Cancer risk and screening

Information for people who are transgender, non-binary, and gender-diverse

Live
Through
This

Live Through This is a charity registered in England and Wales (1190756) and works to support and advocate for LGBTIQ+ people affected by cancer.

This booklet describes the national cancer screening programmes in England. There may be regional differences in the devolved nations of Scotland, Wales and Northern Ireland.

Over time, there can be changes to the national screening programmes. The information in this booklet is correct at the time of publishing, but we recommend that you always follow the most up to date NHS guidance:

https://www.nhs.uk/conditions/nhs-screening/

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Contents

Introduction

Why do I need this booklet?

Welcome to your guide to cancer risk and screening in England. We understand that you may have questions about cancer, screening eligibility and how transition may affect your individual risk or access to the right tests.

This booklet was produced to help you answer these questions and protect your own health. We encourage you to keep this handy and take it to any GP appointments where you think it might help.

The first part of this booklet focuses on cancer types that form part of the national screening programmes (breast, cervical and bowel) as well as Targeted Lung Health Checks, which is a pilot programme being rolled out by NHS England and Cancer Alliances.

The second part discusses cancer types without routine national screening programmes but where risk may be affected by gender affirming treatments like hormones or surgery, or where dysphoria might result from where the cancer is on your body or the tests you need to have as a result.

What does ‘screening’ mean?

Screening is a type of test we give to healthy people who may have an increased risk of a particular condition. The NHS offers a range of screening tests to people who are most likely to benefit from them.

Cancer screening has the potential to save lives by finding cancers at an early stage, or in some cases even prevent them. Screening is not the same process as when a person goes to their GP with symptoms, which may result in them being referred to a clinic for diagnostic tests.

The NHS currently offers three national screening programmes: Cervical, Breast and Bowel.

Certain cancers do not have reliable tests to detect them. For this reason, they do not have a national cancer screening programme. If you do have a symptom that you think is related to one of these cancers, you can still be tested, but we do not call this ‘screening’. This is because ‘screening’ refers to tests conducted on people with no symptoms.

Additionally, the NHS is exploring the use of Lung Health Checks for people aged from 55 to less than 75 who smoke or used to smoke. These are available at specific locations across England at the point of publication, but may now be more widely available. Check with your GP if you feel you may benefit from this service.

National cancer screening programmes

Screening at a glance

Programme	Ages	Eligibility	Access
Cervical	**25 to 49** Every 1, 3 or 5 years depending on previous results **50 to 64** Every 5 years **65 or older** Only if 1 of your last 3 tests was abnormal or if you have never been screened	For people with a cervix	By automated letter if the gender marker on your medical records at the GP is female By speaking to your GP if the gender marker on your medical records at the GP is male
Breast	**50 to 71** Every 3 years **71 and over** By request, every 3 years in England, Northern Ireland and Wales	For people with breasts For people assigned female at birth who have not had top surgery / bilateral mastectomy	By automated letter if the gender marker on your medical records at the GP is female By speaking to your GP or a local NHS Breast Clinic if the gender marker on your medical records at the GP is male
Bowel	**60 to 74 years** Every 2 years The programme is expanding to make it available to everyone aged 50 to 59 years. This is happening gradually over 4 years and started in April 2021.	Everyone	Faecal immunochemical test (FIT) sent in post

Cervical screening

What is the test for?

Cervical screening is a highly effective way of preventing cancer. It looks to find the high-risk types of human papillomavirus (HPV) which are the cause of most cases of cervical cancer. If HPV is found, with the same sample they then look for abnormal cells in the cervix that could develop into cancer if left untreated.

Estimates suggest that screening prevents 70% of cervical cancer deaths, but 83% could be prevented if everyone attended regularly.

Do I need to be screened?

Cervical screening is for anyone who was assigned female at birth (AFAB) who still has a cervix. In England it is offered between the ages of 24.5 and 49 every 3 years. At the time of writing, it is recommended that this is extended to every 5 years, however this has not yet been implemented. For those between the ages of 50 and 64, screening is offered every 5 years.

People who are eligible may include:

- transgender men
- non-binary people AFAB
- cisgender women

If you do not have a cervix, you do not need to attend for cervical screening. This may include:

- people AFAB who have had a total or radical hysterectomy as these involve the removal of the cervix
- trans women and non-binary people assigned male at birth (AMAB)

What if I have been vaccinated?

The HPV vaccine Gardasil is given to protect people from certain types of HPV that are known as "high-risk" because they're linked to the development of some cancers like cervical cancer, anal cancer, genital cancers, and cancers of the head and neck. Gardasil can also prevent genital warts.

Gardasil does not have any effect in individuals who already have a persistent infection or disease associated with the HPV types in the vaccine. However, because Gardasil offers protection against multiple strains, an infected person receiving the Gardasil vaccine will still gain protection against strains they have not previously been infected with.

Screening is still recommended even if you have been vaccinated because there are multiple types of HPV, some of which the vaccine may not protect against.

Does transition affect my cervical cancer risk?

Hormone therapy

Testosterone is not known to affect the risk for cervical cancer, but it can sometimes make it harder to take an adequate sample during screening. This is because long term testosterone use can lead to thinning of the vaginal walls and a reduction in the amount of natural lubrication which may make the procedure more uncomfortable.

Surgery

A total hysterectomy will remove the cervix and remove the risk of cervical cancer. Partial hysterectomy leaves the cervix in place, so ongoing screening is required. Check with your surgeon or other health professional if you are unsure what surgery you have had.

Vaginoplasty for people assigned male at birth does not create a cervix so does not create a risk of cervical cancer.

How do I access cervical screening?

If your GP records have your gender marker as female

You will be automatically invited to cervical screening unless you have opted out.

If your GP records have your gender marker as male

You will not be automatically invited to cervical screening.

You can organise your own cervical screening by making an appointment with your GP, at a local sexual health clinic or with a local trans health clinic where available. You can find details about available trans health clinics on our website: https://livethroughthis.co.uk/

Some GPs have a separate register to help remind patients who are not automatically called for screening. If your GP has not taken this step, you can request for them to do so and direct them to RM Partners (West London Cancer Alliance) who have clear guidelines on how to do this: https://rmpartners.nhs.uk/publications-and-resources/

The NHS is due to update their systems with an opt-in to the automatic invite system (known as The Call and Recall System). This will allow people with a male gender marker at their GP to opt-in for the automatic reminders for cervical screening. At the time of publication, this service was not yet live, however it may have since been activated. Try asking your GP about this option at your next appointment.

What happens at the appointment?

When you arrive at the appointment you will be asked to remove your clothing from your waist down. You'll be able to do this behind a screen and will be given a sheet to put over you.

The doctor or nurse will ask you to lie back on a bed, usually with your legs bent, feet together and knees apart. Sometimes you may need to change position during the test, such as putting your fists under bottom, to make the cervix easier to see.

A smooth, tube-shaped tool called a speculum will be gently inserted into the vagina with a small amount of lubricant.

The doctor or nurse will then open the speculum so they can see the cervix.

Using a soft brush, they will take a sample of cells from the cervix.

Once the cells have been collected, the doctor or nurse will close and remove the speculum and leave you to get dressed.

The doctor or nurse may give a tissue to wipe the lubricant off yourself but if they do not, you can ask for one if you need it.

What happens if I need further tests?

You may be asked to come back within 3 months to have the test again if the result is unclear. This is known as an inadequate result. This doesn’t mean anything is wrong but means there wasn’t a good enough sample taken initially.

If your results show that you have tested positive for high-risk HPV, you will be invited for your next screening sooner to check that your body has managed to clear the HPV infection. This will usually be a year after your previous test.

If your results show that there are changes to your cells that are caused by certain types of human papillomavirus (HPV) you will be invited to a colposcopy appointment. Colposcopy is a test that takes a closer look at your cervix using a lighted, magnifying instrument called a colposcope. This is done because these cell changes can turn into cervical cancer if left untreated.

The procedure will usually take place at a colposcopy unit at a local hospital or clinic. For the 24 hours before your colposcopy, you should not have penetrative vaginal sex or use any products that you place inside the vagina, such as tampons, vaginal creams or medicines.

During the procedure, a speculum is gently placed into the vagina and opened. The colposcope is then used to look at the cervix in greater detail. The colposcope stays outside your body. The doctor or nurse will put liquids on the cervix that help them see any abnormal cervical cells.
They may also take a small sample of cells for testing. This is called a biopsy.

There may be some minor bleeding after the colposcopy, so it’s a good idea to bring a sanitary pad or panty liner to the appointment. If this type of product has the potential to trigger any dysphoria, you could use a male incontinence pad.

If you have a coil (IUD, or Mirena coil) it does not usually need to be taken out, but you should tell the person doing the colposcopy that you have one.

Are there any tips for attending an appointment?

Embarrassment and fear of discomfort of pain can be common reasons people give for avoiding a cervical screening appointment. Here are some tips that can lead to a better screening experience:

- Call the clinic ahead of your appointment to discuss how to make it a better experience
- Ask for a double appointment so you have enough time to ask any questions you may have
- Ask to bring a friend, partner, or family member with you to your appointment
- Let them know which name and pronouns you would like to use for the appointment
- Ask to be seen at the beginning or end of a clinic to avoid long stays in the waiting room
- Discuss the potential to use topical oestrogen gels before the appointment if you are afraid of pain due to dryness
- If you are anxious about your name appearing on a waiting room screen, ask them to call you in without using the display
- Tell the person carrying out the screening the language you would like them to use when referring to your body
- Ask your GP about pain relief or a medication that can relax you before the test
- Ask for a smaller speculum to be used during the procedure
- Ask if you can insert the speculum yourself
- Ask about the amount of lubrication being used
- Tell the GP or nurse if the test feels too uncomfortable or if you are in pain
- Remember that you can stop the procedure at any time if you need to
- Ask your GP to remind you when you’re next due for a smear test
- Let the person taking the sample know if you are taking testosterone and if you still have menstrual periods. This helps the accuracy of the test.

Breast cancer screening

What is the test for?

Breast cancer screening uses a test called a mammogram which involves taking x-rays of the breast tissue on your chest. The scan looks to find breast cancers at an early stage, when they may be too small to see or feel. Identifying cancer at this stage increases the chance of treatment being successful. These tests are conducted at Breast Screening Clinics or mobile screening centres, not at your local General Practice (GP).

Do I need to be screened?

Routine breast cancer screening is for anyone between the ages of 50 and 71 who has breasts, due to either oestrogen produced by the body or oestrogen hormone therapy. This might include:

- transgender men and non-binary people assigned female at birth (AFAB) who have not had a a bilateral mastectomy (an operation that removes the breasts) or top surgery (bilateral mastectomy with masculine chest reconstruction)
- transgender women and non-binary people assigned male at birth (AMAB) and who have taken feminising hormones
- cisgender women

You may be called for screening earlier if you are known to have a higher risk of breast cancer or undergo a procedure that requires ongoing observation.

If you have had top surgery, it is not possible to perform a mammogram so you should continue to monitor your chest yourself for any signs and symptoms of cancer where breast tissue remains. This may include the nipple and its surrounding area, up to the collarbone and into the armpit. If you have had a complete (radical) mastectomy, you do not need to go for screening.

If you have undergone a breast reduction, you can continue to attend breast cancer screening.

Current recommendations suggest that trans women should attend routine breast screening after five or more years of taking feminising hormones.

You can always request to be screened if you identify a risk symptom. You should report any of the following symptoms to your GP, even if you have had top surgery / a mastectomy. Symptoms to watch out for include:

- discharge or liquid that comes from the nipple without squeezing
- new, unusual lumps or an area that feels thicker than the rest
- puckering or dimpling of the skin (it may look like orange peel)
- a sudden, persistent or unexplained change in size or shape
- a nipple that becomes inverted or points in a different direction
- a lump, swelling or thickening in your upper chest or armpit area
- redness or inflammation of the skin
- a rash or crusting of the nipple or the surrounding skin

On its own, pain is not usually a sign of breast cancer. But look out for pain in your breast / chest or armpit that's there all or almost all the time.

Does transition affect my risk?

Chest binding

There is no evidence that chest binding increases your risk of breast cancer.

Hormone therapy

Research shows that the risk of breast cancer in trans women is about three times lower than it is for cisgender women. The risk is still much higher than for cisgender men (although the risk of breast cancer in cisgender men is low overall). Oestrogen therapy leads to breast tissue growth which can increase breast cancer risk. We also know that oestrogen helps some breast cancers to grow. Some trans women also take the hormone progesterone. There is now evidence that progesterone can produce a slight increase in the risk of breast cancer in cisgender women.

Trans men have a five times lower risk than cisgender women, but this is still higher than for cisgender men. This reduction might be due to taking testosterone which reduces the amount of oestrogen in the body.

Surgery
There are risks with all surgery, and there are risks with all implants (prostheses). However, breast implants do not increase your risk of breast cancer.

Breast implant-associated anaplastic large cell lymphoma (BIA-ALCL) is an uncommon cancer of the white blood cells (lymphoma) that develops in response to the body's reaction to a breast implant. In the UK, the majority of BIA-ALCL is diagnosed early and cured by removal of the implants with surrounding scar tissue with no additional cancer treatment required. However, in a small number of cases further treatment such as chemotherapy, immunotherapy or radiotherapy may be required. More information about BIA-ALCL can be found on the Government's website.

Breast implants can make the breast tissue harder to screen with mammography, but breast clinics are trained to handle this.

The risk of breast cancer is reduced after top surgery. This is because most of your breast tissue is taken away during the procedure. Even if your surgeon has attempted to remove all of your breast tissue, approximately 1% can remain. Therefore, it is important to be aware of the signs and symptoms of breast cancer listed above.

How do I access breast cancer screening?

If your GP records have your gender marker as female

You will be automatically invited to breast screening when you reach 50, and then every three years until you reach 71.

If your GP records have your gender marker as male

Currently you will not be automatically invited for breast screening.

- If you have not had top surgery / bilateral mastectomy and would like to take part in screening, you can discuss this with your GP or call the local breast screening service to ask for an appointment.

What happens at the appointment?

During the appointment you will have 4 breast x-rays (mammograms) taken, 2 for each breast/ side of the chest. The mammograms are done by a specialist who will be a woman.

The mammograms only take a few minutes. The whole appointment should take about 30 minutes.

Before starting, the mammographer will check your details and ask if you have had any breast problems. You may also be given a questionnaire. They will explain what will happen during the screening and answer any questions you may have.

Before you can have a mammogram, you will need to undress so that you are naked from the waist up. You will be given a private changing area and you may also be given a hospital gown to wear. If you wear a binder, you will need to remove this before having a mammogram.

When you are ready, you will be called into the x-ray room and the mammographer will explain what will happen during the procedure. Remember, you can ask as many questions as you feel you need to.

The mammographer will place your breast / the breast tissue on your chest onto the x-ray machine. It will then be squeezed between 2 ‘plates’ (made out of plastic and metal) to keep it still while the image is taken. This can be uncomfortable but does not take long

Once completed, the mammographer will tilt the machine and prepare you to be screened from the other side.

Your other breast / side of your chest will be x-rayed in the same way.

You will then return to the changing area to get dressed.

Your results will be sent to you in the post.

Screening for those identified as at ‘very high risk’

Some people are identified as very high risk (VHR) for breast cancer, usually due to inherited gene mutations (for example BRCA) or a strong family history of cancer. The national cancer strategy requires that the NHS Breast Screening Programme screens VHR people with digital X-ray mammography and/or magnetic resonance imaging (MRI). The national breast screening system manages the invitation process and records all outcomes for people screened through the very high risk programme.

Every screening service is expected to have arrangements in place for managing people in their area who are eligible for 'very high risk' screening.

If it is decided that you require this type of screening, you will be referred into the programme by:

- a genetics service
- an oncology service
- a breast cancer after radiotherapy database (BARD)

If you think you might be eligible but are concerned you may have been missed due to your gender identity being different to your sex assigned at birth, speak to your GP, gender identity clinic, breast surgeon or oncologist.

Are there any tips for attending an appointment?

Breast cancer and breast tissue are clinical terms and are commonly used during the screening process. If you prefer to refer to this area as your chest, this is something that the healthcare professionals at the screening service should respect. There may be times they need to speak clinically, and times when they can speak personally and should be able to explain to you the difference between these two.

Breast Clinics can be a very gendered environment. Some people find that these spaces may trigger their dysphoria. If you feel that this is the case, here are some tips that may help:

- Call the clinic ahead of your appointment to discuss any concerns
- Let them know which name and pronouns you would like to use for the appointment
- Ask to be seen at the beginning or end of a clinic to avoid long stays in the clinic or waiting room
- Ask to not have any medical students present
- Tell the person carrying out the mammogram the language you would like them to use when referring to your body
- Let the person carrying out the test know if you have implants
- Ask if you can bring a friend, partner, or family member with you to your appointment

- Let the person know if people touching your breasts / chest is a dysphoria trigger for you
- Tell the person carrying out the mammogram the language you would like them to use when referring to your body
- Tell staff about any phrases or words that make you uncomfortable or nervous
- Do not use talcum powder or spray deodorant on the day as this may affect the mammogram – roll-on deodorant is OK
- Wear something comfortable that you can easily undress to the waist
- Remove necklaces and nipple piercings before you arrive for your appointment
- Tell them if you have found screening uncomfortable or painful in the past

Bowel screening

What is the test for?

Bowel screening checks for bowel cancer or abnormalities that could lead to bowel cancer using a test known as a FIT test (faecal immunochemical test). The FIT test is very good at detecting blood in your poo that cannot be seen by the naked eye.

Do I need to be screened?

In England, Wales and Northern Ireland, everyone aged 60 to 74 years old is invited to screening regardless of their gender. The programme is expanding to make it available to everyone aged 50 to 59 years. This is happening gradually over 4 years and started in April 2021, so it is worth checking with your GP if you are eligible. In Scotland, bowel screening already starts at 50.

Does transition affect my bowel cancer risk?

Gender affirming hormones and surgeries are not known to affect your risk of bowel cancer.

However, if you are offered a colonoscopy (a procedure to look inside of your bowel) as a further investigation after your FIT test and you have had a vaginoplasty using a piece of your bowel, you should let the doctor or nurse know. This is because if abnormal growths called polyps are seen in your bowel, they could also be present in the neovagina.

How do I access bowel screening?

The bowel screening programme sends out a testing kit every 2 years to people who are eligible to take part. You need to be registered with a GP to receive your kit. The FIT test is simple and done in your own home. About 2 weeks after your test, you will get a letter with your results.

What happens if I need further tests?

If your letter says ‘further tests needed’ this means that a certain level of blood was found in your sample. This does not necessarily mean you have cancer. You may be offered an appointment to see a specialist nurse at a bowel cancer screening centre who will talk to you about colonoscopy.

Are there any tips for attending a colonoscopy appointment?

If you are asked to attend for a colonoscopy, you will be required to undress from the waist down for this procedure. This makes many people uncomfortable, but you may be more anxious if you are trans. If this is a concern for you, these tips might help:

- Call the clinic ahead of time to discuss your concerns
- Let them know the name and pronouns you wish to use
- Ask to be seen at the beginning or end of a clinic to avoid long stays in the clinic or waiting room
- Ask for a clinician of a specific gender that will make you feel most comfortable
- Ask to bring a friend, partner, or family member to the appointment
- Request a chaperone if it will make you more comfortable
- Ask about the level of privacy in the changing rooms or request to

undress in the treatment room

- Request that no additional persons be present (i.e. medical students)
- Ask staff not to use any phrases or words that make you uncomfortable or nervous
- Discuss any dysphoria triggers or concerns you may have related to the procedure
- Discuss the language you wish to use for your body
- Remember that you can pause or stop the procedure at any time
- Plan something enjoyable to do after the appointment

You are entitled to use a changing room that aligns with your gender regardless of any surgery you may or may not have had.

Pilot screening programme

Lung Health Checks

What is the test for?

The NHS Lung Health Check is a new service that is offered in some parts of England. It aims to help diagnose lung cancer at an earlier stage when treatment may be more successful. It involves assessing your lifestyle and risk factors and may involve offering you lung cancer screening.

Lung cancer screening is a low-dose CT scan to check for the early signs of lung cancer, before you have any symptoms. This is a special scan that uses a very low dose of radiation and a computer to take a detailed picture of your lungs. People are nearly three times more likely to be diagnosed with early-stage lung cancer through lung cancer screening. Lung cancer found early can be cured.

Do I need to be screened?

It is your decision whether to attend your lung health check or not.

Does transition affect my lung cancer risk?

There is no evidence to suggest that any aspects of transition affect your lung cancer risk.

How do I access a Lung Health Check?

Lung Health Checks are available in some areas of England. If you live in an area where they are taking place, you will receive an invitation if all of the following apply to you.

- You are 55 to 74 years old
- You are registered with a GP
- You have ever smoked

You will either receive a letter or a phone call inviting you to take part.

Lung health checks are only offered to people who currently smoke or people who used to smoke. If you think that your GP doesn’t know you smoke, or used to smoke, let them know.

What happens at the appointment?

Your lung health check will take approximately 30 minutes. You will have plenty of time to chat to the nurse and ask any questions.

A nurse will ask you some questions about your breathing and your overall lung health. They will ask you about your lifestyle, family and medical history.

If your appointment is in person, they may look at how well you are breathing to find out whether there are any problems with your lungs. This is a simple test for which you blow into a hand-held machine called a spirometer. The machine measures how much air you breathe in and out.

The nurse may talk to you about having a lung scan. This checks for early signs of lung cancer and is called lung cancer screening.

They will ask you if they can keep your information on file to help them improve the lung health check programme.

There are three potential outcomes from a Lung Health Check:

No problems found – The nurse may find nothing to look into further. They will write to your GP so they know about the appointment.

Referral to your GP – If problems with your breathing or lungs are found, the nurse may refer you on to your GP. They will write to your GP so they know about the appointment.

Offer of a lung cancer screening scan – whether or not you are offered a lung cancer screening scan will depend on your chance of having lung cancer now or in the future. The clinical team will work out your risk from your lifestyle, medical and family history. The nurse will help you to choose whether the test is right for you. They will write to your GP so they know about the appointment.

What happens at a lung cancer screening appointment?

During the scan, you will usually lie flat on your back on a bed that moves slowly into the CT scanner. The scanner is shaped like a ring and rotates around a small section of your body as you pass through it.

Specially trained staff called radiographers control the scanner from behind a screen in the CT room. You will be able to see and speak to them during the scan.

When a scan is taken, you will need to lie still and follow simple breathing instructions for 10 seconds. This makes sure the pictures are not blurry. The scan is painless and you will be able to eat, drink or drive as normal after your scan.

You will get your results within four weeks. There are four possible results:

No abnormalities found – This means that no signs of lung cancer or other abnormalities were seen on the scan. They will write to you with the results and ask you to come back for another scan in two years. However, it is still possible that lung cancer could develop or that the scan may have missed it. If you notice anything that is not normal for you before your next scan, tell your doctor.

Further scan needed – This normally means there are small nodules on the scan. These are often the result of recent infection or inflammation and are usually harmless. They will write and ask you to come for another scan sooner than normal, in around three to six months, just to check that everything is okay and that they are not growing.

Abnormal result – This means there is something abnormal on the scan and you need further tests. They will call you and write to the hospital so you can be seen by a doctor. It could mean you have lung cancer. Around half of people with an abnormal result will have lung cancer.

Incidental finding – This means there is no sign of lung cancer but there are signs of other problems on the scan that may need treatment or medical advice. They will write to you and your GP, and you may need to see your GP or another doctor.

Are there any tips for attending an appointment?

- Call the clinic ahead of your appointment to discuss any concerns
- Let them know which name and pronouns you would like to use for the appointment
- Ask to be seen at the beginning or end of a clinic to avoid long stays in the clinic or waiting room
- You can bring a friend, partner, or family member if you are nervous
- Let people know if people touching your chest area makes you uncomfortable
- Ask staff not to use any phrases or words that make you uncomfortable or nervous
- Remove necklaces and nipple piercings before you arrive for your appointment

Other cancers and screening in special circumstances

Endometrial cancer

Why is there no routine screening programme?

Most womb cancers (also known as uterine cancers) start in the lining of the uterus, the endometrium. This gives us the term endometrial cancer. There is no evidence that screening by ultrasound reduces mortality from endometrial cancer. Most cases are diagnosed relatively early due to the patient's symptoms, resulting in good survival rates.

At present, it is recommended that trans men and non-binary people on testosterone therapies should be screened for endometrial thickening (called hyperplasia) every two years. This is because this thickening can indicate a cancer may be present. As there is no routine programme for endometrial screening, patients need to request a referral from their GP.

Who is at risk of endometrial cancer?

People assigned female at birth (AFAB) who have a uterus are at risk and may wish to consider screening. This may include:

- trans men
- non-binary people AFAB
- cisgender women

People with polycystic ovary syndrome are known to have an increased risk of endometrial cancer. People with a strong family history of endometrial and/or bowel cancer are also at increased risk, as are those with Lynch syndrome.

Does transition affect my endometrial cancer risk?

Hormones

There is a theoretical risk of endometrial cancer in trans men and non-binary people assigned female at birth on testosterone therapy who do not opt for hysterectomy. This is based on findings in cisgender women on androgen (male hormone) therapies, and polycystic ovary syndrome where a androgen circulates in the blood. Studies looking at whether testosterone leads to thickening of the endometrium (which is associated with cancer) have shown conflicting results. Further data is required to confirm whether trans men and non-binary people assigned female at birth on testosterone therapy are actually at increased risk.

Surgery
You cannot get endometrial cancer if you've had surgery to remove your uterus (hysterectomy).

When should I see my GP?

Main symptoms of endometrial cancer can include:
- bleeding or spotting from the vagina after the menopause, or after periods have stopped on testosterone
- heavy periods, if you still have them, that are unusual for you
- vaginal bleeding between your periods, if you still have them
- a change to your vaginal discharge

Other symptoms of endometrial cancer can include:
- a lump or swelling in your tummy or between your hip bones (pelvis)
- pain in your lower back or between your hip bones (pelvis)
- pain during sex
- blood in your pee

How do I access endometrial screening or symptom-based tests?

If you are requesting screening based on the two-year recommendation, you may need to disclose your trans status. This is so that your GP can:
- understand your body
- appreciate your reasons for requesting the test
- send you for the correct screening
- advocate for you if it is necessary

If you are attending after experiencing any of the symptoms listed above, it is important to note that these are common and can be caused by many different conditions. Experiencing one or more of these symptoms does not definitely mean you have endometrial cancer. But if you do notice any of these symptoms, it is important to get them checked by your GP as soon as possible.

What happens at the appointment?

When you visit your GP, you will be asked some questions about your health, family medical history, your own medical conditions, and your current symptoms. You should tell the GP if you or your family have any history of cancer or Lynch syndrome.

The GP may ask to examine you. You will be asked to undress from the waist down, behind a screen. You will be given a sheet to cover yourself.

When you are ready, the GP may:

- feel inside the vagina with 2 fingers while pressing on your tummy (they will be wearing gloves)
- feel inside your bottom
- use a speculum to look into your vagina and check your cervix, like they do during cervical screening

Before doing any of these, they should explain what will happen during each step and answer any questions you have.

The GP may refer you for more tests or to see a specialist if they think that you have a condition that needs further investigation. These might include:

- a scan of your uterus using device around the size of a finger that is inserted into your vagina, called a transvaginal ultrasound
- hysteroscopy – a narrow telescope with a light and camera at the end that is used to see inside your uterus. It passes through the cervix, so no incisions are made
- a biopsy of the cells from the lining of your uterus
- blood tests

Are there any tips for attending an appointment?

- Call the clinic ahead of your appointment to discuss how to make it a better experience
- You can ask for a doctor or nurse of the gender you prefer
- Asking to be seen at the beginning or the end of the clinic
- Ask any questions you may have about the appointment

- Check ahead of time if you can bring a friend, partner, or family member
- Ask for a chaperone for the procedure
- Discuss lubrication or topical anaesthetics if you are worried about pain from the procedure
- Discuss the potential to use topical oestrogen gels before the appointment if you are afraid of pain due to dryness
- Ask the nurse or doctor to explain the procedure to you before you begin
- Remember that you can pause or end the procedure at any time
- Discuss any potential dysphoria triggers
- Ask for consent check-ins throughout the procedure
- Discuss whether it might be possible for you to insert the speculum or transvaginal ultrasound wand yourself
- Plan something nice to do after the appointment

Prostate cancer

Why is there no routine screening programme?

Prostate screening looks to identify if a patient has cancer in their prostate. There is currently no national screening programme for prostate cancer in the UK. This is because it has not been proved that the benefits would outweigh the risks. Research is ongoing to see if there are people who would benefit from prostate screening.

Testing a person’s prostate-specific antigen (PSA) level is an unreliable indicator for prostate cancer. Around 1 in 7 of those with prostate cancer have normal PSA levels. Occasionally, this test can give a false positive, indicating cancer where there is none. This is why it is recommended to confirm a tumour with an MRI scan before undergoing biopsies.

The PSA test can find aggressive prostate cancer that needs treatment, but it can also find slow-growing cancer that may never cause symptoms or shorten life. Some people may face difficult decisions about treatment, although this is less likely now that most people are offered an MRI scan before further tests and treatment.

Who is at risk of prostate cancer?

People who were assigned male at birth (AMAB) and have not had their prostate removed may wish to consider screening. This may include:

- trans women
- non-binary people AMAB
- cisgender men

Symptoms that might indicate a problem with the prostate include:

- frequent urination
- weak or interrupted urine flow
- the need to strain to empty the bladder
- the urge to urinate frequently at night
- blood in the urine
- new onset of erectile dysfunction
- pain or burning during urination (less common)
- discomfort or pain when sitting (caused by an enlarged prostate)

People who have a family history of breast, ovarian or prostate cancer, or are known to have a mutation in the BRCA2 gene are at increased risk of prostate cancer and may choose to undergo screening.

Black cisgender men are also known to be at increased risk of prostate cancer with 1 in 4 being diagnosed, compared to the average rate of 1 in 8 seen in other cisgender men.

Does transition affect my prostate cancer risk?

Taking oestrogen, testosterone blockers (antiandrogens) or having the testicles removed (orchidectomy) all reduce the levels of testosterone in the body and can reduce prostate cancer risk. Trans women receiving androgen deprivation therapy and oestrogens may have a 5-fold decrease in prostate cancer risk. The reduction of testosterone in the body can also lower PSA (prostate specific androgen) levels, making the test less reliable.

Most experts think you should have a PSA test (blood test) before starting feminising hormones or testosterone blockers if you’re aged 50 or over, or over the age of 45 if you have a family history of prostate cancer, or if you are Black.

How do I access prostate screening?

Instead of a national screening programme, there is an informed choice programme. This is known as ‘prostate cancer risk management’. It applies to healthy people aged 50 or over who ask their GP about PSA testing and aims to provide good information on the pros and cons of a PSA test.

If you are aged 50 or over and decide to have your PSA levels tested after talking to a GP, they can arrange for it to be carried out for free on the NHS. If results show you have a raised PSA level, the GP may suggest further tests.

Because oestrogen, testosterone blockers and testicle removal can lower PSA levels, some experts believe that in these cases a modified PSA threshold should be used.

What happens at the appointment?

A nurse or medical technician will use a needle to draw blood from a vein, most likely in your arm. The blood sample is then analysed in the lab to measure your PSA level. You should abstain from prostate stimulation for at least a week before having a PSA test.

If you’re a trans woman or a non-binary person assigned male at birth who has not had any genital reconstructive surgery, or you have had a labiaplasty (rather than a vaginoplasty), you may also be offered a digital rectal examination (DRE) to check the size and surface texture of your prostate. The DRE is not a completely accurate test. Your doctor or nurse can’t feel the whole prostate and someone with prostate cancer might have a prostate that feels normal.

If you have had a vaginoplasty, this test may happen through your vaginal wall, instead of your rectum (back passage).

What happens if I need further tests?

After the tests at your GP surgery, you may have further tests at a hospital. These can include an MRI scan and/or a biopsy.

An MRI scan is done to see if there is any cancer inside your prostate, and how quickly any cancer is likely to grow. An MRI scan may not be possible if you have a pacemaker or other metal inside your body. You might have to wait a few weeks for a scan if you’ve recently had genital reconstructive surgery. You can read more about what to expect during an MRI scan on the NHS website: https://www.nhs.uk/conditions/mri-scan/

A biopsy will either be done as a transperineal biopsy or a transrectal ultrasound (TRUS) guided biopsy. If you’ve had genital reconstructive surgery that includes vaginoplasty then you may have a biopsy via the vagina or other routes. The urologist doing the biopsy will look at your scans before discussing the best approach with you. Prostate Cancer UK have further information on the methods used to diagnose prostate cancer, including pages written specifically for trans women and non-binary people assigned male at birth.

Are there any tips for attending an appointment?

Prostate screening is typically done with your GP, and you will need to request this. If you are not out to your GP, this may require you to disclose your trans status. Not all GPs are aware that trans women retain their prostate after vaginoplasty, so it may be helpful to show them this leaflet.

Other tips that might support you during your appointment include:

- Call the clinic ahead of time to discuss the appointment and waiting room arrangements
- Ask to be seen at the beginning or end of the clinic
- Discuss any language that might make you feel uncomfortable
- Discuss any potential dysphoria from the language around prostate health
- Remember you can pause or end the procedure at any time
- Ask to bring a friend, partner, or family member to the appointment

- Request a member of staff of a specific gender
- Ask for a chaperone

Ovarian cancer

Why is there no routine screening programme?

There is no national screening programme for ovarian cancer in the UK. This is because there isn't a test that reliably picks up ovarian cancer at an early stage.

A recent trial showed that annual ovarian cancer screening for asymptomatic people did not reduce the overall mortality rate for ovarian cancer.

Who is at risk of ovarian cancer?

Ovarian cancer mostly affects people over 50, however anyone who was assigned female at birth can get ovarian cancer. This may include:

- trans men
- non-binary people AFAB
- cisgender women

Even if you have had your ovaries removed (oophorectomy), a small risk of ovarian cancer remains. A small number of people have a family history of ovarian cancer.

Does transition affect my ovarian cancer risk?

Hormones
Currently there is no conclusive evidence that trans men have a higher risk of ovarian cancer.

Surgery
If the ovaries are removed, this can reduce the risk of ovarian cancer. The operation is known as oophorectomy. This operation lowers ovarian cancer risk but does not entirely eliminate it as the membrane forming the lining of

the abdominal cavity (the peritoneum) is made from the same cells and can continue to carry a small cancer risk.

When should I see my GP?

Symptoms of ovarian cancer are not always obvious. Symptoms to look out for include frequent episodes of having:

- a swollen tummy or feeling bloated
- pain or tenderness in your tummy or the area between the hips (pelvis)
- no appetite or feeling full quickly after eating
- an urgent need to pee or needing to pee more often

Other symptoms of ovarian cancer may include:

- indigestion
- constipation or diarrhoea
- back pain
- feeling tired all the time
- losing weight without trying
- bleeding from the vagina after the menopause

What happens at the appointment?

You will be asked about your health and the symptoms that you are experiencing. You should also tell the GP if anyone in your family has or previously had ovarian or breast cancer.

The GP or practice nurse may ask to examine you. If this is the case, you will be asked to undress from the waist down, behind a screen. You'll be given a sheet to put over you.

The examination may involve inserting a speculum into your vagina so they can check inside this area. They may also press on your tummy and inside your vagina to check for any lumps or tender areas. The test should not be painful but might be uncomfortable.

You may be referred for a CA125 blood test. This is a protein that acts as a cancer marker.

You may be referred for a transvaginal ultrasound where a small transducer (ultrasound probe) is placed inside your vagina, using ultrasound waves to create images of your ovaries. You can request an abdominal ultrasound instead if you prefer. This is where a transducer is moved across your abdomen externally. However, this may not always be able to get accurate pictures of the ovaries, and further scans, such as MRIs may be required.

Are there any tips for attending an appointment?

Presenting to your GP with symptoms of ovarian cancer can be the start of various tests to try to identify if your problems may suggest cancer. You can decline any examination if you do not wish to go ahead with it and you do not have to give a reason. These tests are however there to help you, so it is important that you feel confident in discussing the risks and benefits of undergoing any examinations. The goal is to work with the clinicians to make an appointment or plan that works for you.

Other tips that might help you achieve this include:

- Asking for a doctor or nurse of a specific gender when you book your appointment
- Asking to have a friend, partner, or family member with you during the appointment
- Asking for a smaller speculum where possible
- Asking for as much lubrication as you feel is necessary
- Discussing any need for oestrogen gels ahead of the appointment if testosterone has resulted in any dryness or tightness in the vagina
- Tell the person carrying out the screening the language you would like them to use when referring to your body
- Remembering that you are in control and can ask the doctor to stop at any time
- Explaining any potential triggers for dysphoria that you are concerned about
- Booking a double appointment, so you don’t feel rushed during the appointment
- Taking notes with you about what you want to say
- Planning something enjoyable to do after the appointment

Testicular cancer

Why is there no routine screening programme?

Testicular cancer is one of the less common cancers, making up just 1% of cancers seen in people assigned male at birth (2,300 cases per year). It tends to occur between 15 and 49 years of age.

There is no routine screening programme or standard test used for early detection of testicular cancer. Most often, testicular cancer is first found by the person themselves, either by chance or during self-exam. Sometimes the cancer is found by a doctor during a routine physical exam. If a lump is found in the testicle by either the patient or doctor, tests may be done to check for cancer.

Testicular cancer can usually be cured at any stage, though finding it early may make it easier to treat. Patients who are diagnosed with testicular cancer that has not spread to other parts of the body may need less chemotherapy and surgery, resulting in fewer side effects.

Who is at risk of testicular cancer?

People who were assigned male at birth (AMAB) and have not had their testes removed can develop testicular cancer. This may include:

- trans women
- non-binary people AMAB
- cisgender men

Does transition affect my testicular cancer risk?

The long-term effects of hormone therapy on testicular cancer among trans women are largely unknown.

A study of Dutch trans women on hormone therapy found that the chance of being diagnosed with testicular cancer is similar to cisgender men. They also found no risk related to the length of time that a person is on hormone therapy, further suggesting that hormonal treatment does not increase the risk for testicular cancer.

If you have had both of your testicles removed (bilateral orchidectomy), you will no longer be at risk of testicular cancer.

When should I see my GP?

Symptoms that might indicate a problem with the testicles include:

- painless swelling or a lump in one of the testicles
- any change in shape or texture of the testicles
- an increase in the firmness of a testicle
- a difference in appearance between one testicle and the other
- a dull ache or sharp pain in your testicles or scrotum which may come and go
- a feeling of heaviness in your scrotum

Most lumps or swellings in the scrotum are not in the testicle and are not a sign of cancer, but they should never be ignored. If you notice anything unusual, consult your GP.

What happens at the appointment?

Your GP will examine you and if they think the lump is in your testicle, they may consider cancer as a possible cause. If it is confirmed that you have testicular cancer it is best to start treatment as soon as you are able. The sooner treatment begins, the greater the chance that you will be completely cured.

If you do not feel comfortable visiting a GP, you can go to your local sexual health clinic, where another healthcare professional will be able to examine you.

Are there any tips for attending an appointment?

Testicular cancer screening usually begins with a visit to your GP and describing your symptoms. If you are not out to your GP, this may require you to disclose your trans status. If you are nervous about this interaction, you may prefer to present to a local sexual health clinic instead.

Other tips that might support you during your appointment include:

- Calling the GP or clinic ahead of time to explain what is needed from your appointment
- Sharing the name and pronouns and asking them to be respected in clinical notes
- Ask to be seen at the beginning or end of a clinic to avoid long stays in the waiting room
- Asking for a doctor or nurse of a specific gender when you book your appointment
- Explaining the terminology that you prefer to use for your body
- Discuss any potential dysphoria triggers for this appointment
- Ask to bring a friend, partner, or family member to your appointment

Reducing risk

Giving up smoking

In the UK, more than 25% of deaths from cancer are caused by smoking.

It is important to keep your home and environment smoke free as passive smoking can also increase a person’s risk of cancer.

If you do want to give up smoking, your GP will have resources to help you. You can also download the NHS Quit Smoking app for your smartphone. To find out more, visit:
https://www.nhs.uk/better-health/quit-smoking

Macmillan Cancer Support has more information about giving up smoking. If you would prefer to get support from an LGBTIQ+ charity, you can find information and support from LGBT Foundation and Brighton & Hove LGBT Switchboard.

If you have had problems trying to give up smoking in the past or cutting down on your cigarette use, vaping may be a risk-reducing alternative. Although not completely risk free, they are significantly safer than cigarettes. Cancer Research UK states that there is no good evidence that vaping causes cancer. However, we don't yet know their long-term effects, so people who have never smoked should not use them.

Human papillomavirus (HPV) vaccine

The HPV vaccine given in the UK (Gardasil) protects against HPV types 6, 11, 16 and 18. HPV types 16 and 18 are responsible for approximately 70% of cervical cancer cases, 75–80% of anal cancer cases, 70% of HPV-related pre-cancerous lesions of the vulva and vagina, 75% of HPV related pre-cancerous lesions of the anus. HPV type 16 is responsible for almost 90% of HPV-positive oropharyngeal (mouth and throat) cancers. HPV types 6 and 11 are responsible for approximately 90% of cases of genital warts.

Children aged 12 to 13 years (who were born after 1 September 2006) are offered the HPV vaccine as part of the NHS vaccination programme.

The vaccine helps protect against cervical cancer, some mouth and throat cancers, and some cancer of the anal and genital areas.

Since April 2018, men who have sex with other men (MSM), trans women, and non-binary people assigned male at birth who are up to the age of 45 have been eligible for free HPV vaccination on the NHS when they visit sexual health services and HIV clinics in England.

Trans men and non-binary adults assigned female at birth are eligible if they have sex with men and are aged 45 or under. If they have previously completed a course of HPV vaccination as part of the children's HPV vaccine programme, no further doses are required.

Alcohol, diet, and exercise

Eating a balanced diet with lots of nutritious options is good for your body. For example, high fibre foods can help promote good bowel health and reduce the risk of bowel cancer. Limiting the amount of alcohol that you drink can also reduce your risk of cancer.

Being overweight can increase the risk for many different types of cancer. Keeping to a healthy weight can avoid this risk and reduce your risk of other health conditions, like diabetes and heart disease.

Many studies show that having an active lifestyle can reduce the risk of cancer. It is recommended that you should do at least 30 minutes of physical activity every day.

If you are worried about your weight or would like more information about how to improve your diet, speak to your GP or a dietitian.

Sun exposure

Getting out into the sunshine can be a great way to get a boost of vitamin D. However, we need to be careful not to over-expose ourselves to the sun and risk burning our skin as this can increase our risk of cancer.

Some practical steps you could take include:

- covering your skin with clothing or a hat
- using sun cream with a high sun protection factor (SPF) that protects against UVB rays and a high star-rating to protect you from UVA rays
- avoiding the sun at the hottest point of the day
- switching out sunbeds or sun lamps for fake-tanning lotions or sprays

HIV

HIV can increase the risk for certain cancers because it can lower your immune system’s ability to respond to disease. If you are HIV negative, you should continue to practise safer sex such as using condoms or dental dams. You may also want to consider taking pre-exposure prophylaxis (PrEP), which is free from NHS sexual health clinics.

According to a 2016 study, people with HIV were more likely to show what we call ‘behaviours associated with developing cancer’, such as smoking or other risk factors mentioned above. If you are HIV positive, it is important that you take your medications as prescribed and try to reduce any additional risk of cancer.

The NHS recommends that people with a cervix who are HIV positive should have a cervical smear when they are first diagnosed with HIV, six months after this, and then every year. Usually, cervical screening will be arranged through your GP.

We hope this booklet has been useful to you. It is just one of our many resources available for free on our website. If you have any feedback about this booklet, please email contact@livethroughthis.co.uk

All content in this booklet has been reviewed by clinicians, representatives of third sector organisations, and trans and non-binary community members.

Recommendations are informed by the most up-to-date scientific evidence available at the point of publication. A list of key references is available on request by emailing contact@livethroughthis.co.uk

This booklet should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Live Through This does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it.

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