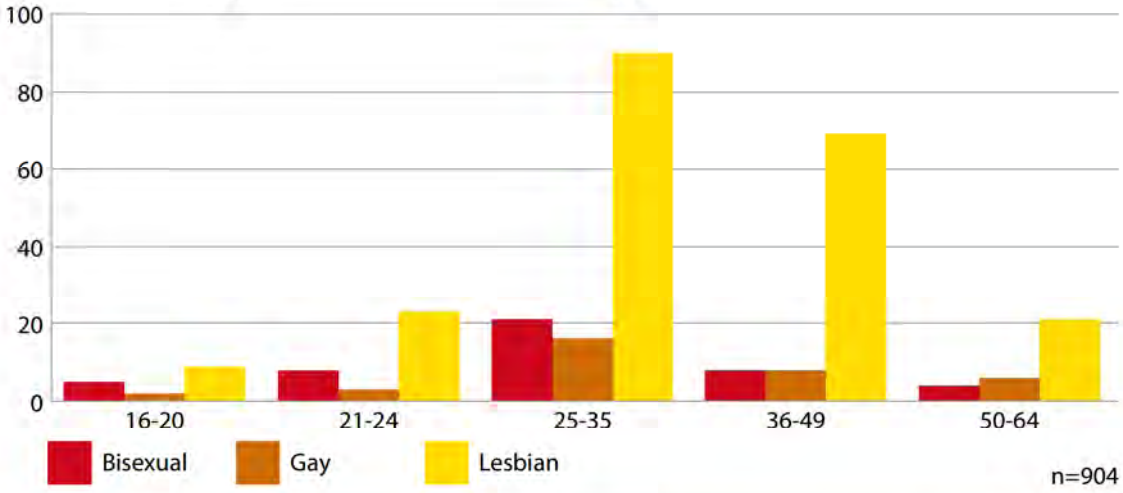


Figure 20: Sexual orientation (by age range - survey two)

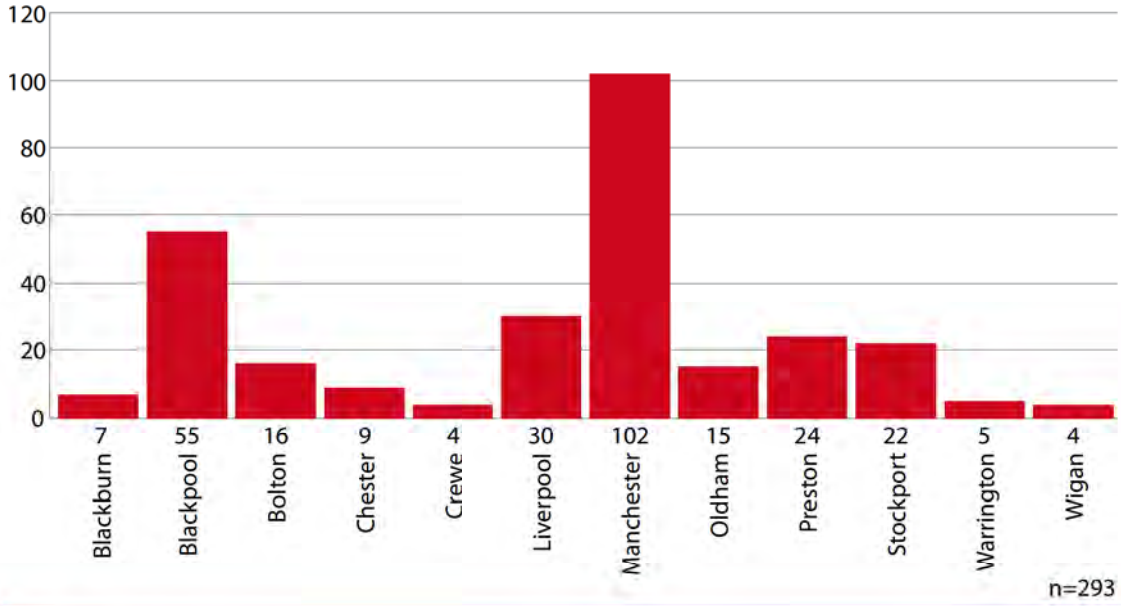


As with survey one it is important to note that not all age groups will be included in the analysis and that we will group certain age ranges together on a question by question basis. Specifically, for example, questions regarding such things as awareness would include the whole sample, whereas the specifics of having undertaken screening would be reserved for those aged 25 years and over. Moreover, within the 25 and over age group, it is at times necessary to create two groups 25-49 and 50-64 in order to analyse areas such as the timeliness of cervical screening attendance in the light of NHS guidance.

5.2.2 Location

LGB women who responded to the survey originated from 12 different areas across the North West and this was captured by recording the first half of their postcode (to protect anonymity). The three highest regions represented by the sample were: Manchester (35%, 102), Blackpool (19%, 55) and Liverpool (10%, 30) (Figure 21), in line with the view that there is a higher LGB population in more urban areas. Notably, in comparison to survey two, Carlisle and Lancaster were not represented.

Figure 21: Domiciles of particpants (survey two)



5.2.3 Focus groups

One focus group, rather than the three initially proposed, took place following the campaign. This reflected the difficulties experienced at baseline in recruiting LGB women in different areas to participate in a group interview. This focus group took place in Manchester, 65 people were invited, eight attended and it lasted 60 minutes. The purpose of this focus group was to gain further feedback regarding the campaign.

5.2.4 Analysis

As with survey one, quantitative data generated by survey two and the campaign (for example data generated via the use of the Google Analytics tool) was analysed using SPSS and predominantly descriptive statistics.

Qualitative thematic analysis of focus group interviews, the qualitative data obtained via survey two and that generated via the campaign are presented alongside statistical findings to add contextual information regarding the impact of the campaign and cervical screening uptake.

The main themes of analysis were:

- Campaign Awareness.
- Discovering the Campaign.
- Evaluation of the Campaign in terms of Web Traffic.
- Evaluation of the Campaign via participant feedback.

- Shaping Knowledge and Increasing Confidence.
- Increasing Knowledge Regarding the Need for a Cervical Screening Test.
- Increasing Confidence in Going for a Screening Test.
- Confidence in Dealing with Health Professionals in a Cervical Screening.
- Affecting Behaviour Change Regarding Cervical Screening Uptake.
- Are Women Going for Screening and at the Right Time?

5.3 Campaign awareness

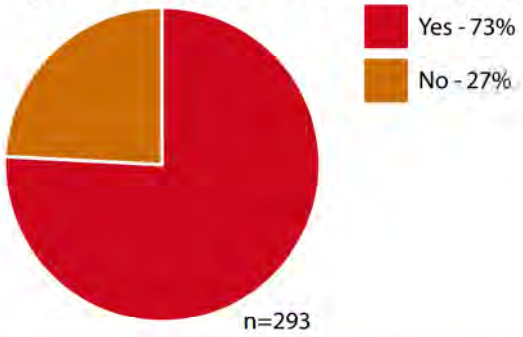
In survey two, we asked participants if they were aware of The Lesbian & Gay Foundation's campaign and information around cervical screening (Table 14, Figure 22)

Table 14: Campaign awareness (by age range)

	16-20	21-24	25-35	36-49	50-64	Total
Yes	8	16	100	65	24	213
No	8	18	27	20	7	80
Total	16	34	127	85	31	293

n=293

Figure 22: Awareness of the campaign



Overall 73% (213) of participants reported that they were aware of the LGF's campaign. Further, table 12 suggests that the campaign was picked up more by the those aged 25 and over - the target group for screening. In this sample, sexual orientation (referring to identity as either lesbian, gay or bisexual) and domicile were not linked with awareness of the campaign.

However, if those aged 16-24 are removed, then the distribution is more even and it does not seem that the campaign has been picked up by one particular age group over others. Again, sexual orientation did not figure in the extent of awareness across this group.

Further, with those aged 16-24 removed, reporting regarding awareness of the campaign becomes slightly higher than might be expected within the sample in Blackpool and Preston and slightly lower in Liverpool. Beyond these small mismatches, the distribution is fairly even.

5.4 Discovering the campaign

We also asked participants of survey two how they had found out about the campaign (Table 15). The results indicate 29 sources. However, it was noticeable that some of these sources would benefit from grouping and these are represented in (Table 16). From

this grouping the importance of online, print, events and the LGF's role become clear. We also see though, that despite widespread circulation of materials to surgery's and clinics, and radio coverage, participants reported these minimally.

Table 15: Source of discovery of the campaign

	Frequency
LGF - Not Specified	20
Facebook	15
DIVA Magazine	14
Online	14
Blackpool Pride	13
Outreach	12
Word of Mouth	12
Campaign Poster	10
LGF - Email	8
OutNorthWest	8
LGBT Group	7
LGF - Website	6
Campaign Booklet	5
Email	5
GP Surgery	5
Press	4
Sugar & Spice	4
Bar/Pub	3
Event	3
Gaydio	3
Radio	3
Shiver	2
Twitter	2
Workplace	2
BBC Radio Manchester	1
LGF - Event	1
Sexual Health Clinic	1
Stepping Stones	1
TV	1
Total	191

n=191

Table 16: Source of discovery of the campaign (grouped categories)

	%
Online	26
Print Media	21
Event/Group	18
LGF - Not Specified	10
Outreach	6
Word of Mouth	6
TV/Radio	4
Surgery or Clinic	3
Other	1
Total	100

n=191

5.5 Evaluation of the campaign – web traffic

For the period 1 October 2010 until 20 June 2011 the site www.lgf.org.uk/screening was viewed 3348 times. Of this, the top ten sources (Figure 23) accounted for 92 per cent of traffic. Of this top ten, 24% landed on the page as a result of directly typing in the URL of the page into their browser indicating that is highly likely that they had found the URL on a piece of promotional material. Moreover, if we combine this with other direct links provided by the LGF (the LGF Press List and LGF weekly bulletin) we see that 30% of all visitors to the site were motivated by this mode. The LGF also produced and distributed a series of news items which also attracted over a thousand hits combined (Table 17). This data seems to suggest a 'shelf life' for each news story of around four to five months.

Figure 23: Traffic to www.lgf.org.uk/screening during the campaign

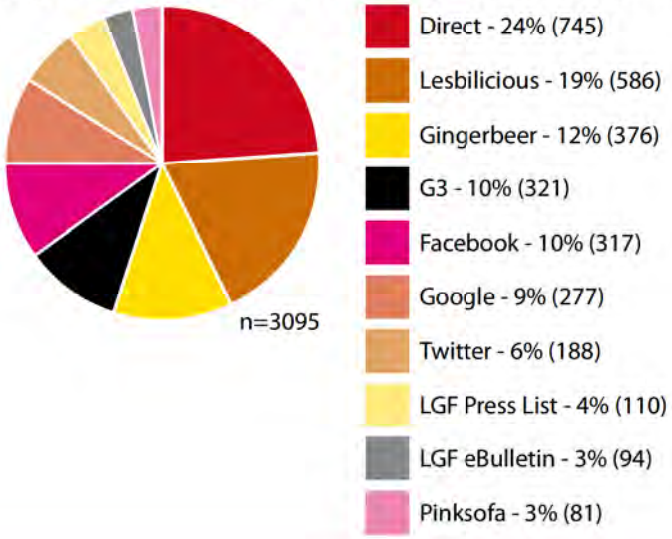


Table 17: Campaign news items

	Page Views									
News Items from: www.lgf.org.uk	October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011	June 2011	**Total**
/are-you-ready-for-your-screen-test-launch-event	14	5	0	4	0	0	0	0	1	24
/fact-lesbian-and-bisexual-women-need-a-cervical-screen-test	104	38	33	32	4	6	2	2	6	227
/women-are-you-ready-for-your-screen-test	64	38	25	17	2	3	0	1	1	151
/lgf-launch-new-campaign-for-lesbian-bisexual-women	0	142	30	21	2	5	0	0	2	202
/now-screening-a-pretty-woman-goes-for-her-screen-test	0	0	0	0	279	22	10	12	15	338
/are-you-ready-for-your-screen-test	0	0	0	0	22	18	15	15	12	82
										1024
										n=1024

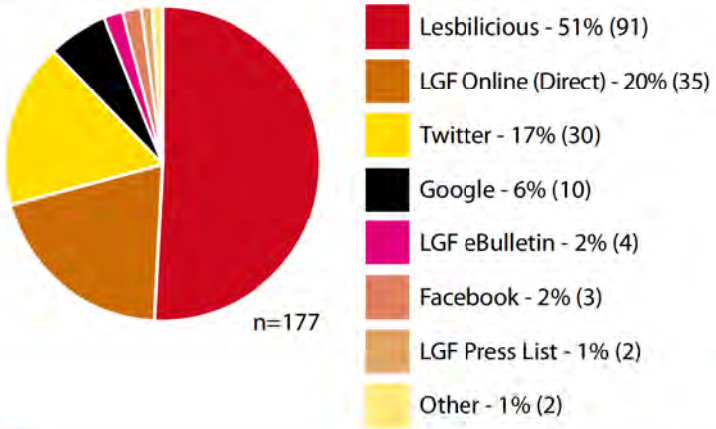
Other facilitators of high traffic were lesbilicious.co.uk and g3mag.co.uk – where advertisements and editorial were placed. However, another site where paid advertising was undertaken, DIVA, produced very few hits. The websites Gingerbeer and Pinksofa also produced a good degree of traffic throughout the campaign. Table 18 provides an overview of the campaign in terms of coverage and traffic on a month-by-month basis.

Table 18: Analysis of web traffic by month and source

		October 2010	November 2010	December 2010	January 2011	February 2011	March 2011	April 2011	May 2011	June 2011
LGF eBulletin	Online Coverage	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Traffic Generated	22	22	20	7	9	9	3	2	
LGF Online (Direct)	Online Coverage	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Traffic Generated	12	30	48	149	82	81	113	181	49
LGF Press List	Online Coverage		✓	✓	✓	✓	✓		✓	✓
	Traffic Generated		69	3	4	8	1		7	18
Facebook	Online Coverage	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Traffic Generated	46	3	3	206	36	11		9	3
Twitter	Online Coverage	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Traffic Generated	1		4	169	5	3	1	5	
DIVA Advert	Online Coverage			✓	✓	✓				
DIVA Article					✓				✓	
	Traffic Generated								3	
G3 Advert	Online Coverage			✓	✓	✓	✓	✓	✓	
G3 Article			✓	✓						
	Traffic Generated		26	52	42	9	105	46	16	25
Lesbilicious Advert	Online Coverage				✓	✓	✓	✓	✓	
Lesbilicious Article					✓	✓	✓		✓	
	Traffic Generated				115	125	89	60	113	84
Gingerbeer	Online Coverage					✓	✓	✓	✓	✓
	Traffic Generated					147	132	30	24	43
Pinksofa	Online Coverage				✓	✓	✓	✓	✓	
	Traffic Generated				36	21	9	2	13	

A similar profile of sources are revealed in respect of the web based 'Put your cervix in the spotlight' game (Figure 24). Again direct links to the Screen Test site at the LGF and those from Lesbilicious feature highly, but also there is a slight difference.

Figure 24: Traffic to the 'Put your cervix in the spotlight' during the campaign



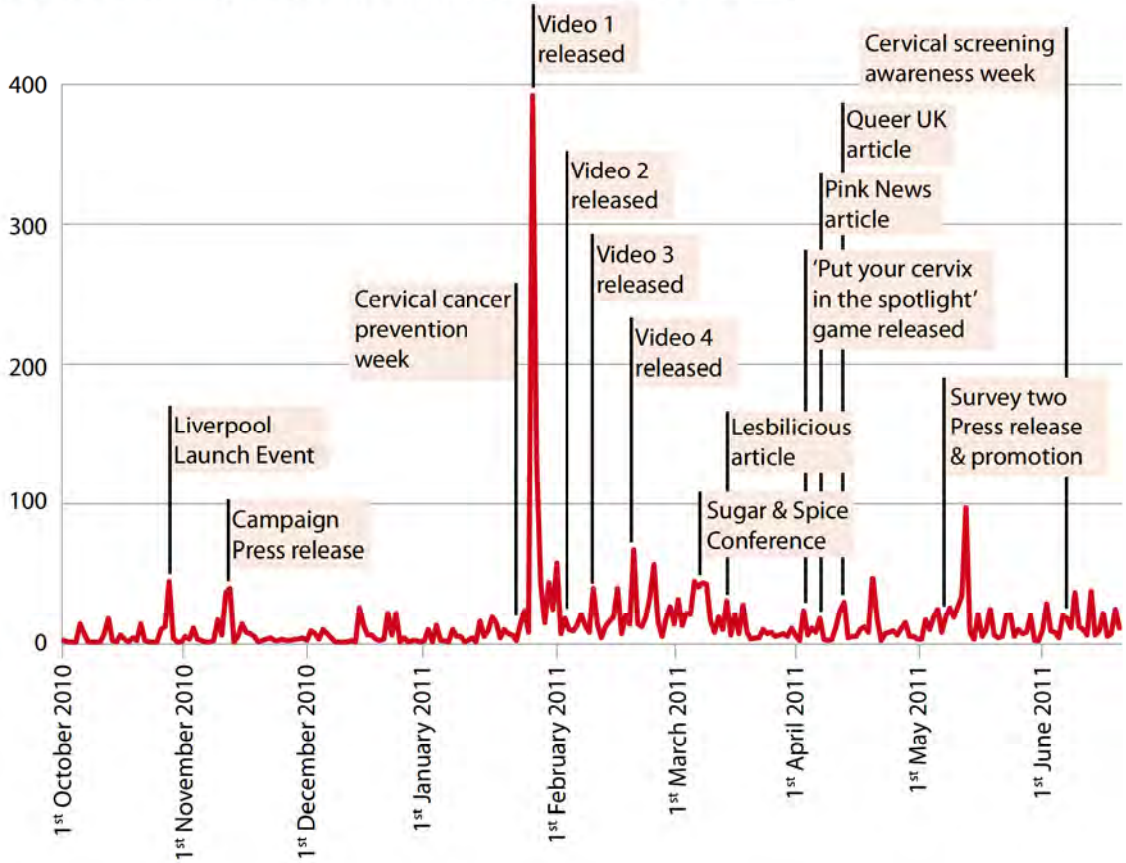
Twitter referrals move up the rankings table from position number seven to position number 3. With respect to this we noted, on Twitter, threads of exchange whereby players tweeted their scores to each other resulting in a further promotion of the campaign that was started by a member of staff at the LGF (Figure 25).

Figure 25: Twitter Interaction

In total, 177 people played the game during the campaign. Indeed, in this respect and more generally, the LGF's Twitter followers further assisted in the promotion of the game, and campaign more broadly. One high profile case is that of the actor and singer, Heather Peace, known particularly for her roles in London's Burning and LipService and has 13,764 followers.

Drawing upon data generated by Google Analytics software and combining this with data regarding activities and events running throughout the campaign also provides some interesting insights into the drivers of web traffic. Overall we can see that the campaign has benefited from a steady flow of visitors as it has progressed (Figure 26). However, we also noticed peaks in the campaign and have mapped these to the figure to provide additional context. Perhaps most striking is the role of the 'Screen Test' videos in generating traffic, but clearly other activities and events play a part too.

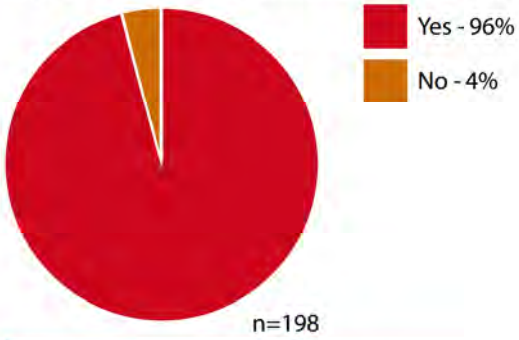
Figure 26: Analysis of campaign impact upon web traffic



5.6 Evaluation of the campaign – survey two participant feedback

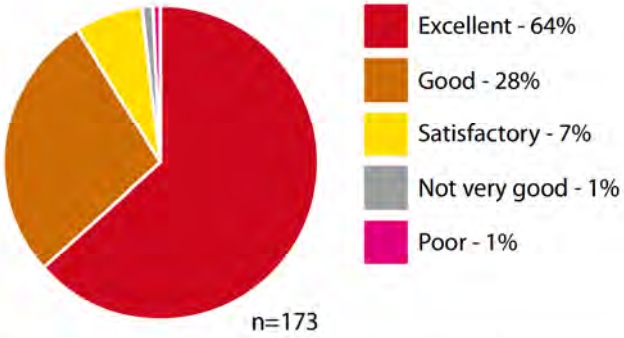
We asked our survey two participants to rate various elements of the campaign, and there is much evidence to suggest its value (Figures 27-37). Of those that replied (198), **96% (181) felt that the campaign was effective and the vast majority of participants rated the materials as either excellent or good, with 99% feeling it would be worthwhile to run such a campaign nationally.**

Figure 27: Do you think the campaign is effective?



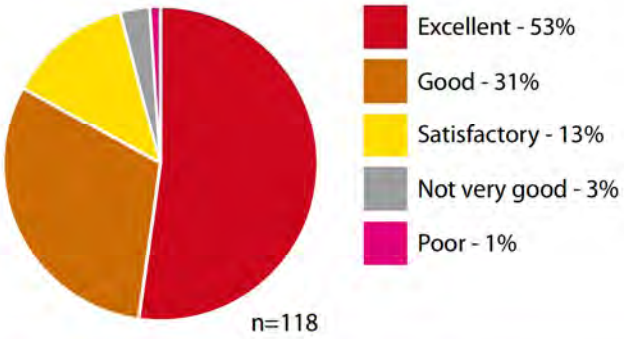
Specific campaign materials had each been experienced by the participants to varying degrees from a low of 71 for Radio to a high of 173 for Posters (Figure 38). By comparison we can see that the vast majority of participants thought the materials were, overall, either excellent or good.

Figure 28: What did you think about the campaign posters?



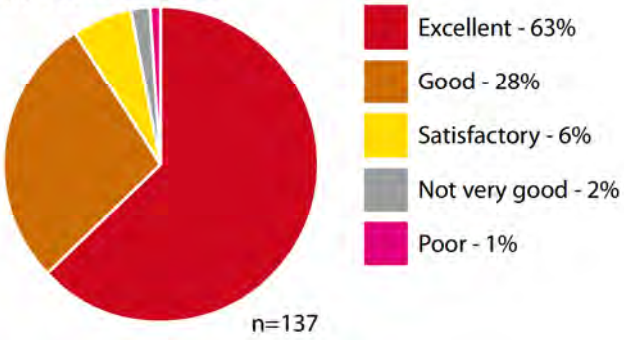
n=173

Figure 29: What did you think about the campaign postcards?



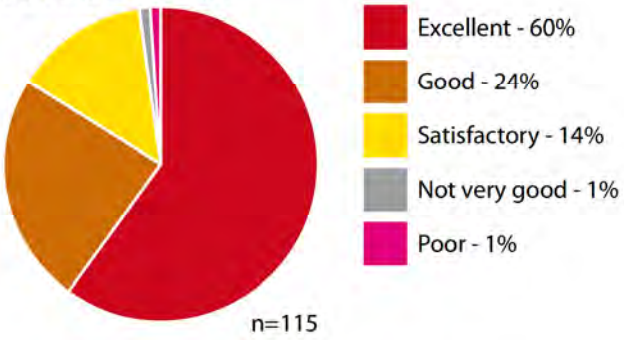
n=118

Figure 30: What did you think about the campaign magazine articles and advertisements?



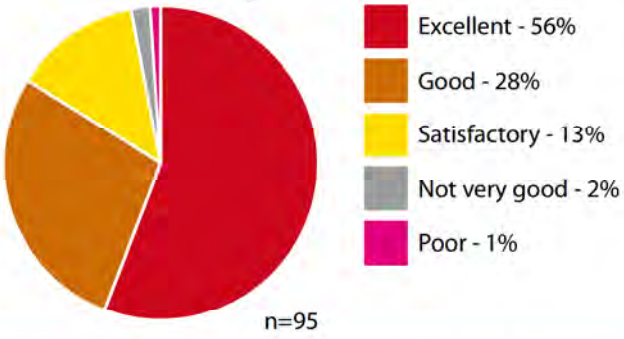
n=137

Figure 31: What did you think about the campaign online articles and advertisements?



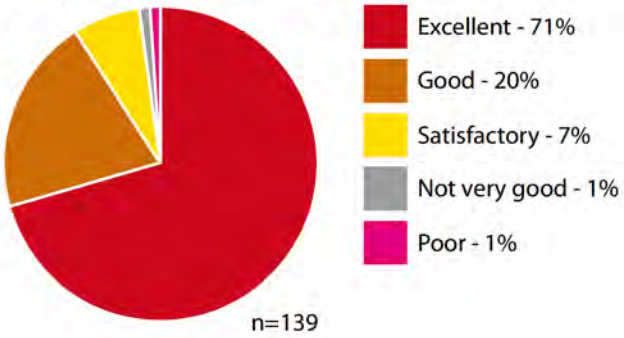
n=115

Figure 32: What did you think about the campaign coverage on Facebook, Twitter and online more generally?



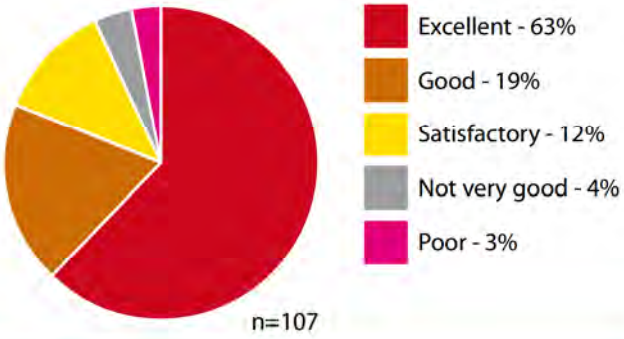
n=95

Figure 33: What did you think about the campaign information booklet?



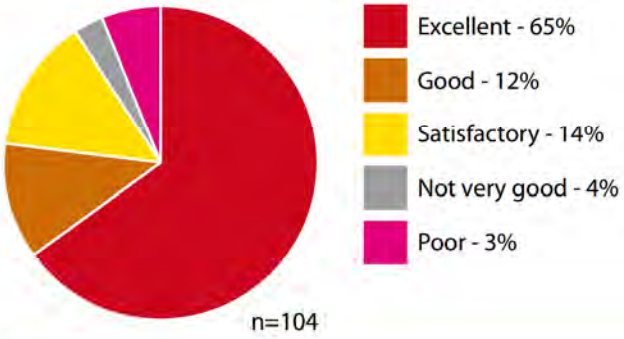
n=139

Figure 34: What did you think about the campaign promotional goodies?



n=107

Figure 35: What did you think about the campaign videos?



n=104

Figure 36: What did you think about the campaign 'Put your cervix in the spotlight'?

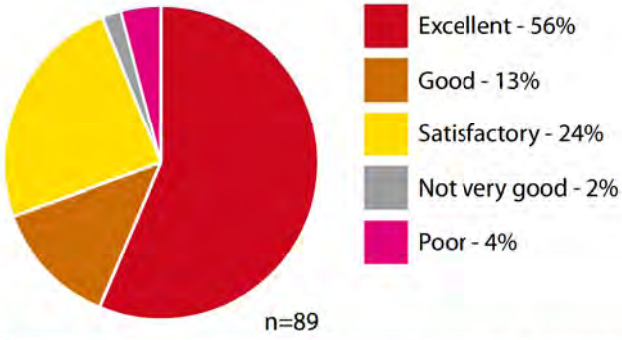


Figure 37: What did you think about the campaign radio presence?

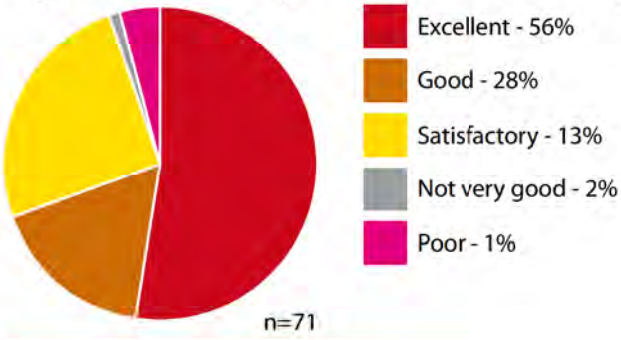
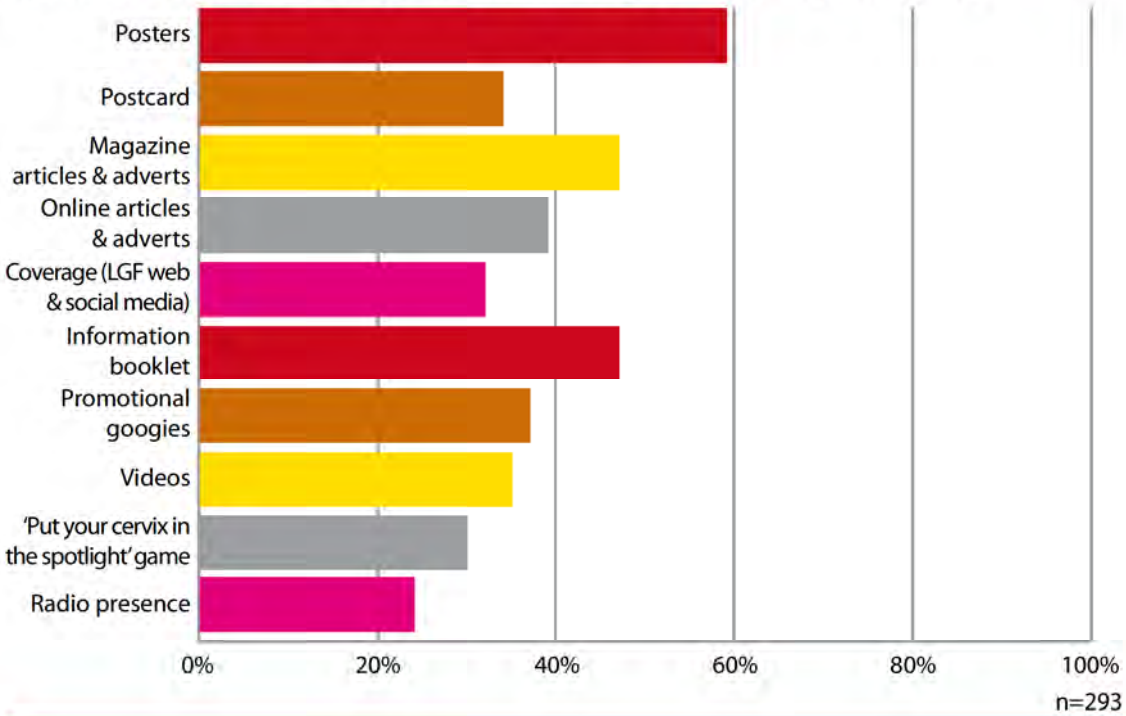


Figure 38: Sightings of campaign materials by survey two participants

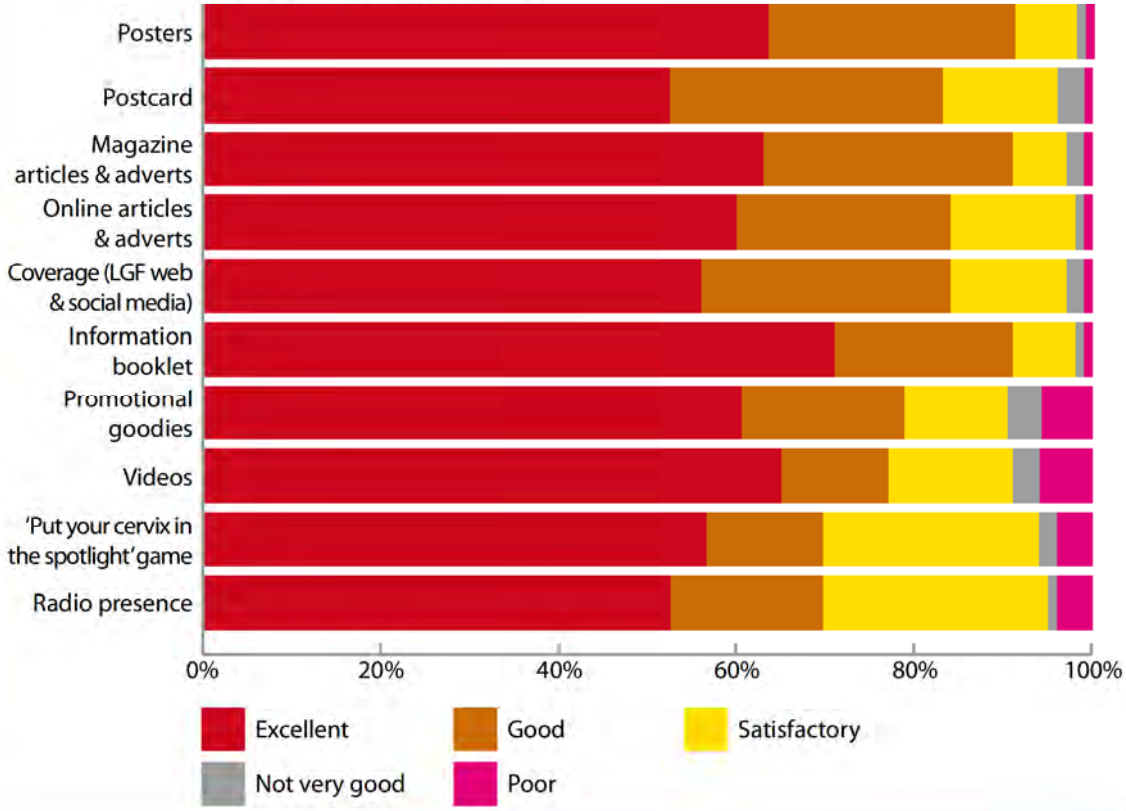


However, in certain areas it is clear that participants were less positive. For example:

- 25% (18) of participants thought the Radio presence was satisfactory and 4% (3) thought it was poor.
- 24% (21) of participants thought the 'Put your cervix in the spotlight' game was satisfactory and 4% (4) thought it poor.

These cases were also the two lowest experienced parts of the campaign and thus the actual numbers of people involved are very low, although of course still worth considering. Figure 39 details the amount each specific campaign material had been experienced as a percentage of the total survey population, allowing of course, for the fact that a participant could have experienced multiple campaign materials.

Figure 39: Comparative analysis of evaluations of campaign materials and approaches



5.6.1 What participants liked about the campaign

We asked survey and focus group participants what they liked about the campaign. Overall, the following seven messages emerged:

- 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.
- There was good use of humour but the materials were still informative and sensitive to the severity of the issue.
- Events were helpful as they facilitated discussion of the issues in a 'safe' and welcoming environment.
- The campaign videos were highlighted on many occasions as funny, shareable, informative and useful.
- The approach was professional and not condescending.
- A campaign aimed directly at LGB women was a good thing.

"Well this is great - what a great booklet! Health info is never this engaging! I have just read this and immediately booked in for a test. I, like many others, just didn't think I needed one. Will be telling all my friends too. Thank you for this."
Katie, Comment on G3 website, February 2011

"I liked how it was quite queer (printed leaflets) - it was like weird humour but something that I could kind of relate to so it definitely struck a chord with me, obviously it was a serious issue but I found it quite funny. The snakes and ladders campaign and the whole cervix in the spotlight I really liked it - it's different - there is nothing like that (imagery wise and the humour) in any of the other magazines really, it's quite different..."
Participant, Post-Campaign Focus Group

A selection of positive comments about the campaign are shown in box 3.

Box 3: Why people liked the campaign

'Although I had heard that lesbian and bisexual women should have smear tests, seeing that fact published validates it and gives me more confidence.'

'The campaign is bright, fun, engaging, got my attention and really made me think.'

'I liked the design and feel - humourous without being insensitive! Very clear message!'

'It draws attention to the fact that lesbian and bisexual women need to be targeted as a separate group in this area of health.'

'I like the glamourous theme – it would get your attention even if a smear test was the last thing on your mind!'

'I find the videos pastiches a really funny and an attention grabbing way to raise awareness and also point to the information leaflet. The information in the pdf also provided a really empowering resource to help give you the evidence to fight for the right to get screened and also feel less daunted by the bad stories.'

'I like the concern that campaign has - that people care, that a lot of care and thought has gone into it.'

'I liked the video's best, I thought they were really inventive and because they were put on facebook it made it easy to share them with my friends.'

'I liked the videos most, i thought they were absolutely right on the money, humourous and really informative and easy to remember.'

'I was pleased that the issue was being highlighted in a way which made it clear that lesbians were at risk too.'

'It makes an important point… very important that lesbian/bisexual women's health is made public and not just hidden away from the norms of heterosexual media.

'It's camp!'

'I loved the movie theme, made it non-threatening, most people feel guilty enough about not going as it is!'

'The fact it was engaging in the concept and design - that it wasn't boring like all other health stuff. It was actually enjoyable to read this information - I can't say I've ever said that about any other health related information!'

'The message. For a long period of my adult life I have been discouraged by medical professionals NOT to have smears [sic] as they are not necessary for lesbians. So I think it is important to raise awareness.'

'Whilst the booklet was quite long and detailed, the message of the campaign was recognisable from a quick glance, and easy to understand. I liked the fact that it did not assume that every woman is the same, giving reasons for example why it might be a good idea to come out to your GP, but equally understanding that some women won't want to do that.'

5.6.2 What participants didn't like about the campaign

We also asked survey and focus group participants what they didn't like about the campaign. Overall, the four following messages emerged:

- Some people felt that the videos could have been a little longer and more informative and it was noted that they did not have subtitles.
- Several people felt that the campaign deserved a wider coverage and should not be restricted to what they saw as places where only LGB women frequent.
- Some raised issues related to gender. Specifically, one person complained that the campaign was too 'girly', another was concerned that a man's voice was used on a radio advertisement. A further comment was made regarding the need to expand the campaign to trans men.
- A few people raised questions regarding the extent to which the campaign might be trivializing a serious issue and being too 'soft' in its approach, although these comments were often tempered with recognition of the potentially 'scary' nature of the issue. Box 4 details some comments in this respect.

Box 4: Why people didn't like the campaign

'The campaign could have said more/made it more impactful about the life/death aspect of not getting tested… But I guess you don't want to scare people off.'

'I am now scared about going in case anything is wrong with the results.'

'I don't like the entertainment/light hearted theme for such a serious issue but thats just a personal view. If the campaign having a 'funny' element to it makes women get a smear test then I support it.'

'I think it is in danger of over glamourising what is, in my experience, a clinical and painful procedure - a necessary evil.'

'I think it's great - being handed the postcard and having a chat to an LGF staff member about it has resulted in me booking for and going for a test (my first one ever). However, despite the booklet having loads of information - I was still petrified. The booklet does give great tips and advice on what to expect and dealt with my concerns and questions well (more so than any other information I have had from the NHS or through the internet), however I was still really scared about the procedure. I'm not sure how you can tackle that huge amount of fear that many women have about having such an intimate procedure done. There really isn't much you can do but I think it's good that the booklet actually acknowledges it's not an amazing experience! Other information seems to gloss over that aspect, but glossing over it is not useful as it's what the majority of women are scared about and aware of.'

"I would like to see materials for health professionals to help them understand and deal with women's sexuality better."
Participant, Survey two

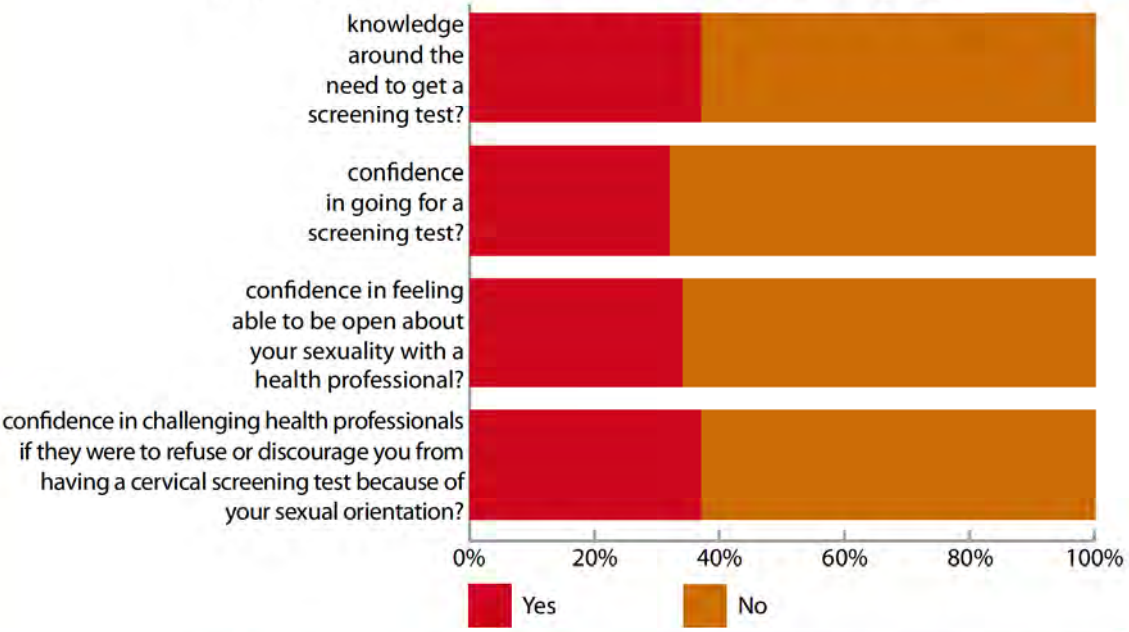
5.7 Overall effectiveness of the campaign

Overall, of those that replied 190 women (96%) felt that the LGF's 'Are You Ready For Your Screen Test? ' campaign was effective. This figure did not seem to be affected by the age, sexual orientation or domicile of participants. The reasons for the effectiveness of the campaign, we believe, are broadly covered in Section 5.6 and Box 3.

5.7.1 Shaping knowledge and increasing confidence

Overall in the region of 32% to 39% of survey participants aged 25 and over felt that the campaign had either increased their knowledge or improved their confidence with respect to cervical screening (Figure 40). The following sections examine this in more detail.

Figure 40: Comparative analysis of changes in levels of knowledge and confidence as a result of the campaign



5.7.2 Increasing knowledge regarding the need for a cervical screening test

Participants were asked if, as a result of the campaign, they had increased their knowledge around the need to get a screening test. Overall 37% (102) of women felt that the campaign had increased their knowledge around the need to get a screening test and that this figure rose to 39% (107) if we included only those 25 years old and above (Table 19).

Table 19: As a result of the campaign, have you increased your knowledge around the need to get a screening test?

	Age Range					
	16-20	21-24	25-35	36-49	50-64	Total
Yes	6	5	56	26	9	102
No	7	22	69	55	20	173
Total	13	27	125	81	29	275

n=293

Further analysis indicates that the campaign has affected the 25-35 group slightly more than the other two groups. 36-49 year olds are underrepresented by some way and 50-64 year olds are slightly underrepresented.

Overall sexual orientation (in terms of identity as lesbian, gay or bisexual) does not seem to have any bearing on the reporting in this area and this remains the same if we focus only upon those aged 25 years and above.

Overall the domicile of a participant does not seem to have had any bearing on any increase in knowledge. That said, there are slightly more people reporting an increase in knowledge than the overall survey data would lead one to expect where participants are living in Blackpool. This may of course be due to the LGF's presence at Blackpool Pride for survey two.

5.7.3 Increasing confidence in going for a screening test

We asked participants if, as a result of the campaign, they had increased their confidence in going for a screening test. 32% (88) of women felt that the campaign had increased their confidence in going a screening test and his figure rose to 33% (91) if only those 25 years old and above were included (Table 20).

Table 20: As a result of the campaign, have you increased your confidence in going for a screening test?

	Age Range					
	16-20	21-24	25-35	36-49	50-64	Total
Yes	5	7	46	21	11	90
No	8	20	79	60	18	185
Total	13	27	125	81	29	275
						n=275

Sexual orientation (again, in terms of identity as lesbian, gay or bisexual) does not seem to have any bearing on the reporting in this area and this remains the same if we focus only upon those aged 25 years and above.

Overall the domicile of a participant does not seem to have had any bearing on any increase in confidence. That said, there are slightly more people reporting an increase in confidence than the overall survey data would lead one to expect where participants are living in Blackpool. This may of course be due to the LGF's presence at Blackpool Pride for survey two.

5.7.4 Increasing confidence in dealing with health professionals in a cervical screening context

We asked two questions in the area of dealing with health professionals in a cervical screening context. First, participants were asked, if as a result of the campaign, their confidence in feeling able to be open about their sexuality with a health professional had increased.

In this respect, 32% (88) of women felt that the screening campaign had increased their confidence in feeling able to be open about their sexuality with a health professional and this figure rose to 34% if only those 25 years old and above were included (Table 21). In both cases, sexual orientation does not seem to have any bearing on the reporting in this area.

Table 21: As a result of the campaign, have you increased your confidence in feeling able to be open about your sexuality with a health professional?

	Age Range					
	16-20	21-24	25-35	36-49	50-64	Total
Yes	5	4	47	22	11	89
No	8	23	78	59	18	186
Total	13	27	125	81	29	275

n=275

Moreover, the domicile of a participant does not seem to have had any bearing on any increase in confidence. That said, there are slightly more people reporting an increase in than the overall survey data would lead one to expect where participants are living in Blackpool and Preston. This may of course be due to the LGF's presence at Blackpool Pride.

We then asked if, as a result of the campaign, participants 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.

Overall 35% (96) 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 and this figure rose to 37% if only those 25 years old and above were included (Table 22). In both cases, sexual orientation does not seem to have any bearing on the reporting in this area.

Table 22: As a result of the campaign, have you increased your confidence in challenging health professionals if they were to refuse or discourage you from having a cervical screening test because of your sexual orientation?

	Age Range					
	16-20	21-24	25-35	36-49	50-64	Total
Yes	4	4	52	27	9	96
No	9	23	73	54	20	179
Total	13	27	125	81	29	275

n=275

The domicile of a participant does not seem to have had any bearing on any increase in confidence. That said, there are slightly more people reporting an increase in confidence than the overall survey data would lead one to expect where participants are living in Manchester, Stockport and Preston.

"...If you turn up and you have a practice nurse or someone who says 'No you don't (need a test)', it can be quite daunting to challenge that and so to be able to go well actually I do, it gives you something to go in with than stand there yourself saying I do... it's like back up to challenge that and know that you are right and you can say something..."

Participant, Post Campaign Focus Group

5.7.5 Affecting behaviour change regarding screening uptake

Participants were asked if, as a result of the campaign, they had gone for a cervical screening test. Of those aged 25 and above, 22% reported that they had ***actually been*** for a cervical screening test as a direct result of the LGF's campaign (Table 23). Of these women, 84% of them were aged 25-49, and 16% were aged 50-64.

Table 23: As a result of the campaign, have you gone for a cervical screening test?

	Age Range			
	25-35	36-49	50-64	Total
Yes	24	19	8	51
No	101	62	21	184
Total	125	81	29	235

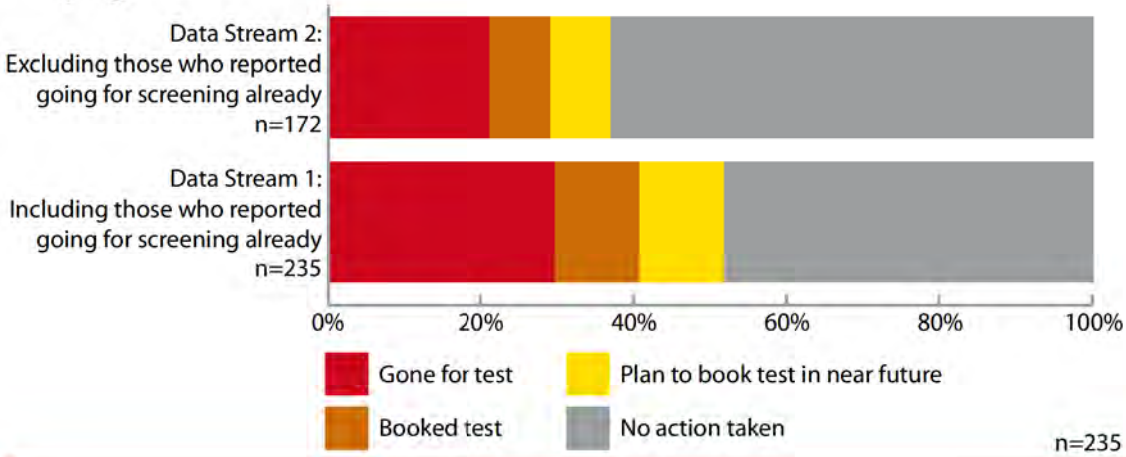
n=235

We also asked if, as a result of the campaign, participants had booked a cervical screening test. Of those aged 25 and above 19 women (8%) reported that they ***had booked*** a cervical screening test as a result of the LGF campaign. It does not appear that age, sexual orientation or domicile affected whether someone had booked a screening test.

Finally, participants were asked if, as a result of the campaign, they had decided to book a cervical screening test in the near future. Of those aged 25 and above 19 women (8%) reported that they book a cervical screening test in the near future as a result of the LGF campaign. It does not appear that age, sexual orientation or domicile affect whether someone has booked a screening test.

If the figures for those who have gone for a test and those who have booked a test are combined, we see that 70 women (30%) have taken positive action with respect to the maintenance of their health as a result of the LGF campaign. If those who plan to book a test in the near future are included, then this figure rises to 89 women and 38% respectively. And finally, if those women (63) reporting no behaviour change because they already go for screening tests regularly are removed, then the overall behaviour change figure rises to 51% (Figure 41). This indicates a significant change of behaviour specifically within the main target group (those LGB women who did not already access regular screening).

Figure 41: Analysis of overall behaviour change as a result of the campaign



If we focus upon non-participation in screening, participants were also asked to inform us if they were not going to make any kind of change as a result of the campaign. If women aged 16 and above are included, then 71 of 293 women (24%) reported not making any changes as a result of the screening test campaign. If the sample is adjusted to focus just upon those aged 25 and above, (and on the radar for cervical screening), 70 of 243 women (28%) reported not making any changes as a result of the screening test campaign (Figure 42). Of those that stated they would not make any changes, we also asked why this might be the case. Of this group, 61 women reported not making any changes because they already went for screening tests. **Taking this information into account, only 4% of women over the age of 25 reported that they would still not go for a screening test (Figure 43, Box 5).**

Figure 42: Analysis of those reporting some kind of change as a result of the campaign aged 25+

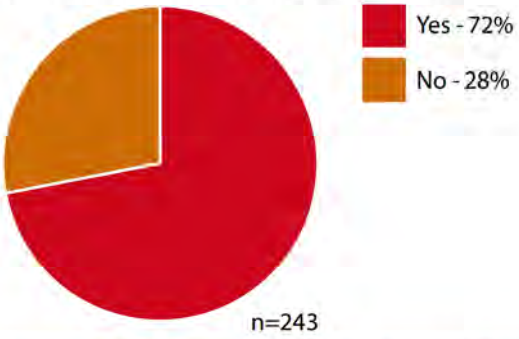
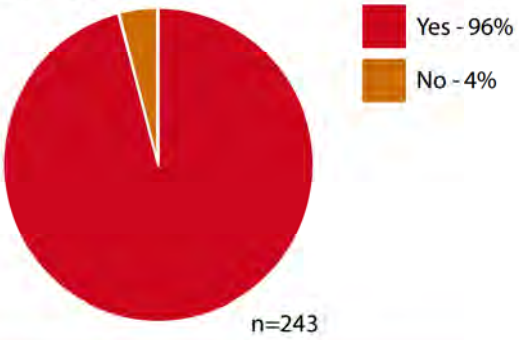


Figure 43: Analysis of those reporting some kind of change as a result of the campaign aged 25+ (excluding those already being screened)



Box 5: Reasons given for not wanting to go for a cervical screening test

'I have had a hysterectomy.'

'I am extremely low risk having never had sexual contact with a man. I am however aware that here is SOME risk and am fully aware that I am stubborn and somewhat irresponsible.'

'I have an eczema skin condition.'

'I am not sexually active.'

'Recent pregnancy.'

'I am uncomfortable with the intimacy of the procedure.'

5.7.6 Are women going for screening and at the right time?

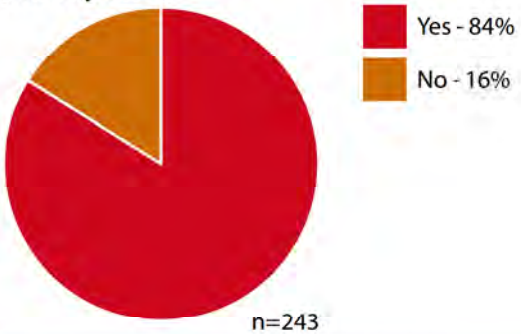
Survey two participants as a group reported that 86% (203) of them had a cervical screening test at some point in their life meaning that 14% (33) had not (this excludes those seven women that did not answer the question) (Table 24, Figure 44).

Table 24: Have you ever had a cervical screening test? (survey two by age range)

	Age Range			
	25-35	36-49	50-64	Total
Did not answer	5	2	0	7
Yes	24	9	0	33
No	98	74	31	203
Total	127	85	31	243

n=243

Figure 44: Have you ever had a cervical screening test? (survey two)



n=243

As in the initial survey, we also asked participants when they had last had a test. Based on these responses (Table 25):

- 70% (141) of women aged 25-49 years old have had a test in the last three years, as per NHS guidance.
- 90% (28) of women aged 50-64 years olds have had a test in the last five years, as per NHS guidance.
- Combining all eligible age groups, 73% (172) of women at an eligible age have been for a cervical screening test within the NHS recommended timescales.
- 79% (186) of all women at an eligible age have had a test within the last five years.

Table 25: If you have ever had a cervical screening test, when was this? (survey two by age range)

		0-12 months ago	1-3 years ago	3-5 years ago	Did not answer	More than 5 years ago	Did not answer	Total
Age Range	25-35	52	33	7	1	5	1	98
	36-49	31	28	7	0	8	0	74
	50-64	12	14	2	0	3	0	31
	Total	95	75	16	1	16	1	203

n=203

Specifically, it is notable that 79% of women aged 25 and over have had a test within the last five years which compares favourable with national NHS data that stands at 78.9% (The NHS Information Centre 2010).

6. Conclusion & Recommendations

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 study focussed upon LGB women in the North West who are statistically 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 premise of the study was that an intervention campaign targeting LGB women to increase awareness, confidence and knowledge would positively influence their screening behaviour.

The experiences of LGB women were captured and the data strengthens the 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 at beginning to change the cervical screening behaviour of LGB women.

6.1 Conclusions from the pre-campaign survey and focus groups

The baseline findings resonate with earlier studies (Hunt and Fish 2008a, Fish 2009) and provide strong evidence that many LGB women continue to be misinformed regarding their need for cervical screening by health professionals, despite there now being clear guidance (NHSCSP 2009a). LGB women reinforced the need for specific and targeted information to clarify their risks and whether they 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 accurate and relevant information in order to encourage participation in national screening programmes (Weller *et al.* 2009, Fish 2009). We found that:

- 51% of LGB women of an eligible age had either never had a test, or not had one within the recommended NHSCSP timescales (either three or five 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 five years than heterosexual women. 70.5% of LGB women of an eligible age reported screening within the last five 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 programmes, 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 (Bailey *et al.* 2000, Gunstone 2010). 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. Unpacking this area further we found a range of significant barriers that 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'.
- 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 this information to health care workers, and avoided this situation. This was often based on previous negative experiences.
- 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.

These findings indicate that such barriers still exist and have not yet been addressed, despite being known for a number of years (Henderson 2009, Fish 2009, Hunt and Fish 2008a). 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. Indeed, our findings strongly indicate that health care professionals require increased training to expand their own knowledge and communication skills in managing the needs of LGB women effectively. Our research concurs with prior work in the area (Fish 2009, Giordano *et al.* 2008, Hinchliff *et al.* 2005).

6.2 Conclusions from the post-campaign survey and focus groups

As has been noted by Weller *et al.* (2009) customising uptake strategies is particularly useful in low-uptake minority groups, and this was central to the campaign's approach. We envisage therefore that this study goes someway to address the recent finding reported that there is little or no evidence of what interventions are effective in addressing the differences and increasing the awareness of LGB women (NCEI 2010). We also aim to provide evidence to inform and instigate further work in this area, including national coverage of this issue. Following the 'Are You Ready for Your Screen Test?' sustained and intensive campaign there is much evidence to suggest its value. Of those that replied, 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. 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 five 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.
- 73% of LGB women of an eligible age have been for a cervical screening test within the recommended NHS timescales (either three or five years depending on age). 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.

Specifically, it is notable that 79% of LGB 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 were bolstered by the fact that this study resonates with earlier research with the same target population (Hunt and Fish 2008a). Two key overarching conclusions that can be made from the study are detailed below.

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:

- 37% of women aged 16 and above felt that the campaign had increased their knowledge around the need to get a screening test and this figure rose to 39% for those women at an eligible age.
- 32% of women aged 16 and above felt that the campaign had increased their confidence in going for a screening test and this figure rose to 33% for those women at an eligible age.
- 32% 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 and this figure rose to 34% for those women at an eligible age.
- 35% 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 and this figure rose to 37% for those women at an eligible age.

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:

- 25% of women at an eligible age reported that they had actually been for a cervical screening test as a direct result of the LGF campaign.
- 8% (19) of women at an eligible age reported that they had booked a cervical screening test as a result of the LGF campaign.
- 8% (19) of women at an eligible age reported that they planned to book a cervical screening test in the near future as a result of the LGF campaign.
- Overall 51% of women at an eligible age reported some form of positive behaviour change with respect to the uptake of cervical screening testing as a result of the LGF campaign.
- Only 4% of women at an eligible age reported that they would still not go for a screening test.

On a more general note, age, sexual orientation and domicile did not usually have any bearing upon participant responses and experiences (except the few areas we detail in the report and acknowledging the geographically specific recruitment strategies deployed in

survey one and survey two). However, we leave this conclusion open as a larger study with a greater number of distributed participants may provide a different picture.

Finally, it is worth noting that the affects of the campaign have been achieved in a relatively short period. Although the project began in August 2010, the campaign was not engaged until after survey one in October 2010 and we began survey data collection for round two from March 2011, and more substantially in May 2011. We would expect that stronger results would be achieved had the campaign run for longer and also, importantly, it needs to be remembered that some women may not have been influenced to go for screening as it was not the right time for them. In this respect, they may have just had a screening before the campaign, or may not be due one for several years. This emphasises the need for sustained longitudinal study and intervention in the area.

6.3 Recommendations

6.3.1 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.

6.3.2 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 two 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 (Figures 45, 46). 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.

Figure 45: Do you think campaigns like this are needed for LGB women?

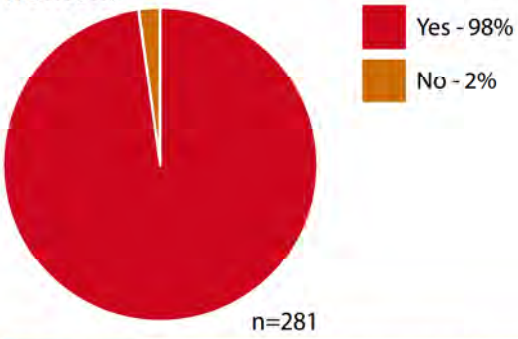
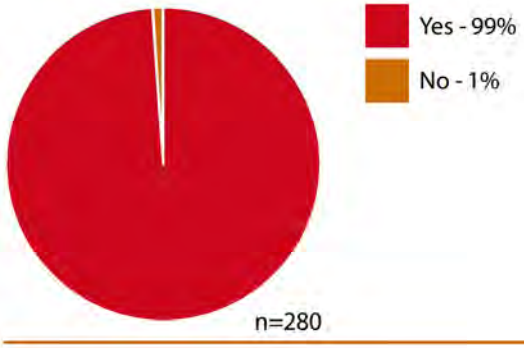


Figure 46: Should this campaign be rolled out nationally?



6.3.3 Targeted campaign approaches

Based on our experience and evidence we would recommend that campaigns:

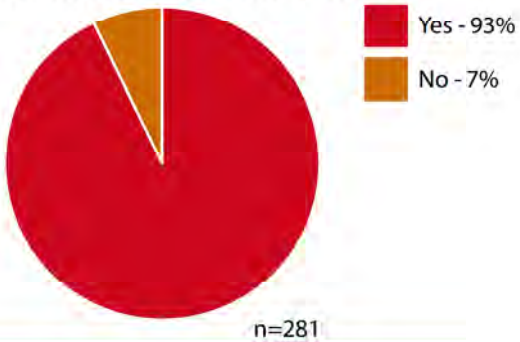
- Require strong design elements and clarity of message.
- Are widely distributed, extending to areas beyond those places LGB women might be assumed to frequent regularly.
- Utilise targeted outreach opportunities within and with the LGB community for one-to-one engagement with LGB women.
- Understand 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.

6.3.4 LGB specific training for health professional

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 (Figure 47). 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). This expertise needs to be translated into health practitioner training prior to and continually updated during professional practice.

Figure 47: Do health professionals need training regarding the health needs of LGB women?



n=281

6.3.5 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.

6.3.6 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.

6.3.7 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

Bailey JV, Kavanagh J, Owen C, McLean KA, Skinner C.J. Lesbians and Cervical Screening. *British Journal of General Practice*, 2000; 50: 481-482.

Bailey JV, Farquhar C, Owen C, Whittaker D. Sexual behaviour of lesbians and bisexual women. *Sexually Transmitted Infections*, 2003; 79: 147-150

Cancer Research UK (CRUK). *Health inequalities in cancer and Lesbian, Gay, Bisexual and Trans (LGBT) communities*. Policy Statement 2008, accessed 16th June 2011: http://infocancerresearchuk.org/images/pdfs/lgbt_policystatement2008

Department of Health (DH). *Cancer Reform Strategy*. London: Department of Health 2007

Department of Trade and Industry (DTI). *Final Regulatory Impact Assessment: Civil Partnership Act 2004*. London: DTI 2004

Dutton WH, Helsper EJ, Gerber MM. *The Internet in Britain: 2009* Oxford Internet Institute, University of Oxford, 2009.

Edwards M. Ensuring cervical cytology is inclusive for all women. Significant Event Review, *Practice Nursing*, 2008; 19(11): 569-571

Fish J. *Cervical screening in lesbian and bisexual women: a review of the worldwide literature using systematic methods*. Leicester: De Montfort University. 2009

Giordano L, Webster P, Anthony C, et al. Improving the quality of communication in organised cervical screening programmes. *Patient Education and Counseling*, 2008; 72:130-136

Gruskin EP, Hart S, Gordon N, Ackerson L. Patterns of cigarette smoking and alcohol use among lesbians and bisexual women enrolled in a large health maintenance organization. *American Journal of Public Health*, 2001; 91(6): 976-979

Gunstone B. *Cancer awareness: the impact of sexual orientation*. YouGov, 2010, accessed 15th June 2011: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_115244.pdf

Hall B, Howard K, MCCaffery K. Do cervical cancer screening patient information leaflets meet the HPV information needs of women? *Patient Education and Counseling*, 2008; 72:78-87

Hall N, Panton D. *Improving the region's knowledge base on the LGB&T population in the North West*, ECOTEC, 2010

Henderson HJ. Why lesbians should be encouraged to have regular cervical screening. *Journal of Family Planning Reproductive Health Care*, 2009; 35(1): 49-52

Hinchliff S, Gott M, Galena E. 'I daresay I might find it embarrassing': general practitioners' perspectives on discussing sexual health issues with lesbian and gay patients. *Health & Social Care in the Community*, 2005; 13:345-53

HMSO, *Equality Act*. Crown, 2010, accessed on 15th June 2011: http://www.legislation.gov.uk/ukpga/2010/15/contents

Hunt R, Fish J. *Prescription for Change: Lesbian and bisexual women's health check 2008*. London: Stonewall, 2008a

Hunt R, Fish J. *Prescription for Change: Lesbian and bisexual women's health check 2008: Supplementary Report: North West*. London: Stonewall, 2008b

Jepson R, Clegg A, Forbes C, *et al*. The determinants of screening uptake and interventions for increasing uptake: a systematic review. *Health Technology Assessment*, 2000; 4: 1-33

Joloza T, Evans J, O'Brien R, Potter-Collins A. *New ONS Integrated Household Survey: Experimental Statistics. Measuring Sexual Identity: An Evaluation Report*. Newport: Office of National Statistics, September 2010

Lewin K. Action research and minority problems. *Journal of Social Issues,* 1946; 2(4):34-46

Lincoln YS, Guba EG. *Naturalistic Enquiry*. Beverly Hills: Sage, 1985

McNair R.P. Lesbian health inequalities: a cultural minority issue for health professionals. Sexuality, *Medical Journal Association,* 2003; 178:643-645

McNiff J, Whitehead D. *Doing and Writing Action Research.* London: Sage, 2009

Meads C, Buckley E, Sanderson P. Ten years of lesbian health survey research in the UK West Midlands. *BMC Public Health,* 2007 7:251 doi:10.1186/1471-2458-7-251

Meissner HI, Smith RA, Rimer BK, *et al.* Promoting Cancer Screening: Learning from Experience. *CANCER Supplement,* 2004; 101(5): 1107-1117

Miles MB, Huberman AM. A*n Expanded Sourcebook: Qualitative Data Analysis.* 2nd Edition. London: Sage, 1994

Mitchell M, Howarth C, Kotecha M, Creegan C. *Sexual orientation research review 2008.* National Centre for Social Research, Equality and Human Rights Commission Research Report Series, Equality and Human Rights Commission, 2009

National Cancer Equality Initiative (NCEI). *Reducing cancer inequality: evidence, progress and making it happen.* Department of Health, 2010

NHS Cancer Screening Programme (NHSCSP) *Cervical screening: The Facts.* 2009a, accessed 15th June 2011: http://www.cancerscreening.nhs.uk/cervical/publications/in-04.html

NHS Cancer Screening Programme (NHSCSP). *Cervical screening for lesbian and bisexual women.* 2009b, accessed 15th June 2011: http://www.cancerscreening.nhs.uk/cervical/publications/lesbian-bisexual-leaflet-sep09.pdf

NHS Cancer Screening Programme (NHSCSP) *Cervical screening: a pocket guide.* 2009c, accessed 15th June 2011: http://www.cancerscreening.nhs.uk/cervical/publications/cervicalpocket2009.pdf

NHS North West, *Everything you always wanted to know about sexual orientation monitoring... but were too afraid to ask,* NHS North West, 2011

Phillips-Angeles E, Wolfe P, Myers R, *et al.* Lesbian health matters: a pap test education campaign nearly thwarted by discrimination. *Health Promotion Practice,* 2004; 5(3):314-25

Reason P, Bradbury H. (Ed.) *The SAGE Handbook of Action Research. Participative Inquiry and Practice.* 1st Edition. London: Sage, 2001

Roberts SJ. Lesbian health research: a review and recommendations for future research. *Health Care for Women International,* 2001; 22(6): 537-552 doi: 10.1080/07399330127194

Sasieni P, Castañón A, Cuzick J. Effectiveness of cervical screening with age: population based case-control study of prospectively recorded data. *British Medical Journal,* 2009; 339:b2968

Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* Thousand Oaks, CA: Sage, 1998

The NHS Information Centre. *Cervical Screening Programme: England 2009-2010.* Health and Social Care Information Centre, Public Health Indicators and Population Statistics Team, Oct 2010

Trent Cancer Registry. *Profile of Cervical cancer in England: Incidence, Mortality and Survival.* Trent Cancer Registry, NHS National Cancer Screening Programmes, Feb 2011

Weller DP, Patnick J, McIntosh HM, Dietrich AJ. Uptake in cancer screening programmes review. *Lancet Oncology,* 2009; 10:693-699