

A GUIDE TO CERVICAL SCREENING FOR LESBIAN AND BISEXUAL WOMEN

Are you ready for your

Screen Test?



Reg. Charity No. 1070904

University of
Salford
MANCHESTER



Cervical Screening Programme

YOUR CERVIX IS WORTH IT!

Cervical screening of women began in the UK in the 1960s. Since then, some lesbian and bisexual women accessing screening have experienced homophobia, assumptions that they are heterosexual, inappropriate treatment and, most damaging of all, misinformation about their health when it comes to cervical screening.

But times are changing! Thankfully as we move forward in the 21st century the needs of lesbian and bisexual women are starting to be examined and understood.

In 2009 the NHS changed their guidance regarding cervical screening due to evidence being established that all women (with a cervix who are aged between 25 and 64) need cervical screening regardless of their sexual orientation or sexual history.

This guide tells you everything you need to know when it comes to you and cervical screening. It's been very kindly funded through the NHS Cancer Screening Programmes without whom this vital guide for lesbian and bisexual women would not be sitting in your hands.

Read it – your cervix is worth it.

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MYTH



"I'M A
LESBIAN SO
I DON'T
NEED A
CERVICAL
SCREENING
TEST."

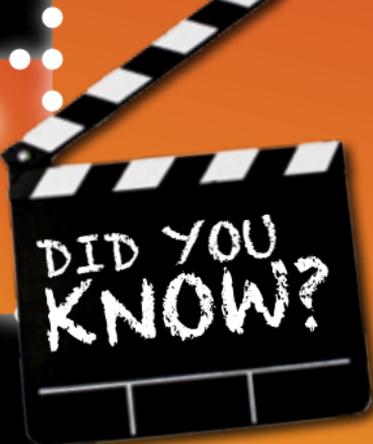
Photo: Sarah Quinn

FACT

All women between the ages of 25 and 64 who have a cervix need to get screened, regardless of whether or not they've slept with a man.

The Human Papilloma Virus (HPV), which causes cervical cancer, can be passed on during sexual activity between two women. Genital HPV is transmitted primarily by skin-to-skin contact. The time from exposure to the virus to the development of cervical disease is highly variable and the virus can remain dormant in some people for long periods of time. Practising safer sex reduces the risk of being infected with HPV but it will not completely eradicate the risk as HPV lives on the skin in and around the whole genital area.

DON'T GET LEFT
IN THE DARK



DID YOU
KNOW?

REGULAR
SCREENING
PREVENTS AROUND
75% OF CERVICAL
CANCERS FROM
EVER DEVELOPING
SO BE SURE TO
GET TESTED AND
SPREAD THE
WORD TOO, BY
ENCOURAGING YOUR
FRIENDS TO GO
FOR SCREENING.

SO WHO NEEDS THE TEST?

In England, all women aged between 25 and 64 with a cervix are eligible for free cervical screening tests every 3 or 5 years, and are strongly advised to attend.

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WHO GETS INVITED, AND WHEN?

AGE	FREQUENCY OF TESTING
25	FIRST INVITATION
25-49	3 YEARLY
50-64	5 YEARLY
65+	WOMEN WHO HAVE NEVER BEEN SCREENED CAN REQUEST A TEST AND WOMEN WHO HAVE HAD RECENT ABNORMAL RESULTS WILL STILL BE INVITED UNTIL THEIR FOLLOW-UP IS COMPLETE.

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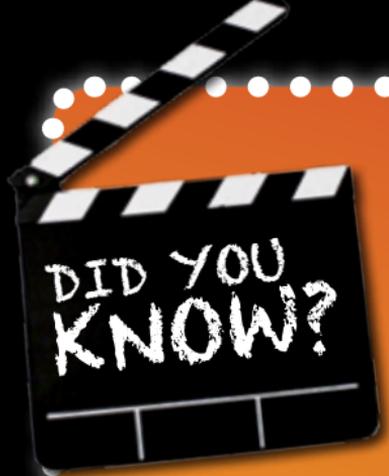
IF YOU'VE NEVER BEEN SEXUALLY ACTIVE WITH ANYONE (MAN OR WOMAN), THEN RESEARCH SHOWS THAT YOUR CHANCE OF DEVELOPING CERVICAL CANCER IS VERY LOW.

In these circumstances, the NHS advises that a woman might choose to decline the invitation for cervical screening. However, remember it's low risk, not no risk - so discuss it further with your doctor.

If you're not currently sexually active but have had partners in the past, then you should still continue screening.

If you have any unusual symptoms, such as bleeding after sex or between periods, then don't wait until your next screening test is due - you should visit your doctor to see if you need other investigations.

If you've had a hysterectomy then speak to your doctor about whether you need testing as it will depend on the type of hysterectomy you've had.



SOME SCHOOL AGED GIRLS ARE BEING GIVEN THE HPV VACCINATION - BUT THEY STILL NEED TO ATTEND SCREENING WHEN THEY'RE THE RIGHT AGE AS THE VACCINE DOESN'T PROTECT AGAINST ALL TYPES OF HPV.

"That's so, 2009!"



Sometimes, lesbian and bisexual women have been advised by health workers that they don't need to have a cervical screening test if they don't sleep with men, or aren't currently sleeping with men.

The old leaflet from the NHS used to advise that you might choose to decline the invitation for screening if you've never been sexually active with a man. Or, you may have been told by friends, partners or family that you don't need to be screened.

Let's face it – cervical screening tests aren't the nicest of procedures, so if someone mentions you don't need to be screened, then you're probably not going to argue with them! However, new research was carried out and this all changed. Whilst it is still believed that you may be more at risk if you've had sexual contact with a man, research states that women exclusively sleeping with women are still at risk.

Either way, it doesn't matter who you sleep with, or who you've slept with in the past – you're eligible for screening, so go and get your test!

THE EXPERT OPINION

“THE BIGGEST RISK FACTOR FOR CERVICAL CANCER IS NON-ATTENDANCE FOR SCREENING SO WE ENCOURAGE ALL WOMEN AGED 25 TO 64, IRRESPECTIVE OF THEIR SEXUAL ORIENTATION, TO ACCEPT THEIR INVITATIONS FOR CERVICAL SCREENING.”



NHS CANCER
SCREENING
PROGRAMMES

WHY DO YOU NEED THE TEST?

SADLY AROUND 900 WOMEN DIE OF CERVICAL CANCER EACH YEAR IN ENGLAND. HOWEVER, MANY OF THOSE WHO DEVELOP IT HAVEN'T BEEN SCREENED REGULARLY. THANKS TO CERVICAL SCREENING, CERVICAL CANCER IS NOW AN UNCOMMON DISEASE IN THIS COUNTRY.

Cervical cancer can often be prevented. Nearly all cases of cervical cancer are associated with the HPV virus, which is a sexually transmitted infection.

The virus causes changes in the cells of the cervix, which can go on to develop into cancer over time if left untreated. That's why it's important to check the health of the cells regularly.

Unlike other cancer screening methods, cervical screening is not a test for cancer. It is a method of preventing cancer by detecting and treating early abnormalities. So, the best way to prevent cervical cancer, is to go and get screened.

EARLY DETECTION AND TREATMENT CAN PREVENT 75% OF CANCERS DEVELOPING.

WHAT IS A CERVICAL SCREENING TEST?

A cervical screening test checks the health of the cervix (the lower part of the womb).

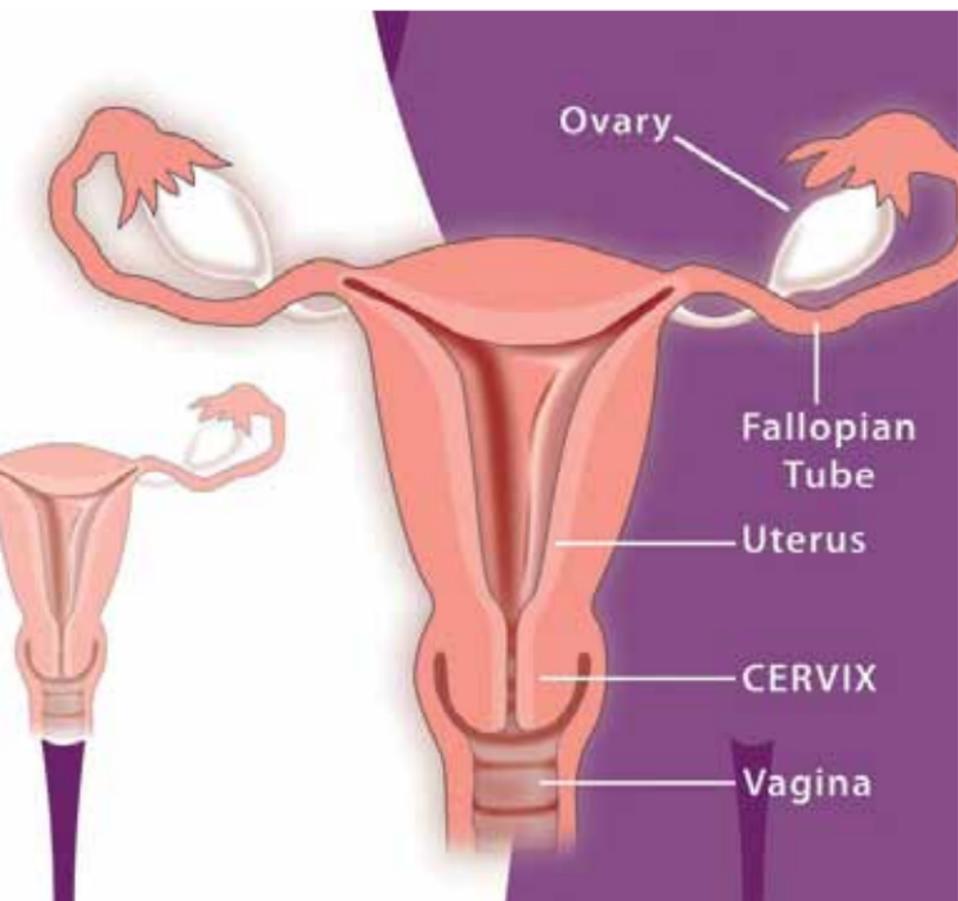
You may be more familiar with the term 'smear'. This is what the procedure used to be called and refers to the way the test was carried out, as cells were taken from the cervix and smeared onto a microscope slide.

Something called 'Liquid based cytology' is a newer and more reliable method of preparing and examining cell samples and has replaced the smear method. The sample is collected using a special device which brushes cells from the neck of the womb. Rather than smearing the sample onto a slide, the cells are transferred into preservative fluid.

The sample is sent to the laboratory where it is examined under a microscope by a cytologist.



“WHERE’S MY CERVIX?”



WHAT HAPPENS?

THE NHS CERVICAL SCREENING PROGRAMME HAS A SYSTEM TO INVITE ELIGIBLE WOMEN WHO ARE REGISTERED WITH A GP TO ATTEND CERVICAL SCREENING.

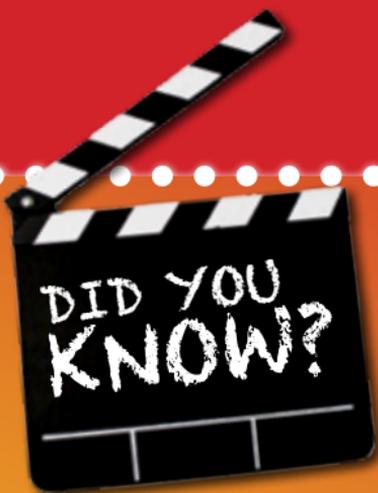
As long as your contact details on your medical records are correct, you will get a letter inviting you to book a cervical screening test when you are due one.

Women are first invited at 25, and will get repeat invites every 3 or 5 years thereafter until they reach 65.

Usually, cervical screening is carried out at your GP practice, by the practice nurse. You can choose to be screened at a Sexual Health Clinic if you prefer, and information about your different options is often sent out with this invite letter. You can also be screened at a Family Planning Clinic or a Well Woman Clinic.

Along with your invitation to attend cervical screening you will receive a leaflet which tells you more about the screening process, and may answer any questions you might have.

WHAT SHOULD I DO BEFORE THE TEST?



IT'S BEST NOT TO BE TESTED DURING YOUR PERIOD - IT'S BETTER TO HAVE YOUR TEST MID-CYCLE - USUALLY 14 DAYS AFTER THE START OF YOUR LAST PERIOD.

You will need to contact your GP (or the venue you wish to have your cervical screening test at) to arrange an appointment.

If you have any access needs or if you want to make sure you have a female nurse or doctor to carry out your test, then make this known when you book your appointment.

If you want to have a wash and spruce up down there before your test then go ahead - whatever makes you more comfortable. But remember your vagina is self cleaning so harsh products or excessive cleaning can upset it's delicate ph balance.

CAN I HAVE SEX BEFORE THE TEST?

It's advised that you don't use lubricant, spermicide, or a barrier method of contraception (i.e. condom) for 24 hours before the test, as the chemicals may affect the test.

If you use these, then it might be best to abstain for a day.

ON THE DAY

THE NHS DON'T CURRENTLY MONITOR SEXUAL ORIENTATION, SO YOU SHOULD NOT BE ROUTINELY ASKED ABOUT YOUR SEXUAL ORIENTATION.

However, many women find that they get asked sexual health questions which are more appropriate for heterosexual women, such as 'do you use contraception?'

At this point, you may wish to mention your sexual orientation so that the information you are asked for or are given is more appropriate. On page 18 there's more information about why and how you might want to do this.

Once they have asked a few questions, the person doing the test will talk you through the procedure. This is the chance to ask whatever questions you might have so feel free to ask them.

You will then be asked to take your clothes off from the waist down and lie on an examination bed (If you're cringing at this point then fear not – check out page 23). You'll be told how to position yourself but a good way to do this is to draw your legs up so your feet touch your bum, and then drop your knees to the sides. An instrument called a speculum will be used to gently open your vagina so your GP or nurse can see your cervix and take a sample.

YOUR RESULTS

AND WHAT THEY MEAN

YOU WILL BE NOTIFIED OF YOUR TEST RESULT THROUGH A LETTER, WHICH YOU SHOULD RECEIVE WITHIN 2 WEEKS OF HAVING YOUR TEST.

Most results are normal, but abnormal cells are found in some women. Abnormal cells indicate that cancer may develop. Treatment can be given to prevent cancer from developing in women with abnormal cells. So, getting your results is extremely important.

Normal result

About 9 in 10 routine cervical screening tests are normal. As long as your details are correct, you will be sent another letter when you're next due a test (so make sure your contact details are kept up-to-date with your GP). A normal result means you have a very low chance of developing cervical cancer but is not a 100% guarantee that it will not occur.

Inadequate test

Don't panic - this simply means no result can be given. For example, it could mean that not enough cells were taken. You will be asked to attend for a repeat test and will need to wait three months before going, to give the cells a chance to re-grow.

Abnormal result

Some changes in the cells are found in about 1 in 20 tests. In nearly all cases, these changes do not mean cancer. Minor or borderline abnormal changes are quite common and often clear up on their own. However, any change needs to be monitored so a repeat test after 3-12 months is commonly advised.

Many women worry when an abnormality is found, but often the changes will have gone when the test is repeated. If the changes don't go, then a referral for colposcopy is advised. Rarely is cervical cancer diagnosed by a cervical screening test.

What is colposcopy?

Colposcopy is a more detailed examination of the cervix. A magnifier (colposcope) is used to look at the cervix in more detail. A liquid is used to 'paint' the cervix which shows up the abnormal cells. It takes a little longer than a normal screening test (about 15 minutes).

During colposcopy it is usual to take a small piece of tissue from the cervix (biopsy) to make a more detailed assessment.

Can abnormal cells be treated?

Yes. If the cells remain abnormal after repeat testing, or the changes are more marked, then treatment is offered. In the vast majority of cases this will stop cancer developing from the abnormal cells. These treatments are done as an out-patient (meaning you're in and out of hospital in a day) and don't take long.

Follow up and regular screening is needed for the next few years to check that the treatment has been successful.

Coming Out!

COMING OUT IS OFTEN ONE OF THE MOST DIFFICULT THINGS WE HAVE TO DO, AND WE DON'T JUST DO IT ONCE, WE COME OUT TO PARENTS, FRIENDS, COLLEAGUES, AND STRANGERS ON A REGULAR BASIS.

So why should we come out to this nurse who we are meeting for the very first time, who is about to do something that we wouldn't ordinarily do on a first date?!

Well, because it's going to make your life easier and your experience more comfortable.

If you come out to your doctor, nurse or health practitioner, no longer will you have to deal with those questions about what kind of contraception you are using and questions about sexual intercourse that are clearly aimed at heterosexual women.

They will be aware of the kind of sex you are having and who you are having it with, and will only ask you questions that are appropriate to you. Hoorah! This means that you will be getting a service that is more relevant to you.

Let's be honest, no one gets giddy about the prospect of their cervical screening test but if you are out and open with your nurse you're likely to feel more comfortable and able to be yourself.

The more relaxed you are, the quicker it will be over and the easier the test is likely to be.

We understand it's difficult to come out in the best of circumstances, let alone when feeling vulnerable and about to get half naked with a stranger, and not in a good way!

If you really don't feel able to come out then don't worry, you are certainly not alone because we've all been there.

The most important thing is to get screened, but if you do want more advice about coming out you can call The Lesbian & Gay Foundation - we're here if you need us.

Be brave and come out... your bravery will make it easier for the next generation, as the more lesbian and bisexual women that come out to their health care professionals, the more clued up they will be about our needs and appropriate treatment.



KNOW YOUR BODY, KNOW YOUR RIGHTS

DON'T LET YOUR CERVIX GET LEFT IN THE DARK – LESBIAN AND BISEXUAL WOMEN NEED A CERVICAL SCREENING TEST!

Lesbian and bisexual women need a cervical screening test and don't let anybody tell you otherwise!

If a health care professional refuses you a test... use your rights!

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

So there you have it; if you are refused or have been refused a test on the basis of your sexual orientation, it is against the NHS constitution to deny a test to anyone who is eligible and the health professional involved can be held accountable.

Did you know...? It is illegal to deny public services to lesbian, gay and bisexual people.

Under the Provision of Goods and Services Act 2007, it is illegal for lesbian and bisexual women to be denied access to screening services on the grounds of their sexuality. If you are eligible for a cervical screening and are

denied access - report it!

It's your body so don't be afraid to ask!

We've spoken about all the plus points of coming out to your health care professional, but if you are still unsure because of concerns about confidentiality you might want to ask your health care professional about how sexual orientation is recorded in patient notes. Also, you can ask your GP or local Health Board to view medical notes written about you after November 1991. If your concern is around homophobia then read on.

Other options open to you...

If you really don't want to come out to your GP, you can visit a Sexual Health Clinic for a cervical screening. Sometimes this may be easier as it might seem more anonymous.

USE YOUR RIGHTS!

IF YOU DO COME OUT TO A HEALTH CARE PROFESSIONAL AND FEEL THEY ARE TREATING YOU NEGATIVELY BECAUSE OF YOUR SEXUAL ORIENTATION YOU CAN COMPLAIN ON THESE GROUNDS. DEPENDING ON WHO THE COMPLAINT IS REGARDING YOU CAN COMPLAIN TO THE GP, THE PRACTICE MANAGER OR THE PCT.

MAKE IT WORK FOR YOU!

FOR MANY WOMEN, SHOWING A STRANGER YOUR INTIMATE REGIONS AND WORRYING ABOUT WHETHER IT IS GOING TO HURT IS A REAL CONCERN, AND CAN MAKE WOMEN RELUCTANT TO ATTEND.

If you're worried about this, then bring it up with your Doctor or Nurse. What's important to remember is that the person doing the test will have seen countless lady gardens in all shapes and sizes so yours really won't be anything special (no offence).

Performing a cervical screening test is likely to be as 'normal' to them as it is for a post woman to deliver a parcel - it's a routine procedure and part of their job.

Another concern women have is that the procedure might be painful. However most women find it painless, or only slightly uncomfortable. In the unlikely event that you find it painful, you can tell your nurse to stop.

Fanny, lady garden, twinkle, nether regions... whatever you call it, they've tested it!

Countless numbers of women aren't keen on the thought of exposing themselves and having someone do this 'down below' procedure. But, at the end of the day, this procedure can detect pre-cancerous cells, which could save your life. For a few minutes (which is all it takes) - it's well worth it.

HINTS AND TIPS

There are loads of ways to make the experience work best for you – here are just a few!

- Relax! If you're tense it will be less comfortable.
- If you're not comfortable going in for the test alone, you can always take a partner, friend or family member in with you.
- If you are more comfortable having your cervical screening test carried out by a male or a female nurse, just ask your GP's surgery when you make your appointment.
- Ask the nurse or doctor doing the test to explain exactly what happens before they start.
- If you have any concerns raise them with nurse or doctor before the test.
- If you are feeling nervous let the nurse or doctor know and then they can help you to relax.
- You can ask for a smaller or larger speculum. Like lesbian and bisexual women, vaginas come in all shapes and sizes. The taller you are, the longer your vagina – so having a smaller or larger speculum could mean a much more relaxing and comfortable test.
- You can ask for the speculum to be warmed.
- The best time to go for your cervical screening is in the middle of your menstrual cycle.
- Your test is often more comfortable if you have a wee before hand.

THE GOOD THE BAD & THE EXPERT...

Different women have different experiences of cervical screening - for some it's no big deal, for others it's something they dread.

Lesbian and bisexual women have told us about their positive and negative experiences of testing.

Cervical screening is something we need to do regularly - so it's all about making it part of our routines.



As a rule, it only takes a few minutes and taking the test could save your life! When you think about it like that, it's minimum fuss for a maximum result.

So don't be left in the dark, have the confidence to make your cervical screening the best experience for you - because you're worth it!

THE GOOD...

"I'VE HAD SOME BAD EXPERIENCES IN THE PAST WITH SOME PRETTY SURLY NURSES, BUT MY LAST CERVICAL SCREENING ONLY A FEW MONTHS AGO WAS PRACTICALLY A CAUSE FOR CELEBRATION. I WAS PUT AT EASE STRAIGHT AWAY BY THE NURSE WHO ACKNOWLEDGED THAT CERVICAL SCREENING WASN'T THE MOST ENJOYABLE THING IN THE WORLD.

She spoke to me before, during and after the test letting me know what was going on and what to expect, which encouraged me to be more open with her! I let her know that in the past nurses had trouble finding my cervix, this meant she was able to locate it easier and the procedure was over quickly.

It might sound odd, but it was the best cervical screening I've ever had."

Jo, Manchester

THE BAD...

"I WENT FOR A CERVICAL SCREEN TEST AND WAS ASKED IF I WAS SEXUALLY ACTIVE. WHEN I SAID YES I WAS ASKED IF I WAS TRYING FOR A BABY. WHEN I SAID NO, I WAS ASKED WHAT CONTRACEPTION I WAS USING. WHEN I SAID NONE, I HAD TO ENDURE A 10 MINUTE TIRADE ABOUT HOW IRRESPONSIBLE I AM.

When I said I only sleep with women, the nurse physically recoiled, looked appalled and told me I would never need a cervical screening test, and refused to test me.

However that was a long time ago and I've had plenty of good screening tests with great nurses since. Times have definitely changed for the better."

Anne, Blackpool.

THE NURSE

“LESBIAN AND BISEXUAL
WOMEN NEED TO GET
SCREENED, IT DOESN'T MATTER
WHO YOU SLEEP WITH -
WE'RE HERE TO TEST YOU,
SO TAKE ADVANTAGE OF THIS
SERVICE IT'S VERY IMPORTANT
AND IT CAN SAVE YOUR LIFE.
TAKE CHARGE OF YOUR BODY
GIRLS!”

**Juliette Clegg, Nurse
Practitioner, Ambleside
Health Centre, Cumbria.**



IF YOU ARE A
TRANS LESBIAN OR
BISEXUAL WOMAN
YOU ONLY NEED TO
BE SCREENED IF YOU
HAVE A CERVIX.

SEX & HPV

Many sexual transmitted infections are transmitted through bodily fluids, so prevention can take on many forms (for example through using dental dams, lube, not sharing sex toys or using condoms on sex toys, etc.).

However, HPV is transmitted primarily through skin to skin contact in the genital area, and because of this, it is harder to prevent.

Because of the way it is primarily transmitted, it's not surprising that most sexually active women will have HPV at some point in their lives, but there are a bunch of things which can be done to help prevent it leading to cervical cancer.

Attending regular cervical screening is one of the most effective ways to do so, as abnormal cells can be identified and dealt with before they develop into cancer. Other factors, such as a healthy diet and not smoking, are key ways of reducing your risk.



ALONG WITH HPV, OTHER STIs CAN BE TRANSMITTED BETWEEN WOMEN. FOR MORE GENERAL SEXUAL HEALTH ADVICE, AND INFORMATION ON HOW TO PREVENT OTHER STIs, E-MAIL WOMEN@LGF.ORG.UK, OR VISIT WWW.LGF.ORG.UK/WOMEN

“I AM WOMAN HEAR ME ROAR!”

You are wonderful, you are unique, you are a superstar and the world is a richer place with you in it!

So make sure you *are* in it!

All women between the ages of 25 and 64 who have a cervix need to have a cervical screening test, regardless of whether or not they've slept with a man.

Lesbian and bisexual women – this includes YOU! The Human Papilloma Virus (HPV), which causes cervical cancer, can be passed on during sexual activity between two women.

Making an appointment for a cervical screening test takes seconds, taking the test takes a few minutes – not long for something that could save your life!

So don't be left in the dark, ring or visit your GP to book a cervical screening, or check when your next one is due.

**GET TESTED - BECAUSE YOUR
CERVIX IS WORTH IT!**

FURTHER INFORMATION

If you have any specific questions about any aspects of cervical screening, in the first instance you should contact your doctor. If you are not registered with a doctor or do not feel confident about asking questions there are other sources of help:

The Lesbian & Gay Foundation

0845 3 30 30 30

www.lgf.org.uk/screening

NHS Cancer Screening Programmes

www.cancerscreening.nhs.uk

NHS Choices

www.nhs.uk

Jo's Cervical Cancer Trust

www.jostrust.org.uk

Cancer research

www.cancerhelp.org.uk

Macmillan Cancer Support

www.macmillan.org.uk



We believe in a fair and equal society where all lesbian, gay and bisexual people can achieve their full potential.

This guide is available in large print by calling **0845 3 30 30 30** or email **info@lgf.org.uk**



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