

## Section 6

### Frequently asked questions and glossary

#### Human papillomavirus (HPV)

We get lots of questions about HPV because it is a topic that worries people. A big part of this worry comes from not understanding it. Luckily, you can help answer many of those questions with the information in this section. However, it is really important to understand that there are still things we, and the scientific community, don't know about HPV – so we do not have an answer for everything.

In this section, we talk through some common questions about HPV and how you can answer them.

##### What is HPV?

HPV is a common virus that is passed on through skin-to-skin contact.

Key facts:

- About four out of five or 80% of us (men and women) will have at least one type of HPV and some point in our lifetime – so it's really common.
- When we talk about HPV being linked to cervical cancer, we mean HPV that affects our genital area. There are over 200 types of HPV and about 40 affect our genital area<sup>1</sup> – and about 13 types are linked to cancer. These types are sometimes called high risk.
- Having any type of HPV does not mean you will get cell changes, cancer or warts. Most of the time, our immune system will get rid of HPV without any problems. You can explain it as being a bit like a cold – you get it, but then clear it with no treatment.
- HPV has no symptoms, which means you can't tell if you have it. This can be scary for people, but you can remind them that most of the time it doesn't cause problems and just goes away.
- There is no treatment for HPV itself, but there is care and treatment for conditions it can cause (like warts, cell changes and cancer). Again, this can be scary for people to hear, but you can remind them that having the cervical screening programme means we can pick up any changes early, before they develop into something more serious.

##### How does HPV cause cancer?

Some types of HPV, called high risk, can cause changes to the cells of the cervix. There are images on our website that help explain this:

[www.jostrust.org.uk/information/hpv/hpv-cervical-cancer](http://www.jostrust.org.uk/information/hpv/hpv-cervical-cancer)

---

<sup>1</sup> Trottier H. and Franco E. L., The epidemiology of genital human papillomavirus infection, Vaccine, 2006.

At Jo's, we call these cell changes, but people may call them abnormal cells or abnormalities. It is important for people to know that cell changes are not cancer, but if they are not monitored or treated there is a chance they may develop into cancer over time.

### **Do all HPV types cause cervical cancer?**

As HPV becomes a bigger topic of conversation, it's important that people understand only about 13 high-risk HPV types are linked to cancer<sup>2</sup>. There are lots of other HPV types – over 200 – that are not linked to cancer.

As well as cervical cancer, high-risk HPV types are linked to cancer in the vagina, anus, vulva, penis, and some head and neck cancers<sup>3</sup>.

It is not usual for people to be told what type of HPV they have. This is because it doesn't really matter – all high-risk types are monitored in the same way through the screening programme. It is also to stop extra worrying and people searching for information that may be wrong.

However, some private HPV tests may tell people the type of HPV they have. For your information, high-risk HPV includes types 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59 and 68<sup>4</sup>. Types 16 and 18 are generally the most well-known, because they are linked to 70% of all cervical cancers<sup>5</sup> and the HPV vaccine protects against them.

### **Is HPV the same virus that causes genital warts?**

Yes, HPV can also cause genital warts. But it is important for people to understand that the HPV types that cause genital warts and the HPV types that cause cervical cancer are different. The HPV types that cause genital warts are called low risk.

HPV 6 and 11 are the 2 most common low-risk types<sup>6</sup>. People may have heard of them because they cause around 9 in 10 (90%) cases of genital warts, and the HPV vaccine protects against them.

Our key message is that having genital warts does not mean that you will get cervical cancer.

### **Who can get HPV?**

HPV is passed on through skin-to-skin contact. We focus on cervical cancer, so we talk about HPV in the genital area. This can be passed on in different ways, including:

- vaginal, anal and oral sex<sup>7,8,9</sup>
- touching in the genital area<sup>10</sup>
- sharing sex toys<sup>11</sup>.

---

<sup>2</sup> Munoz N. et al, Epidemiologic classification of human papillomavirus types associated with cervical cancer, *New England Journal of Medicine*, 200.

<sup>3</sup> Chaturvedi A. K., Beyond Cervical Cancer: Burden of Other HPV-Related Cancers Among Men and Women, *Journal of Adolescent Health*, 2010.

<sup>4</sup> Munoz N. et al, Epidemiologic classification of human papillomavirus types associated with cervical cancer, *New England Journal of Medicine*, 2003.

<sup>5</sup> Braaten K. P. and Laufer M. R., Human Papillomavirus (HPV), HPV-Related Disease, and the HPV Vaccine, *Obstetrics & Gynecology*, 2008.

<sup>6</sup> Lacey C. JN. et al, Chapter 4: Burden and management of non-cancerous HPV-related conditions: HPV-6/11 disease, *Vaccine*, 2006.

<sup>7</sup> Burchell A. N. et al, Human Papillomavirus Infections Among Couples in New Sexual Relationships, *Epidemiology*, 2010.

<sup>8</sup> Goodman M. T. et al, Acquisition of Anal Human Papillomavirus (HPV) Infection in Women: the Hawaii HPV Cohort Study, *The Journal of Infectious Diseases*, 2008.

<sup>9</sup> Chung C. H. et al, Epidemiology of oral human papillomavirus infection, *Oral Oncology*, 2014.

<sup>10</sup> Sabeena S. et al, Possible non-sexual modes of transmission of human papilloma virus, *The Journal of Obstetrics and Gynaecology Research*, 2017.

<sup>11</sup> Ibid.

It is important to be explicit with people when talking about how HPV can be passed on, rather than just saying 'through sex'. This is because everyone's understanding of sex is different and we aren't just talking about penetrative sex.

It is also important for you to know that not every way to pass on HPV carries the same risk. For example, having penetrative sex is more likely to pass on HPV than sharing sex toys. This is because there is more direct skin-to-skin contact with penetrative sex. However, because we know there is a chance of passing HPV on through all the ways listed above, we need to mention them. Our key message is anyone who has ever been sexually active (using the list above) may have HPV.

### **I've read that HPV can stay in the body undetected or inactive. Is this true?**

This is one of the most confusing things about HPV and it's okay to say that. But we can give as much information as possible to reassure people and help them understand what we do know.

We know that HPV is a transient virus – this means, a bit like a cold, we can get it and then clear it without any problems, thanks to our immune system. For most people, this happens within 2 years. However, when we use the term 'clear' we don't know if we are always truly getting rid of HPV or if the virus is still in our body but we can't detect it with a test. More research is needed so we can be 100% certain how the virus works.

If HPV can't be detected, we call it clinically insignificant. This means that whatever type of HPV you have, it's not doing any harm – so, for example, if it was high-risk HPV but undetectable, it wouldn't be causing changes to cervical cells.

HPV can stay undetectable in the body for years, even decades. This is called a persistent infection. At any point, it may become detectable again and, if it's a high-risk type, the HPV may then start causing changes to cervical cells. At the moment, we don't know why the virus does this or why some people may have a persistent infection with HPV. Our key message here is that for most people, HPV will not cause any problems and will clear or become undetectable over time.

### **Is HPV a sexually transmitted infection or disease?**

At Jo's, we don't call HPV a sexually transmitted infection/disease (STI/D) for a number of reasons:

- While sexual contact is the most likely way for HPV that affects the cervix to be passed on, it can be passed on in other ways. For example, there are studies showing that, although very rare, HPV can be passed on during childbirth, if someone has a vaginal delivery. It's important to say that no babies in these studies developed cell changes or cancer as a result, and all cleared the infection.
- HPV itself can't be treated. STI/Ds, like chlamydia or herpes, can generally be successfully treated with a cream or course of tablets.
- There is already a stigma around HPV, cell changes and cervical cancer because of the part of the body it affects. We don't want to add to that by labelling HPV in an unnecessary way.

Some other organisations and healthcare professionals do call HPV an STI/D, so some people may have picked up on this and feel worried or ashamed. We can reassure them with the facts above, as well as talking about how common it is.

### **If I don't have a lot of sex, will I still get HPV?**

You could get HPV during your first sexual contact, whether that's touching, sharing a sex toy, or having penetrative sex. Or you might not get it until you've had any kind of sex for the 100<sup>th</sup> time! Our key message is that if you have ever been sexually active, you are at risk of having HPV.

### **I've only had sex with one person – will I still get HPV?**

Our key message is anyone who has ever been sexually active – whether it's penetrative sex, touching or sharing sex toys – could have HPV. The virus doesn't discriminate and may be passed on during your first sexual experience or your 1000<sup>th</sup>. We know that four out of five or 80% of men and women will have HPV at some point in their lifetime, so it's very common.

### **Did I get HPV from my current partner?**

Currently, we have no way of knowing when we got HPV or who we got HPV from. This is because the virus can stay undetectable in our body for years, so may not be picked up by a test unless it becomes detectable again (see previous question).

This means that the short answer to this question is we don't know – it's possible the HPV is from your current partner, but it's equally possible it's from a past partner or someone you had sexual contact with<sup>12</sup>.

### **I have a long term partner, but have just been told I have HPV. Were they unfaithful?**

As with the previous question, we know that HPV can stay in our bodies for a long time – sometimes decades – but not be detectable, so any test we have won't pick it up. However, it may at any point become detectable and a test could pick it up, even if we've been with a partner for many years. So while the virus seems new because it's the first time someone's been aware of it, that doesn't mean it actually is. This means that the short answer to this question is having HPV while you have a long term partner does not mean they've been unfaithful.

### **I only have sex with women – am I still at risk of getting HPV?**

Men and women can get and pass on HPV, so sexual contact with anyone may mean you get it<sup>13</sup>. It's very important that women who have sex with women understand that they can still get HPV and have the same right to cervical screening and the HPV vaccine as anyone else.

### **Am I still at risk of getting HPV if I use contraception?**

The short answer is yes. Using condoms and dental dams – anything that covers the genitals in some way – to have safe sex can help reduce the risk of getting HPV<sup>14</sup>. But it won't completely get rid of the risk<sup>15,16</sup>, as HPV lives on the skin in and around the whole genital area – not just the part that the contraception covers!

- In men, HPV can affect the skin of the penis, scrotum, anus and rectum.
- In women, it can affect the vulva (area outside the vagina), lining of the vagina, cervix and rectum.

The contraceptive pill and other forms of contraception, like the coil or implant, will not help reduce the risk of getting HPV because they don't cover the skin of the genital area.

### **I am sexually active but don't currently have penetrative sex. Am I still at risk of getting HPV?**

Our key message is that anybody who has ever had any kind of sexual contact is at risk of getting HPV – so that includes:

---

<sup>12</sup> Gravitt P. E., The known unknowns of HPV natural history, The Journal of Clinical Investigation, 2011.

<sup>13</sup> Marrasso J. M. et al, Genital human papillomavirus infection in women who have sex with women: A review, American Journal of Obstetrics and Gynecology, 2000.

<sup>14</sup> Winer R. L. et al, Condom Use and the Risk of Genital Human Papillomavirus Infection in Young Women, New England Journal of Medicine, 2006.

<sup>15</sup> Manhart L. E. and Koutsky L. A., Do Condoms Prevent Genital HPV Infection, External Genital Warts, or Cervical Neoplasia?: A Meta-Analysis, Sexually Transmitted Diseases, 2002.

<sup>16</sup> Chelimo C. et al, Risk factors for and prevention of human papillomaviruses (HPV), genital warts and cervical cancer, The Journal of Infection, 2013.

- vaginal, anal and oral sex
- touching
- sharing sex toys

### **If I haven't been sexually active for many years, could I still have HPV?**

Our key message is anyone who has ever been sexually active may have HPV. This is because we know HPV can stay in the body but be undetectable for years. While in most cases our immune system will clear HPV, it's important that everyone knows they have the right to cervical screening to check that everything's okay.

### **If I have a persistent HPV infection, will I pass it onto my partner and can they then reinfect me?**

We are still learning about HPV reinfection between couples and this is an area where more research is needed. While we can't say it will definitely happen, there is a possibility that it could. But we all respond to HPV differently, so even if you have a persistent infection, your partner's immune system may clear it.

### **Should I tell my partner/people I'm having sex with that I have HPV?**

We are hearing this question more as HPV becomes more talked about. Understandably, people hear or read about HPV being linked to cancer and panic or feel guilty. Unlike some conditions, like sexually transmitted infections (STIs), there is no guidance stating that you must tell anyone about having high-risk HPV.

Our key message is that it is up to that individual whether they want to talk with a partner about HPV. However, if they do, it is important that they fully understand as much as possible about HPV, especially that it is very common and most of the time we will clear it without any problem.

### **Should I stop having sex if I have HPV?**

There is no rule or guidance that you must stop having any kind of sexual contact if you have high-risk HPV. Remember, HPV is so common that four out of five (80%) of us will have it at some point in our lives. The way the virus works makes it really hard to know when we got it or who we got it from, and most of us will clear it within 2 years. We are also still learning about all the ways it can be passed on. But it is your decision whether to stop having sex – make sure you understand everything you can about HPV to help you make it.

### **How likely is it that I could come into contact with HPV after 50?**

The chance of getting HPV doesn't stop at a certain age. While HPV is more common in younger people<sup>17,18</sup> – generally between the ages of 18 and 30 – our key message is anybody who is or has ever been sexually active is at risk of getting it.

### **How can I reduce my risk of getting HPV?**

There is currently no way to completely protect yourself against all types of HPV, but there are some ways to reduce the risk of getting a persistent HPV infection:

- **Not smoking.** In the UK, over 20% of cervical cancers are caused by tobacco<sup>19</sup>. Smoking makes your immune system weaker and can damage your cells. This makes it harder for your body to fight off an infection like HPV. If your immune system can't get rid of HPV, there is a chance it may develop into cell changes or cervical cancer. We know that smoking is a comfort and part of a routine for some people, so stopping may not be easy. But if someone wants to stop, the NHS can support them:

---

<sup>17</sup> Cotton S. C. et al, Lifestyle and socio-demographic factors associated with high-risk HPV infection in UK women, British Journal of Cancer, 2007.

<sup>18</sup> Sargent A. et al, Prevalence of type-specific HPV infection by age and grade of cervical cytology: data from the ARTISTIC trial, British Journal of Cytology, 2008.

<sup>19</sup> Cancer Research UK, Cervical cancer risk, webpage: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/risk-factors>, Accessed October 2019.

- [England](#)
- [Scotland](#)
- [Wales](#)
- [Northern Ireland](#)

- **Have safer sex.** Using condoms or dental dams – essentially, any contraception covers that skin – helps reduce the risk of getting HPV. It's important to remember that they cannot completely protect against, because the virus lives on the skin in the whole of the genital area, not just the covered part.

**I've had HPV – what can I do to make sure I don't get it again?**

There is no definite way to make sure you don't get HPV again, but there are some things you can do to reduce the risk of getting it or a persistent infection:

- Don't smoke, or give up smoking if you do smoke. See the previous question for where to get support.
- Have safer sex by using condoms or dental dams. See previous question for more information.
- Having the HPV vaccine, even after you have had an infection with HPV, offers you protection from infection with other HPV types. The vaccine is only available on the NHS for free until the age of 18, but is it available privately, for a cost, after that.

**As I get older, will I be less able to get rid of HPV?**

As we age, our immune system does tend to get weaker, which means our ability to get rid of any infection does decline<sup>20</sup> – but most of us will still have a good protective response against HPV.

**When I was younger, I had cell changes that went away on their own. Does this mean my immune system is now strong enough to fight HPV on its own?**

We, and the scientific community, don't currently know enough about HPV to give a definite answer to this question. There are some studies that suggest we do develop an immunity if we have had and cleared a certain HPV type. However, there are other studies that suggest we cannot develop complete immunity against some HPV types, including high risk ones, even if we have had them before<sup>21</sup>.

Our key message is to remember that most of us will get rid of an HPV infection, even if we don't develop complete immunity. This is also a benefit of regular cervical screening, as it can pick up an HPV infection or cell changes early, before they develop. This means we can get the right care or treatment.

**If HPV is common and almost all of us have it, why don't more of us get cervical cancer?**

Our key message is that most of us will get rid of HPV thanks to our immune systems and it will never cause any problems.

For those of us who can't get rid of HPV, going for cervical screening when invited can find changes to cervical cells (abnormalities) before cancer develops. Any abnormalities can be removed and, in most cases, this is successful.

For a small number people, changes to cervical cells happen more quickly between cervical screening appointments or, very rarely, changes are not found by cervical screening.

---

<sup>20</sup> Brown D. R. and Weaver B., Human Papillomavirus in Older Women: New Infection or Reactivation?, The Journal of Infectious Diseases, 2013.

<sup>21</sup> Franceschi S. and Baussano I., Naturally Acquired Immunity Against Human Papillomavirus (HPV): Why It Matters in the HPV Vaccine Era, The Journal of Infectious Diseases, 2014.

### **I've had or have genital warts. Does that mean I'm more likely to develop cervical cancer?**

No. Having genital warts may be worrying or unpleasant, but it does not mean you are more likely to develop cervical cancer.

Genital warts and cervical cancer are caused by different types of HPV, so having genital warts does not mean that you are more likely to get cancer. There are over 200 types of HPV and most of them do not cause any health problems. The HPV types that cause genital warts (6 and 11) are called low risk because they aren't linked to cancer.

### **What other cancers does HPV cause?**

High-risk HPV is responsible for about 5% of all cases of cancer. As well as cervical cancer, it is linked to:

- penile cancer (cancer of the penis)
- anal cancer
- vaginal cancer
- vulval cancer
- some head and neck cancers.

### **If I have had cervical cancer, am I at risk of developing another HPV-related cancer?**

If you have been diagnosed with cervical cancer, you have an increased risk of developing another cancer linked to high-risk HPV. This can be upsetting or worrying, but we currently do not have much data on how big this risk is.

If you need more support or have questions, it is best to speak with your doctor, who knows your full medical history.

### **If I have had cell changes, am I at risk of developing another HPV-related cancer?**

Not all low-grade cell changes (abnormalities) are because of high-risk HPV, so it does not necessarily mean you are at increased risk.

If you are worried, speak with your doctor or nurse who know your full medical history and will be able to offer some guidance.

### **If I have been through the menopause, am I still at risk of HPV?**

Yes, you can still get HPV during or after menopause. HPV is passed on through skin-to-skin contact in the genital area – something that is not affected by the menopause.

If you have ever been sexually active, there is also a risk of having HPV that is not currently causing any problems (clinically insignificant), that could start to cause problems (become clinically significant).

### **Can I pass on HPV during childbirth?**

This is a very worrying idea for people, so it is important that they completely understand how low the risk is. We would say that there is a very small risk of HPV being passed on during childbirth<sup>22</sup> – but if it is passed on, studies show that babies cleared the infection within days or months, and none had any serious conditions as a result<sup>23</sup>.

Thanks to the HPV vaccine, less women have the types of HPV that cause most cervical cancers and some other cancers, so the likelihood of pregnant women passing on HPV will become even smaller.

Our key message is that we know the idea of passing on HPV during childbirth may be worrying, but all of this evidence suggests you do not need to worry. If you are very worried,

---

<sup>22</sup> Sabeena S. et al, Possible non-sexual modes of transmission of human papilloma virus, The Journal of Obstetrics and Gynaecology Research, 2017.

<sup>23</sup> Rintala M. et al, Transmission of High-Risk Human Papillomavirus (HPV) between Parents and Infant: a Prospective Study of HPV in Families in Finland, Journal of Clinical Microbiology, 2005.

your doctor or midwife would be the best people to speak with, as they know your full medical history and individual situation.

## The HPV vaccine

### What are the HPV vaccines?

Currently, there are three HPV vaccines available in the UK:

- Gardasil
- Cervarix
- Gardasil 9.

Gardasil is used in the NHS vaccination programme across the UK. If people want detailed information about the HPV vaccine in their country, they can find it at:

- [England](#)
- [Scotland](#)
- [Wales](#)
- [Northern Ireland](#).

### Who can have the HPV vaccine?

The HPV vaccine is offered free in schools to girls and boys between the ages of:

- 11 to 12 in Scotland – school year S1
- 12 to 13 in the rest of the UK – school year 8 (England and Wales) and 9 (Northern Ireland).

The age roughly corresponds to school year 8, or the second year of secondary school.

If you are offered the HPV vaccine in school but miss it, you can have it free at your GP up to your 25<sup>th</sup> birthday<sup>242526</sup>. This change has been confusing for people, but the key is 'if you were offered it at school'. That means it only applies to:

- girls born after 1<sup>st</sup> September 1991 – because the HPV vaccine started being offered to girls in 2008
- boys born after 1<sup>st</sup> September 2006 – because the HPV vaccine started being offered to boys in 2019

We know that some GP surgeries are not aware of this change and are wrongly telling eligible people that they cannot have the HPV vaccine for free. If someone has had this answer at their GP, we can suggest they get in touch with their local immunisation team or health board to find out more about what is happening in their area.

If you are not eligible for the free HPV vaccine, you can pay to have it privately. It is usually available at travel clinics, pharmacies and other health centres. You may also be able to have it at your GP, although you may have to pay an extra administration fee. The HPV vaccine usually costs about £150 per dose.

### What is the benefit of the HPV vaccine?

Having the HPV vaccine protects against at least two high-risk types of HPV (16 and 18) that

---

<sup>24</sup> Public Health England, HPV vaccination (promotional leaflet) , PDF: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/812484/PHE\\_HP\\_Vaccination\\_Leaflet.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/812484/PHE_HP_Vaccination_Leaflet.pdf), 2019.

<sup>25</sup> NHS Wales, Vaccinations, Website: [www.nhsdirect.wales.nhs.uk/livewell/vaccinations/HPVvaccine/](http://www.nhsdirect.wales.nhs.uk/livewell/vaccinations/HPVvaccine/), Accessed October 2019.

<sup>26</sup> NI Direct, HPV vaccine for adolescents aged 12 to 13 years old, Website: [www.nidirect.gov.uk/articles/hpv-vaccine-adolescents-aged-12-13-years-old](http://www.nidirect.gov.uk/articles/hpv-vaccine-adolescents-aged-12-13-years-old), Accessed October 2019

cause about 7 in 10 (70%) of all cervical cancers<sup>27</sup>. Our key message is that, along with cervical screening, the HPV vaccine is one of the best ways to protect against cervical cancer. It also helps protect against other HPV-related cancers, including ones that affect boys and men.

The HPV vaccine also protects against low-risk HPV types 6 and 11, which cause 9 in 10 (90%) cases of genital warts.

### **When is the best time to have the HPV vaccine?**

The HPV vaccine is given before puberty because it works best before you come into contact with HPV. Because we know HPV is usually passed through sexual contact, that means it works best before someone is sexually active.

### **My child is not sexually active. Should they still have the HPV vaccine?**

Some parents think that the HPV vaccine is only for people who are sexually active or that it may encourage their child to become sexually active. This is not true. The HPV vaccine is given before puberty, when most children are not sexually active, because it works best at that age as they probably do not have an HPV infection.

We know that protection from the HPV vaccine lasts a really long time, with some studies suggesting it may last for decades<sup>28</sup>. Because the HPV vaccine started in 2008 (for girls) there is ongoing research to check how long the protection truly lasts for, so it may be even longer.

### **Does the HPV vaccine protect against genital warts?**

Yes, two of the three HPV vaccines protect against genital warts. Gardasil, which is used in schools as part of the NHS vaccination programme, protects against:

- HPV types 16 and 18, which cause 7 in 10 (70%) cervical cancers.
- HPV types 6 and 11, which cause around 9 in 10 (90%) cases of genital warts.

Gardasil 9 also protects against genital warts. Cervarix does not protect against genital warts, but does protect against high-risk HPV types 16 and 18.

### **Will having the HPV vaccine prevent all cases of cervical cancer?**

All the HPV vaccines (Gardasil, Cervarix and Gardasil 9) protect against high-risk HPV 16 and 18. These HPV types cause 7 in 10 (70%) cases of cervical cancer. So although the HPV vaccine can't prevent all cervical cancers, it does protect against the most common HPV types that cause it. The remaining cases are why cervical screening remains important in helping prevent cervical cancer.

### **If I've had the HPV vaccine, is cervical screening (a smear test) still important?**

We've spoken with lots of people who have had the HPV vaccine and think it means they are completely protected against cervical cancer, so cervical screening isn't important for them. Our key message is that while the HPV vaccine protects against 70% of cervical cancers, it doesn't protect against all cervical cancers, so cervical screening is still important. It can help pick up any cell changes caused by other high-risk HPV types early.

### **What are the side effects of the HPV vaccine?**

The HPV vaccine is safe to have. It has been studied in hundreds of trials, with thousands of men and people of all ages, to check that it does not have any serious impact on someone's health.

---

<sup>27</sup> Braaten KP and Laufer MR, Human Papillomavirus (HPV), HPV-Related Disease, and the HPV Vaccine, Reviews in Obstetrics & Gynecology, 2008.

<sup>28</sup> Lehtinen M. et al, Ten-year follow-up of human papillomavirus vaccine efficacy against the most stringent cervical neoplasia end-point—registry-based follow-up of three cohorts from randomized trials, BMJ Open, 2017.

In the UK, the Medicines and Healthcare products Regulatory Agency (MHRA)<sup>29</sup> is responsible for making sure that vaccines are safe, which includes collecting and reporting on information from healthcare professionals and people who have had the vaccine.

There are some common, non-severe side effects that you may experience after having the HPV vaccine. These are ones you would have after any injection, including:

- redness, swelling or pain at the injection site
- a headache, but it should not last long
- bruising or itching at the injection site
- a high temperature or feeling hot and shivery (fever)
- sickness (nausea).

All of the effects listed above should go away completely within a day or so. But if someone feels very ill, the effects get worse, or they last for more than three days, we suggest that they visit their GP.

We also know that lots of people are worried about having an injection. This can make them feel sick or faint, especially if they are very scared or have to watch other people having injections. If someone feels this way, it can help to ask if they can have the vaccine before everyone else or if they can sit down quietly for about 15 minutes after.

There is a growing movement against all vaccines, with the people who are part of that movement sometimes called ‘anti-vaccine’ or ‘anti-vaxxer’. These are people who believe that vaccines have a negative impact on the people having them. This belief tends to happen when someone has developed a condition or died shortly after having a vaccine, and people have linked it back to the vaccine **without** scientific proof.

There are some people who believe that the HPV vaccine causes harm. If you speak with someone who is anti-vaccine, they may mention:

- paralysis or Guillain-Barré syndrome (GBS)
- postural orthostatic tachycardia syndrome (POTS)
- myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS)
- chronic regional pain syndrome (CRPS)
- infertility or early menopause
- death.

All of these claims have been looked into by researchers and health bodies who approve the vaccines. No evidence has been found linking having the HPV vaccine to any of these conditions<sup>3031323334</sup>.

---

<sup>29</sup> The Medicines and Healthcare products Regulatory Agency, Website: [www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency](http://www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency), Accessed October 2019.

<sup>30</sup> World Health Organisation, Safety update of HPV vaccines, Website: [www.who.int/vaccine\\_safety/committee/topics/hpv/June\\_2017/en/](http://www.who.int/vaccine_safety/committee/topics/hpv/June_2017/en/), Accessed October 2019.

<sup>31</sup> Andrews N. et al, No increased risk of Guillain-Barré syndrome after human papilloma virus vaccine: A self-controlled case-series study in England, Vaccine 2017.

<sup>32</sup> Arana J. et al, Reports of Postural Orthostatic Tachycardia Syndrome After Human Papillomavirus Vaccination in the Vaccine Adverse Event Reporting System, Journal of Adolescent Health, 2017.

<sup>33</sup> Feiring B. et al, HPV vaccination and risk of chronic fatigue syndrome/myalgic encephalomyelitis: A nationwide register-based study from Norway, Vaccine, 2017.

<sup>34</sup> McCarthy NL. et al, Vaccination and 30-Day Mortality Risk in Children, Adolescents, and Young Adults, Pediatrics, 2016.

### **If I have or have had HPV, should I get the HPV vaccine?**

Because we are still learning about HPV, this is another question where research that is currently happening may add to our answer in future. What we know at the moment is that the HPV vaccine cannot get rid of an HPV infection you already have. However, it does stop you getting infected by other types of HPV. There is also a chance it could stop you being reinfected with the same type of HPV you currently have<sup>35</sup>.

### **I have cell changes or cervical cancer. Can the HPV vaccine help?**

Currently, there is no vaccine that can treat or get rid of cell changes or cervical cancer. However, there are studies happening at the moment that are looking at whether giving the HPV vaccination after treatment for cell changes or cervical cancer helps prevent recurrence. We will probably know the outcomes of these studies in a few years.

## **Cervical screening (smear tests)**

### **What is the difference between cervical screening and a smear test?**

There is no difference between cervical screening and a smear test. They are different names for the same test.

A smear test is the older name for the test. It was called that because of the way the test used to be done – cells were smeared on a glass slide, which was sent to the laboratory for testing.

The test is different now and most healthcare professionals call it cervical screening. But we know that the general public still tend to call it a smear test. It's best to reflect the language someone is using back to them – so for example, if a caller calls it a smear test, you do too.

### **What does cervical screening check for?**

We know from research we have done that many people don't know exactly what cervical screening is for. Our key message is that cervical screening only looks for high-risk HPV and cervical cell changes. It does not check for:

- sexually transmitted infections/diseases (STI/Ds)
- ovarian cancer – there is currently no screening test for this
- womb cancer – there is currently no screening test for this
- the general health of the genitals or reproductive system.

### **What are the benefits of cervical screening?**

The evidence shows that the benefits of cervical screening outweigh the risks for people who are eligible to have it.

- Cervical screening prevents about 75% of cervical cancers<sup>36</sup>. Along with the HPV vaccine, it is the best way to protect against cervical cancer.
- Cervical screening looks for cell changes caused by high-risk HPV before they develop into cervical cancer. This means you can get any treatment or care you may need early.
- A more effective test. Across the UK, cervical screening will test your sample of cervical cells for HPV first. If HPV is found, it will then look for cell changes in the same sample. This means we can identify those with the highest risk of developing cervical cancer, so they can get the right care. It also means less women overall will need to go for further tests.

---

<sup>35</sup> Ranjeva S. L. et al, Recurring infection with ecologically distinct HPV types can explain high prevalence and diversity, Proceedings of the National Academy of Sciences, 2017.

<sup>36</sup> Peto et al., The cervical cancer epidemic that screening has prevented in the UK, The Lancet, 2004.

### **What are the possible risks of cervical screening?**

The cervical screening programme exists because evidence shows that the benefits of the test outweigh any risks. But, like any screening test, cervical screening is not perfect and there are some risks<sup>37</sup>:

- A false negative. In a few cases, the test will say you do not have HPV or cell changes when you do. Going for cervical screening when invited can help reduce this risk, as it is likely HPV or cell changes that were missed would be picked up by your next test.
- A false positive. In a few cases, the test will say you do have HPV or cell changes when you don't. It may mean you could be invited for tests or treatment that you don't need.
- Sometimes cell changes go back to normal without needing treatment. At the moment, we can't tell which cell changes will go back to normal, so treating means we can be sure we are preventing them from developing into cervical cancer. This means some people may have unnecessary treatment, which is called overdiagnosis or overtreatment.
- Some treatments for cell changes remove the abnormal area of your cervix, which can slightly increase your risk of giving birth early (prematurely) if you get pregnant in future because the cervix is weaker. This is only a risk if the treatment takes more than 10mm of the cervix, which doesn't happen in most cases. In real numbers, after treatment about 2 in every 100 women (2%) will give birth prematurely<sup>38</sup>.

### **How can I opt out of getting invited to cervical screening?**

There is a set process that people can follow if they want to opt out of being invited to cervical screening<sup>39</sup>, but we know that in practice it is often a lot harder for people to opt out. This is because healthcare professionals sometimes don't know about the opt out process.

The process says that you should put your wish to opt out in writing and give it to your GP practice. They should then pass this on to the cervical screening programme, so you no longer receive invites.

### **Where can I go for cervical screening?**

You will get a letter inviting you for cervical screening from the GP surgery you are registered with. You can call them to book a cervical screening appointment.

In some areas of the UK, people may be able to book cervical screening at a sexual health/GUM clinic instead. It is best if they check your local services to find out if they offer it.

Across the UK, there are also specialist clinics for people who are part of a specific group or who have had a specific experience:

- Survivors of sexual violence – A charity called My Body Back<sup>40</sup> runs cervical screening clinics in London and Glasgow, where survivors can have longer appointments and expert support to help them before, during and after the test. The London clinic accepts bookings from anywhere in the UK and the Glasgow clinic accepts booking from Scottish residents only.

---

<sup>37</sup> Petry KU. et al, Benefits and Risks of Cervical Cancer Screening, Oncology Research and Treatment, 2014.

<sup>38</sup> R. Wuntakal et al, How many preterm births in England are due to excision of the cervical transformation zone? Nested case control study, BMC Pregnancy and Childbirth, 2015.

<sup>39</sup> Public Health England, Opting out of screening, Website: [www.gov.uk/government/publications/opting-out-of-the-nhs-population-screening-programmes/opting-out-of-screening](http://www.gov.uk/government/publications/opting-out-of-the-nhs-population-screening-programmes/opting-out-of-screening), Accessed October 2019.

<sup>40</sup> My Body Back, Website: [www.mybodybackproject.com](http://www.mybodybackproject.com), Accessed October 2019.

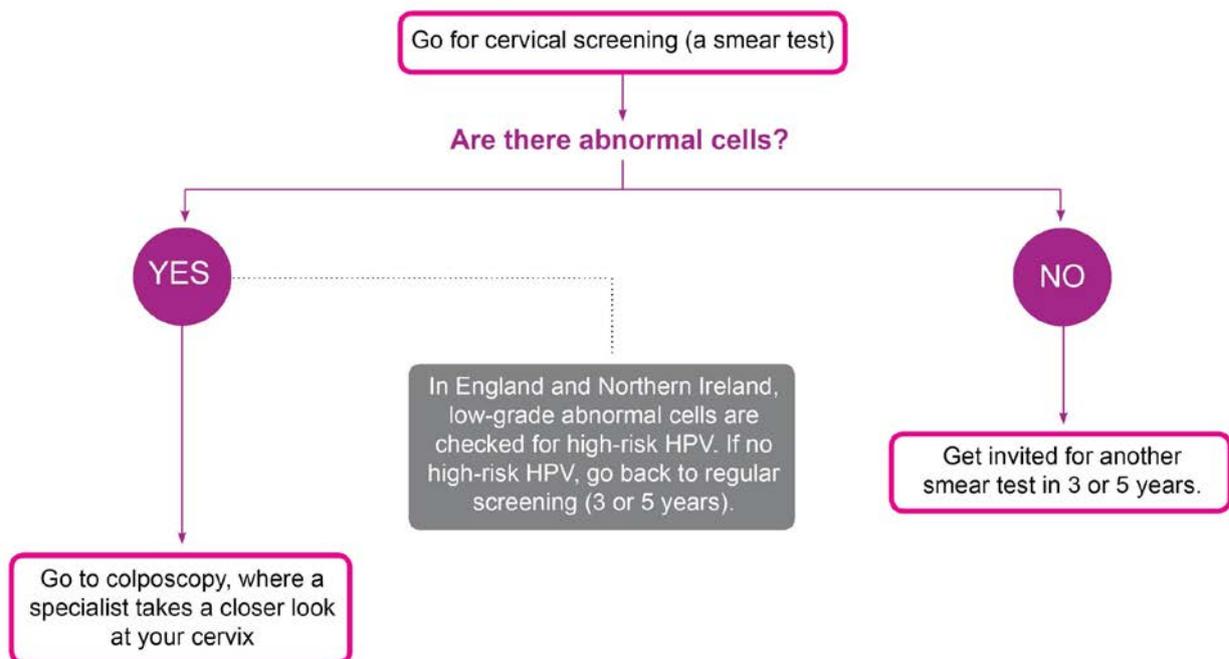
- Trans men and/or non-binary people with a cervix – A transgender man or non-binary person who was assigned female at birth may still have a cervix. There are expert clinics, often staffed by members of that community, that can provide support to these people before, during and after cervical screening. These include CliniQ<sup>41</sup> and 56 Dean Street<sup>42</sup> in London, and Clinic T<sup>43</sup> in Brighton.

### What changes are being made to cervical screening?

Across the UK, the test done to the sample of cells taken during cervical screening is changing. Instead of looking for cell changes first (a process called cytology), a test for high-risk HPV will be done first. This is sometimes referred to as HPV primary testing or HPV primary screening.

Below are images that show the pathway someone would follow with cytology and HPV primary testing/screening. Please note that these are drafts, as some UK countries are still finalising their pathways, so may change.

### Cytology – DRAFT



<sup>41</sup> CliniQ, Website: <https://cliniq.org.uk/>, Accessed October 2019.

<sup>42</sup> 56 Dean Street, Website: <http://dean.st/56deanstreet/>, Accessed October 2019.

<sup>43</sup> Brighton Sexual Health, Clinic T, Website: <http://brightonsexualhealth.com/service/clinic-t/>, Accessed October 2019.

## HPV primary testing/screening – DRAFT



The rough dates for these changes are:

- September 2018 – Wales
- December 2019 – England
- March 2019 – Scotland
- To be confirmed – Northern Ireland.

In England and Scotland, some areas have already switched to looking for HPV first. This means that, at the moment, different people in the same country may be having different tests and getting different results. If you are speaking with someone about cervical screening, check if they know whether their area has switched or not.

### Is HPV primary testing/screening different to cervical screening?

Because there are a few different names being used for the changes to cervical screening, there is some confusion about whether it is a brand new test. Our key message is that it is just a different way of testing the sample of cervical cells taken during cervical screening. The appointment and how the sample is taken will stay exactly the same.

### What happens in HPV primary testing?

Instead of looking for cell changes (abnormalities) first, your sample of cervical cells is tested for high-risk HPV.

High-risk HPV causes almost all (99.7%) cervical cancers, so knowing who has it helps us identify who is at higher risk, so they get the care they need.

If you have high-risk HPV, the same sample is looked at for cell changes:

- If you don't have cell changes, you don't need any further tests. You will be invited back for cervical screening in one year, to check the high-risk HPV has cleared.
- If you do have cell changes, you will be invited to colposcopy, where an expert will take a closer look at your cervix.

### **I've had cell changes or cervical cancer, but I don't have HPV. How will this test protect people like me?**

This is probably one of the most difficult questions we get about HPV and the changes to cervical screening. Currently, we can say with certainty that at least 99.7% of all cervical cancers are linked to HPV<sup>4445</sup>, but that leaves 0.03% where we haven't proven the link. That doesn't mean that HPV didn't cause those cancers – it is possible that, because the virus works by 'coming and going' in the body, it just wasn't detected when the sample of cervical cells or tumour was tested<sup>4647</sup>. However, it is also possible the HPV didn't cause these few cancers. It's an area that needs more research.

Our key message is that the change to cervical screening, so it looks for high-risk HPV first, will be much better for the majority. This is because the test is better at identifying people who are risk of cervical cancer. But it is still important for everyone to be aware of cervical cancer symptoms. While symptoms are usually something other than cervical cancer, you know your body best. Go to your doctor if you are worried about anything – don't wait for your next cervical screening appointment.

### **Who can have cervical screening on the NHS?**

In the UK, anyone between the ages of 25\* to 64 who is registered with a GP as female and has a cervix can have cervical screening. This includes trans men and/or non-binary people with a cervix who were assigned female at birth.

Across the UK, you are currently invited:

- every three years between ages 25 and 49
- every five years between ages 50 and 64.

With the cervical screening programme changing to test for HPV first, these invite intervals may eventually change in some countries. This would mean all people between ages 25 and 64 are invited every five years. We are still waiting for confirmation about this.

\* Note that people often get an invite for cervical screening at 24 ½ – if they choose, they can book in an appointment straight away, rather than waiting until their 25<sup>th</sup> birthday.

### **Can I go for cervical screening when I am pregnant?**

It is usually recommended that you do not have cervical screening while you are or could be pregnant. If you invited for cervical screening while pregnant, wait until three months after your baby is born to have the test. Tell your doctor or nurse you are pregnant if you are invited.

If you have previously had an abnormal cervical screening result, you may need to have the test while pregnant. Your doctor or midwife may ask you to have it at your first antenatal appointment. This test will not affect with your pregnancy.

---

<sup>44</sup> Walboomers JM. et al, Human papillomavirus is a necessary cause of invasive cervical cancer worldwide, *Journal of Pathology*, 1999.

<sup>45</sup> Evans MF. et al, HPV is Detectable in Virtually All Abnormal Cervical Cytology Samples After Reinvestigation of HPV Negatives With Multiple Alternative PCR Tests, *Diagnostic Molecular Pathology*, 2010.

<sup>46</sup> Munoz N. et al, Chapter 1: HPV in the etiology of human cancer, *Vaccine*, 2006.

<sup>47</sup> Walboomers JM. et al, Do HPV-negative cervical carcinomas exist?, *Journal of Pathology*, 1999.

### **Can women who have sex with women go for cervical screening?**

We sometimes hear from women who have sex with women – lesbian, bisexual, queer, or another identifier – who have been told they do not need cervical screening<sup>48</sup>. This is because some healthcare professionals may not understand how HPV is passed on.

Our key message is that all people with a cervix between age 25 and 64 have a right to cervical screening. Because HPV is usually passed on through skin-to-skin contact, any kind of sexual activity means you are at risk of getting it.

### **Can trans men and/or non-binary people with a cervix go for cervical screening?**

A transgender man or non-binary person may be someone who was assigned female at birth, but is actually a man or doesn't identify with a binary (male or female) gender. They may still have a cervix if they haven't had gender confirmation surgery.

If a trans man or non-binary person is registered at their GP as male or has not selected a gender, they may not be invited to cervical screening automatically. At the moment, only people registered as female with their GP are invited automatically. This makes it harder for trans men and non-binary people with a cervix to access cervical screening – they either have to remember to request a test every three or five years, or have a potentially difficult conversation with their GP about why they need to be on the automatic recall system.

Our key message is that all people with a cervix between age 25 and 64 have a right to cervical screening. Because HPV is usually passed on through skin-to-skin contact, any kind of sexual activity means you are at risk of getting it. If a trans man or non-binary person finds the test particularly difficult, there are specialist clinics who may be able to help, including CliniQ and 56 Dean Street in London and Clinic T in Brighton.

### **Is there anyone who may not be invited for cervical screening?**

Some people may not be invited for cervical screening:

#### People aged 24 or under

Cervical cancer is very rare in under-25s. In the UK, per 100,000 women:

- about 4 people are diagnosed with cervical cancer under the age of 25<sup>49</sup> – less than 1% of cases
- there is an average of 0 deaths from cervical cancer among under-25s<sup>50</sup>.

Cervical screening hasn't been shown to reduce the number of cervical cancers in under-25s<sup>51</sup>. We know this because, in countries where cervical screening starts at 20 years old, the number of people under 25 diagnosed with cervical cancer is not significantly different than in countries that start screening at 25 years old. The number of under-25s diagnosed with cervical cancer is likely to fall even further over the next 10 years thanks to the human papillomavirus (HPV) vaccine.

Research also shows that the risks of offering cervical screening under the age of 25 outweigh the benefits. When you are under 25, it is common to have changes in the cells of your cervix (abnormal cells) and these usually go away by themselves. Knowing about these cell changes could lead to treatment when the changes may simply have gone away on their own. It can also lead to anxiety or upset. There are also potential risks

---

<sup>48</sup> Light B and Ormandy P., Lesbian, Gay and Bisexual Women in the North West: A Multi-Method Study of Cervical, Screening Attitudes, Experiences and Uptake, University of Salford Report, 2011.

<sup>49</sup> Cancer Research UK, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/mortality> Accessed: 2018.

<sup>50</sup> Ibid.

<sup>51</sup> Castanon A and Sasieni P, Is the recent increase in cervical cancer in women aged 20–24 years in England a cause for concern?, Preventative Medicine, 2018.

with some treatments, including a slightly increased risk of early (premature) birth if you get pregnant in future.

### People aged 65 or over

Understandably, people aged 65 or over are sometimes worried when they hear they will no longer be invited for cervical screening. But stopping screening at this age is based on evidence and knowing that may be reassuring.

If you are aged 65 or older and have had regular, clear screening results it is very unlikely you will develop cervical cancer<sup>52</sup>.

If you turn 65 or older when you get an abnormal result or are being cared for after an abnormal result, you will continue to have the proper care until it goes back to normal.

If you are aged 65 or over and have never had cervical screening or have not been since age 50, you can have a test. It is best to speak with your GP surgery about booking an appointment.

### People who have had treatment that has removed or damaged the cervix

If you have previously had treatment that affected your cervix for any reason, you may no longer be invited for cervical screening. These treatments include:

- A hysterectomy. This is an operation that removes the womb and cervix. If you have had a hysterectomy, you will not be invited for cervical screening as there is no cervix to take a sample of cells from. You may be asked to have a vaginal smear (vault smear) for a short time after. Your doctor will tell you about this.
- Pelvic radiotherapy. This is a treatment that directs radiation at the part of the body between the hipbones (pelvis). It can damage the cells of the cervix and make it harder to tell if there are any changes, so you may not be automatically invited for cervical screening. Your doctor may do a separate follow up appointment with you.

Our key message is that if you are unsure whether you should still be invited for cervical screening it is best to check with your healthcare team at the GP surgery or hospital.

### **Does cervical screening hurt?**

Everyone has a different experience of cervical screening. Some people will find it absolutely fine, some people may find it uncomfortable and for others it may be painful. Our key message is that if you want to go for the test but finds it difficult, there are ways to make the test better (see next question).

### **Are there ways to make cervical screening better for me?**

If you speak with someone who is worried about cervical screening for any reason, sharing these tips may help them feel more comfortable:

1. **Ask for a nurse or doctor of a particular gender** – for example, a female nurse. If you have a nurse or doctor you trust, check with your GP surgery if they are able to do your test.
2. **Ask to book a longer or double appointment.** If you think you may need more time during or after your test, check if your GP surgery offers it. Be prepared for your GP surgery's receptionist to ask why you need a longer appointment but remember you do not have to disclose anything.
3. **Ask to book the first appointment of the day.** If you are very anxious or find being in a waiting room difficult, getting the first appointment could help ease those feelings.

---

<sup>52</sup> Castanon A. et al, Cervical Screening at Age 50–64 Years and the Risk of Cervical Cancer at Age 65 Years and Older: Population-Based Case Control Study, PLOS, 2014.

4. **Take someone you trust with you.** It could be a friend, family member, partner or someone else. They can be in the waiting room or examination room with you to offer support. They may also be able to speak on your behalf about any worries.
5. **Talk to your nurse or doctor.** If it is your first cervical screening, you feel embarrassed or worried, you have had a bad experience before, or you have experienced anything that makes the test hard for you, telling the person doing the test means they can try to give you the right support. If you don't feel comfortable saying something, try writing it down.
6. **If you feel uncomfortable, wear a skirt or dress.** You can keep this on during the test, which may help you feel more covered. You do get a paper sheet to cover yourself, but check if you can bring a spare shawl or blanket too.
7. **Ask to see the speculum and brush before the test.** Knowing what they look and feel like may help if you feel worried.
8. **Ask for a smaller speculum.** Speculums come in different sizes, so if you find the standard size too uncomfortable, you can ask to try another size.
9. **Ask to put the speculum in yourself.** Putting the speculum in yourself will not affect the outcome of the test and you may find it more comfortable to do it yourself.
10. **Ask to lie in a different position.** The standard position for cervical screening is lying on your back, but if this is uncomfortable or makes you anxious, you can ask to lie on your left hand side with your knees curled up. This is called the left lateral position and does not affect the outcome of the test.
11. **Give yourself time to process the test after.** If you find the test emotionally or physically difficult, making sure you have some time and space after can be important for your wellbeing. This might be having five minutes on the sofa, taking the day off work if you can, or treating yourself to a meet up with friends.

#### **Is cervical screening more painful after the menopause?**

Everyone's experience of cervical screening is different – something that still applies during or after the menopause.

As we get older, the opening of the vagina and vaginal walls become smaller and less able to stretch, which can make the test more uncomfortable. This happens because oestrogen levels in the body fall after menopause. You can ask your nurse to give (prescribe) you a vaginal oestrogen cream or pessary, which may help.

#### **How long will it take to get my cervical screening results?**

The NHS says you should get your cervical screening results within 2 to 6 weeks after your test, depending on where you live in the UK. The length of time varies and sometimes may be shorter or longer than this timeframe.

We know that lots of people are having to wait a long time for their cervical screening results. There is nothing we can directly do about this, but we can explain why this might be happening and signpost to people who may be able to help.

- Cervical screening changing to look for HPV first means that there are some workforce changes happening too<sup>53</sup>. This means that the labs that look at the samples may be processing them more slowly at the moment, which is causing a delay.
- Cervical cell changes and cervical cancer develop very slowly, with most taking years to develop. This means that if you have an abnormal result, a delay in getting results should not affect any outcome of your care.

---

<sup>53</sup> Jo's Cervical Cancer Trust, Delays in smear test results: Why and what to do if you're affected, Website: [www.jostrust.org.uk/about-us/news-and-blog/blog/delays-smear-test-results-why-and-what-do-if-youre-affected](http://www.jostrust.org.uk/about-us/news-and-blog/blog/delays-smear-test-results-why-and-what-do-if-youre-affected), Accessed October 2019.

If you are worried, the best person to contact is your GP. They should be able to tell you how long results are taking to arrive in your area.

### **Are my cervical screening results reliable?**

You may speak to someone who wants to know if their cervical screening results are 'right' or 'accurate'. Like any test there is a margin of error, but cervical screening is most often accurate. We call this 'reliability'.

At the moment, different areas of the UK will use one of two tests on the cervical sample taken during cervical screening:

- Cytology is between 70% and 80% reliable. This means when we use cytology on its own, we find about 7 or 8 in 10 cell changes.
- HPV primary testing is between 90% and 95% reliable<sup>5455</sup>. This means when we use HPV testing as the first test, we find about 9 in 10 cell changes.

### **Why does cervical screening miss some HPV infections or cell changes?**

Like any screening test, cervical screening is not 100% accurate. The test only takes a sample of cells from the surface of the cervix, which does not always show what is happening in the whole skin layer. However, it is between 80% and 90% reliable, making it the best way to protect against cervical cancer.

### **Will cervical screening give a final diagnosis of cancer?**

We speak with many people who are worried that cervical screening is a test to tell them whether they have cervical cancer or not. We can reassure them that isn't the aim of cervical screening and help them understand what the test is for.

Our key message is that cervical screening is not a diagnostic test – it aims to find HPV or cell changes early to *prevent* cancer.

Lots of people you feel anxious after getting an abnormal result, so you are not alone if you feel this way. But it is important that you understand what the abnormality is, so you can talk with your doctor about the results and get the right care and support.

### **Does an abnormal cervical screening mean I have cancer?**

No, it doesn't. Most cervical screening results (9 in 10 or 90%) are normal, with a very small number being either inadequate or abnormal. Remember, most of these cell changes (abnormalities) show early changes to the cells of the cervix, not cancer.

### **Why do some people need further tests and others never do?**

Most cervical cancers are caused by HPV. Almost all of us will get HPV at some point in their lives, but less than 1 in 10 of us will need further tests after cervical screening. This is because some people's immune system gets rid of HPV very quickly, before they develop cell changes.

We know that smoking can increase the risk of cell changes (abnormalities) and makes it harder for our immune system to get rid of HPV. So if you smoke, stopping might help.

Remember, being invited for further tests does not mean you have cervical cancer.

### **I have never had an abnormal result. Should I opt out of the screening programme after 50?**

It is your choice whether to go for cervical screening, whatever your age. If you are not sure whether to go, think about the benefits and any risks.

---

<sup>54</sup> Engesæter B. et al, Quality assurance of human papillomavirus (HPV) testing in the implementation of HPV primary screening in Norway: an inter-laboratory reproducibility study, BMC Infectious Diseases, 2016.

<sup>55</sup> Ogilvie G. S. et al, Effect of Screening With Primary Cervical HPV Testing vs Cytology Testing on High-grade Cervical Intraepithelial Neoplasia at 48 Months: The HPV FOCAL Randomized Clinical Trial, JAMA: The Journal of the American Medical Association, 2018.

Along with the HPV vaccine, going for cervical screening when you are invited is the best way to protect against cervical cancer. But there are lots of reasons you may not want to have the test, including discomfort if you are going through or have been through the menopause. If you are anxious for any reason, we have lots of information about how to make cervical screening better for you, so you can make an informed decision about your health.

### **I've had an abnormal cervical screening result. What happens next?**

If someone says that have an abnormal cervical screening result, the first step is to establish what they mean by that:

- Do they live in an area where cytology is done or where HPV primary testing is done?
- Do they just have cell changes, just have HPV or do they have HPV and cell changes?

### **Cytology results**

#### Inadequate

You may need to repeat the test after three months because the first one couldn't be read properly. This may be because the sample didn't have enough cells, the cells couldn't be seen clearly or there was an infection.

#### Abnormal

An abnormal result may show borderline or low-grade cell changes (dyskaryosis). These changes are very close to being normal and may disappear without treatment.

In the areas of England that are still doing cytology and in Northern Ireland, the same sample will be tested for high-risk human papillomavirus (HPV) if borderline or low-grade cell changes are seen:

- If no HPV is found, they can go back to normal (routine) screening every three or five years, depending on their age.
- If HPV is found, they will be invited to colposcopy where an expert will take a closer look at their cervix.

An abnormal result may show high-grade (moderate or severe) dyskaryosis. This means they will be invited to colposcopy, where an expert will take a closer look at their cervix.

### **HPV primary testing results**

#### HPV result unavailable or unreliable

This means that a true result could not be given. Usually they need to have the test repeated after three months.

#### HPV found (HPV positive) but inadequate

They usually need to repeat the test after three months because the first one couldn't be read properly. This may be because the sample didn't have enough cells, or the cells could not be properly seen.

#### HPV found (HPV positive) but no cell changes found

Because the immune system usually gets rid of HPV, they will be invited for cervical screening again in 1 year to check that the HPV is gone. If they have three HPV positive results in a row, they will then be invited to colposcopy, just to have a closer look at the cervix and check everything is okay.

#### HPV found (HPV positive) and cell changes found

Changes to the cells may be:

- borderline or low-grade changes (dyskaryosis)
- moderate or severe (high-grade) dyskaryosis.

If they have any grade of cell changes and HPV, they will be invited to colposcopy. This is where an expert takes a closer look at your cervix.

**I'm pregnant and have just had an abnormal screening result. What do I do?**

Your doctor will be able to tell you what to do next. If they don't know you are pregnant, tell them so they can give you the best advice.

Usually, you will be invited to colposcopy, where an expert will take a closer look at your cervix. This doesn't put your pregnancy at risk in any way. If you are invited to colposcopy, remember to tell the expert you are pregnant, just in case they are not aware.

## **Colposcopy**

### **What is colposcopy?**

Colposcopy is an examination to take a closer look at your cervix. An expert, called a colposcopist, does the examination. This is a different expert to the one at your cervical screening (smear test).

Colposcopy is used to both diagnose and treat cell changes. If you need treatment, you may

- be diagnosed and treated during your first appointment – this is sometimes called 'see and treat'
- be invited to a separate appointment for treatment.

### **What happens during colposcopy?**

If someone is worried about colposcopy, it may help to talk them through this step-by-step of the appointment.

Colposcopy is usually done at a hospital. A colposcopy appointment usually takes between 15 and 30 minutes.

1. At the start of the appointment, your colposcopist invites you into an examination room. They explain why you have been invited and what will happen during the appointment. You can use this time to ask any questions.
2. Your colposcopist gives you a private space to undress from the waist down and ask you to lie on an examination bed. Some colposcopy clinics have an extra screen next to the bed, in case you want to watch the examination.
3. Like during cervical screening, your colposcopist gently puts a new, clean speculum into your vagina. A speculum is usually a plastic cylinder with a round end – sometimes a metal speculum is used.
4. Your colposcopist uses a microscope with a light at the end to have a detailed look at your cervix. This is called a colposcope. The microscope stays outside your body.
5. Your colposcopist usually puts some liquid on your cervix. This helps show any areas where there are cell changes. Most colposcopists use a combination of acetic acid and Schiller's iodine tests:
  - a. Acetic acid is a very weak acidic liquid. It is sometimes called dilute vinegar. The colposcopist gently applies it to your cervix using a cotton wool ball or with a spray. It shows cell changes by turning them white.
  - b. Schiller's iodine test uses an iodine solution. It stains normal cervical tissue dark brown. Cell changes may not stain, so the colposcopist can see them.
6. Your colposcopist may take a sample of tissue from your cervix. This is sometimes called a punch biopsy. A biopsy only takes a small sample of tissue, so most people

don't have local anaesthetic. If you would like local anaesthetic, ask your colposcopist. Your colposcopist will explain the biopsy before they take it. Some people find it uncomfortable, but it should not be painful. Remember, you are in control. If it hurts, ask your colposcopist to stop. Your colposcopist will take between one to three biopsies to make sure they have enough tissue from different areas of the cervix. They send the sample of tissue to a laboratory for testing.

Our general tips for making colposcopy better for someone are the same as our tips for cervical screening.

**Is it possible to see if I have cancer during colposcopy?**

Not necessarily. It depends on the size, position and appearance of any abnormality seen. If there are any very suspicious areas seen at colposcopy, then the colposcopist will usually take a biopsy or treat it.

After the colposcopy examination, your colposcopist will try to give you as much information as they can. But they will usually need to get the results of a biopsy before you get your full results.

Remember, most people who go to colposcopy do not have cervical cancer. If you have any questions or worries, there is time before and after your colposcopy examination to talk about these.

**What happens if I have an obvious abnormality at colposcopy or a positive biopsy result?**

If there are any very suspicious areas seen at colposcopy, then the colposcopist will usually take a biopsy or treat it.

That depends on the grade of abnormality. If the colposcopy or biopsy show CIN1, treatment is rarely required. Instead, you will be monitored in either colposcopy or back at your GP practice. However, if CIN2 or CIN3 is identified then treatment may be required. In the UK, the most common treatment is large loop excision of the transformation zone (LLETZ).

How long will it take for me to get the results of the biopsy taken at colposcopy?

You usually get a results letter from your colposcopist. It may take 4 to 8 weeks to get the results.

If the colposcopist is concerned you may have cancer, a telephone call or a clinic visit may be offered within two to three weeks.

**My colposcopy results said I have CIN or CGIN. Do I have cervical cancer?**

No. If your results show you have cervical intraepithelial neoplasia (CIN) or cervical glandular intraepithelial neoplasia (CGIN), this means that you have cervical cell changes. These changes are not cancer.

## **Cervical cell changes (abnormal cells) and treatment**

**What are cervical cell changes?**

Cervical cell changes are when the cells of the cervix have changed in a way they shouldn't. They are sometimes called abnormal cells or abnormalities. Our key message is that cervical cell changes are not cancer and can be monitored or treated to make sure they do not develop into cancer.

### **Do cell changes always develop into cervical cancer?**

Most cell changes do not develop into cervical cancer. They may go back to normal by themselves or with treatment<sup>5657</sup>. Once cell changes are found and graded, colposcopists can monitor or treat them as needed.

If someone is really worried or has specific questions, it is best that their colposcopist talks them through their individual situation. They can give support and may be able to reassure you.

### **If cervical cell changes are not cancer, why do I have to have treatment?**

At the moment, we have no way of knowing which cell changes will eventually develop into cervical cancer and which won't. So although cell changes are not cancer, you are monitored and sometimes offered treatment to reduce the risk of cervical cancer developing in the future.

### **What are the symptoms of cell changes?**

Cell changes do not cause symptoms – no pain, discharge, or bleeding. This means that cervical screening is the best way to find cell changes.

Any symptoms are usually caused by conditions other than cancer, but our key message is that if you do have them, it is important to get them checked out straight away.

### **I have been told I have CIN. What does this mean?**

Getting a result of cervical intraepithelial neoplasia (CIN) means you have cell changes (abnormalities) on the outer surface of the cervix. This is not cancer.

CIN is graded depending on how severe or extensive the changes are. The different grades are:

- CIN1 (low grade). One-third of the thickness of the outer surface is affected. It is unlikely these cell changes will develop into cervical cancer. They will probably go back to normal by themselves. You do not need treatment and will be invited for cervical screening (a smear test) in 12 months to check the cell changes are gone.
- CIN2 (high grade). Two-thirds of the thickness of the outer surface is affected. There is a higher chance these cell changes may develop into cervical cancer. Depending on your situation, you may be offered:
  - treatment to remove the cell changes
  - an appointment (monitoring) every 6 months to check if the cell changes go back to normal by themselves.
- CIN3 (high grade). The full thickness of the outer surface of the cervix is affected. If not treated, it is more likely these cell changes will eventually develop into cervical cancer, so you will be offered treatment to stop that happening.

### **I have been told I have CGIN. What does this mean?**

Getting a result of glandular cervical intraepithelial neoplasia (CGIN) means you have cell changes up inside the cervical canal. It is less common than CIN.

CGIN is usually described as low grade or high grade. If you have any grade of CGIN, you will be offered treatment.

### **How are CIN and CGIN treated?**

If you need treatment and didn't have it at your first colposcopy, you should be invited for it within 4 to 6 weeks. Your colposcopist should be able to help with any questions or concerns about timeframes.

---

<sup>56</sup> Matsumoto K. et al, Predicting the progression of cervical precursor lesions by human papillomavirus genotyping: A prospective cohort study, International Journal of Cancer, 2010.

<sup>57</sup> Tainio K. et al, Clinical course of untreated cervical intraepithelial neoplasia grade 2 under active surveillance: systematic review and meta-analysis, BMJ, 2018.

Treatment depends on the type and grade of the cell changes.

Common treatments for cell changes are:

- large loop excision of the transformation zone (LLETZ)
- cone biopsy.

Other treatments for cell changes are laser therapy, cold coagulation (also called thermoablation) and cryotherapy.

You can read or signpost people to our website for more detailed information about different types of treatment: [www.jostrust.org.uk/information/abnormal-cells/treating-abnormal-cells](http://www.jostrust.org.uk/information/abnormal-cells/treating-abnormal-cells)

### **How successful are treatments for cell changes?**

Treatment is usually very successful. After treatment for cell changes:

- over 9 in 10 (over 90%) people will not have further problems<sup>58</sup>
- fewer than 2 in 10 (between 5% and 15%) people may have cell changes that come back<sup>59</sup>.

Our key message is that even if cell changes come back, it does not mean you will develop cervical cancer. They will be monitored or treated as they were before.

Rarely, if cell changes keep coming back, a healthcare team may recommend that someone has hysterectomy<sup>60</sup>. This recommendation depends on other factors, like someone's age and whether they have started or completed their family.

### **Why is LLETZ the most popular treatment for cell changes?**

LLETZ stands for large loop excision of the transformation zone. It is the most common treatment for removing cell changes because it is very successful – the evidence shows that the abnormal area is completely removed and doesn't come back in over 90% of cases<sup>61</sup><sup>62</sup>. It also aims to take the smallest amount of cervical tissue it can, to reduce the impact of any side effects.

Our key message is to talk through all the treatment options with your healthcare team, including the benefits and possible risks, so you can make the best decision for you.

### **How does LLETZ work?**

LLETZ uses a thin wire loop with an electrical current to remove the area of the cervix where there are cell changes. If someone is worried about having LLETZ, it may help to talk through this step-by-step of the treatment with them.

You usually have LLETZ as an outpatient. This means you have it in an examination room at a hospital, but can go home afterwards.

1. Like during cervical screening (smear test), your colposcopist will gently put a new, clean speculum into your vagina.

---

<sup>58</sup> Lili E. et al, Low recurrence rate of high-grade cervical intraepithelial neoplasia after successful excision and routine colposcopy during follow-up, *Medicine*, 2018.

<sup>59</sup> Ibid.

<sup>60</sup> Zhu M. et al, Factors that influence persistence or recurrence of high-grade squamous intraepithelial lesion with positive margins after the loop electrosurgical excision procedure: a retrospective study, *BMC Cancer*, 2015.

<sup>61</sup> Dobbs S. P. et al, Does histological incomplete excision of cervical intraepithelial neoplasia following large loop excision of transformation zone increase recurrence rates? A six year cytological follow up, *BJOG*, 2005.

<sup>62</sup> Lili E. et al, Low recurrence rate of high-grade cervical intraepithelial neoplasia after successful excision and routine colposcopy during follow-up, *Medicine*, 2018.

2. Your colposcopist will inject a local anaesthetic into your cervix. This means you are awake, but the area that needs treating is numb (you can't feel it). The injection might sting for a short time.
3. Your colposcopist may also put a sticky pad on your leg. This makes sure the electric current doesn't shock you or the colposcopist.
4. Once your cervix is numb, your colposcopist removes the area of the tissue with cell changes with the loop. It's normal to notice a slight burning smell and hear a noise like a soft vacuum cleaner. The loop cuts the tissue and seals the cut at the same time. This should not be painful, but you may feel some pressure.
5. The removed area is sent to a laboratory to test the extent of the cell changes and whether all of the cell changes have been removed (there are clear margins).

### **What side effects might I have after LLETZ?**

After all treatments, including LLETZ, you may have some side effects. Our key message is that we all react and heal differently after treatment, so you may not experience all side effects in the way described. If you need some extra support, you may want to get in touch with your healthcare team at the hospital or GP.

#### Emotional wellbeing after treatment

Having treatment can affect your emotional wellbeing, as well as your body. After treatment, you may be worried about whether the treatment has worked or whether you will go on to develop cervical cancer. All your concerns are valid.

#### Pain

Some people have cramping pain, like a period, after LLETZ. The pain varies from person to person, but some pain is expected for a day or two after treatment.

If you are in a lot of pain or find it is affecting your day-to-day life, speak with your colposcopist or GP. They can offer reassurance based on your medical history and, if needed, will be able to check you are healing properly.

#### Bleeding and changes to vaginal discharge

After treatment, a soft scab forms on the cervix where the cells were removed. While this heals, it may cause bleeding and changes to vaginal discharge. This can last about 4 weeks.

Any bleeding is usually like a slightly heavy period. About 10 days after treatment, the bleeding may get heavier. This is very normal and simply the soft scab healing. Your first period (monthly bleeding) after treatment may be slightly heavier or out-of-sync with your regular cycle.

If the bleeding is very heavy and you are soaking through a sanitary pad every few hours, it is important you go to the hospital straight away. It may not be anything to worry about, but they can check everything is okay and offer the right care.

Straight after treatment, you may have a watery vaginal discharge, and about 10 days after treatment, many women notice a coffee granule-like vaginal discharge. This is very normal and simply the soft scab healing.

Speak with your GP if your vaginal discharge smells badly, or is a yellow or green colour. If you have an infection, your GP may give you antibiotics.

Until any bleeding has stopped and vaginal discharge has gone back to normal, your colposcopist may advise you not to have penetrative sex, use tampons, or swim. If you are unsure what you should or shouldn't do, ask your colposcopist or GP.

#### If you get pregnant in the future

If you get pregnant in future, it is important to tell your midwife that you have had LLETZ. They can check if you need a cervical stitch (cerclage) to support your pregnancy. We have

more information about cervical stitches at [www.jostrust.org.uk/information/abnormal-cells/treating-abnormal-cells](http://www.jostrust.org.uk/information/abnormal-cells/treating-abnormal-cells)

## **Cervical cancer**

### **What is cancer?**

Your body is made up of lots of small parts called cells. You are always making new cells to replace old ones when they die or are hurt. This happens in a controlled way. For example, if you cut your hand, your body sends a message that new skin cells should be made until the cut is healed.

Most cancers start when cells change and grow uncontrollably. Eventually, this forms a lump (tumour). Tumours can be malignant or benign:

- A malignant tumour is also called cancer and can spread to other parts of the body.
- A benign tumour is not cancerous and does not usually spread to other parts of the body.

Malignant tumours can spread because the cancer cells are in the blood or lymphatic system (a network of thin tubes and nodes that are part of the immune system). This means the cancer cells can travel to other parts of the body. If this happens and new tumours form, this is called metastasis or secondary cancer.

### **How many types of cervical cancer are there?**

There are a few different types of cervical cancer:

#### Squamous cell cervical cancer

Squamous cell cervical cancer develops in the flat cells that cover the outside surface of the cervix. Squamous cell is the most common type of cervical cancer. 8 out of 10 (80%) cervical cancers are diagnosed as squamous cell.

#### Adenocarcinoma

Adenocarcinoma develops in the glandular cells inside the cervical canal. can be more difficult to detect with cervical screening tests because it develops within the cervical canal. More than 1 in 10 (10%) cervical cancers are adenocarcinomas.

#### Adenosquamous cervical cancer

Adenosquamous cervical cancers are tumours that have both squamous and glandular cancer cells. It is rare – less than 1 in 10 (about 0.5%) of cervical cancers are this type.

#### Other rare types of cervical cancer

Rarely, other cancer types can develop in the cervix, including:

- neuroendocrine carcinoma of the cervix (NECC) – this type includes small cell cervical cancer and large cell cervical cancer
- clear cell cervical cancer
- lymphomas
- sarcomas.

### **What causes cervical cancer?**

Evidence shows that high-risk HPV is the cause of at least 99.7% of all cervical cancers<sup>63</sup>. It is particularly linked to the most common types of cervical cancer<sup>64</sup>, squamous cell and adenocarcinoma, that make up over 90% of all diagnoses.

However, most people with HPV, including high-risk types, will not develop cervical cancer. High-risk HPV by itself is not enough – there must be other factors involved, for example smoking, having HIV, or being more susceptible to a persistent HPV infection. It is likely to be a combination of these things that determines whether someone develops cervical cancer.

There are some other, much rarer cervical cancers, such as clear cell cervical cancer, where the link to high-risk HPV is not always there<sup>65</sup>. We still need more research to understand what, if not HPV, is causing these cervical cancers.

You may get questions about the 0.03% of cervical cancers that we can't definitively link to HPV, especially as we switch to HPV primary screening. You can explain that we need more research to truly understand why this happens, but in the meantime it is best to look out for symptoms and see your GP straight away if anything is worrying you.

### **What are the symptoms of cervical cancer?**

The most common symptoms of cervical cancer include:

- vaginal bleeding that is unusual for you, including after the menopause, after sex, or between regular periods
- pain or discomfort during sex
- changes to vaginal discharge
- unexplained pain in your lower back or between your hip bones (pelvis).

Although the above are the most common, cervical cancer symptoms are not always obvious or it may not cause any. This may cause some worry, but our key message is that it is important to remember that these symptoms usually happen for reasons other than cervical cancer. It is also important to get them checked by a GP straight away so they can give you reassurance and support.

#### Vaginal bleeding that is unusual for you

If you have regular periods, unusual vaginal bleeding happens any time outside of your regular period. It may happen:

- between periods
- during or after sex
- after the menopause\*.

Although this may be worrying, remember there are many different reasons for unusual bleeding that may not be related to cervical cancer, including hormonal contraception (birth control) and cervical ectropion.

\*A side effect of hormone replacement therapy (HRT) can be light bleeding that can last for the first few years of treatment<sup>66,67</sup>. This is common and usually nothing to worry about, but it is best to speak with your healthcare team to make sure you get the right care.

---

<sup>63</sup> Walboomers JM. et al, Human papillomavirus is a necessary cause of invasive cervical cancer worldwide, *Journal of Pathology*, 1999.

<sup>64</sup> Tjalma WAA., HPV negative cervical cancers and primary HPV screening, *FACTS, VIEWS & VISION in ObGyn*, 2018.

<sup>65</sup> Ibid.

<sup>66</sup> Thomas A. M. et al, Disturbances of endometrial bleeding with hormone replacement therapy, *Human Reproduction*, 2000.

### Vaginal bleeding after the menopause (post-menopausal bleeding)

If you are over 45 and haven't had a period for more than a year, you may have gone through the menopause. After the menopause, any bleeding from the vagina needs to be checked by your GP, even if it is light or just happens once.

### Pain or discomfort during sex

You may find sex painful or uncomfortable. This is sometimes called dyspareunia. Sex may be painful for lots of reasons, both physical and psychological, that aren't related to cervical cancer. There are things that may help, such as using more lubrication or seeing a counsellor that specialises in sex therapy.

### Changes to vaginal discharge

Vaginal discharge is a fluid (mucus) that cleans and protects the vagina. Most women have it, but it is good to be aware of any changes. Those changes may be:

- looking different – for example, becoming much thicker or changing colour
- smelling different – particularly if it smells unpleasant.

Vagina discharge can change for lots of reasons that aren't related to cervical cancer, such as an infection or changing hormones.

### Pain in your lower back or between your hipbones (pelvis)

Sometimes we feel pain in our lower back or pelvis for a reason, like pulling a muscle or having a period. But it is a good idea to get this pain checked out if:

- there is no obvious reason for it
- it is affecting your day-to-day life
- it lasts for two to three weeks or longer.

### **What are the symptoms of advanced cervical cancer?**

If cervical cancer spreads to other parts of the body, it can cause further symptoms, including:

- severe pain in your side or back – for example, pain that affects your ability to do day-to-day things or that doesn't get better after painkillers
- unexplained weight loss
- loss of appetite
- finding it hard to poo (constipation)
- weeing or pooing more often than usual
- losing control of your bladder (urinary incontinence)
- losing control of your bowels (bowel incontinence)
- blood in your wee or poo
- swelling in 1 or both legs
- severe vaginal bleeding – for example, if you are soaking through sanitary pads every hour.

All of these symptoms may be caused by conditions other than advanced cervical cancer, but it is important to get any of them checked out by your GP so you can be reassured.

---

<sup>67</sup> Lou Y. Y. et al, Unscheduled bleeding on HRT - do we always need to investigate for endometrial pathology?, International Journal of Reproduction, Contraception, Obstetrics and Gynecology, 2017.

### **What should you do if you have symptoms of cervical cancer?**

It is important to reassure people that all of the symptoms we talk about often happen for a reason other than cervical cancer – but if they have any of these symptoms or are worried about anything else, it is best to see their GP as soon as possible. The GP will be able to examine them and refer them for further tests if needed.

Our key message is that you should not only be offered cervical screening (a smear test) if you have symptoms. Cervical screening is a preventative test, not one to diagnose a condition.

#### Pelvic examination

If you have symptoms, you should be offered a pelvic examination. It checks your reproductive organs for anything that may be causing your symptoms.

A pelvic examination is done by a GP or a trained practice nurse – you can ask for a female. They will wear new, clean gloves for the examination. The examination lasts for a few minutes.

A pelvic examination involves the GP or nurse:

- pressing on your stomach to feel for anything unusual
- looking at the outside of your vagina for any changes, such as redness or swelling
- looking at your cervix for any changes by using a speculum to gently open your vagina (see picture below)
- feeling the inside of your vagina to check whether your womb or ovaries are tender or swollen.

Your GP or nurse should explain each step before they do it, to make sure you are comfortable and consent to the examination. If you are uncomfortable or want to stop at any time, tell them.

### **Can I catch cervical cancer from other people?**

Cervical cancer cannot be passed on between people – it is not infectious. If people ask about this, they may be thinking of HPV and the fact it can be passed on. Our key message is that most people clear HPV within 2 years and it usually does not cause any problems.

### **How is cervical cancer diagnosed?**

Cervical cancer can be found by taking a sample of tissue from the cervix. This is sometimes called a biopsy. You may have a biopsy because:

- of an abnormal cervical screening (smear test) result
- you have symptoms of cervical cancer
- your doctor sees something they are concerned about during a pelvic examination.

### **Is cervical cancer passed on through families (hereditary)?**

Current evidence suggests that cervical cancer does not develop because of a faulty gene that is passed down through families. This means it is not considered a hereditary cancer.

However, we know that the risk of developing cervical cancer slightly increases if a close family member (mother or sister) has had it<sup>68</sup>. This suggests there may be shared environmental factors, including exposure to HPV and how our bodies respond to it, that influence whether we develop cervical cancer. It is very important to note that we do not have enough research in this area to definitively say whether this is the case, or to truly understand how family history influences cervical cancer risk.

---

<sup>68</sup> Hemminki K. et al, Familial risks in cervical cancer: is there a hereditary component?, International Journal of Cancer, 1999.

### **What is the risk of developing cervical cancer?**

In the UK, it has been estimated that the overall lifetime risk of developing cervical cancer is less than 1% for people born after 1960<sup>69</sup>. This estimated risk takes the NHS screening programme into account.

### **I had a LLETZ biopsy treatment for early stage cervical cancer. Will I need a hysterectomy?**

Not necessarily. Very early cervical cancer is often diagnosed after biopsy results from a sample taken at colposcopy. The experts who examine the sample under a microscope may see that because the cancer that is so small and surrounded by normal tissue, that no further treatment is recommended. However, doctors may recommend further tests, such as another biopsy, to check that there is no abnormal tissue in the surrounding area where the first biopsy was taken from.

### **I need a hysterectomy. What does this mean?**

A hysterectomy is when your womb (uterus) is removed by surgery. It is always done under a general anaesthetic. There are different types of hysterectomy:

#### Total hysterectomy

This is sometimes called a simple hysterectomy. It is when the cervix and womb are removed.

#### Radical hysterectomy

This is sometimes called a Wertheim hysterectomy. Most people with cervical cancer have a radical hysterectomy, where the following are removed:

- cervix
- womb
- tissue surrounding the womb
- lymph nodes in the pelvis
- top part of the vagina.

Sometimes, the ovaries are also removed. If you have not been through menopause, your doctor will usually try to keep them, as removing them would trigger the menopause.

### **Will I have a scar after a hysterectomy?**

Any scarring is usually a horizontal line just above your pubic hair line. It tends to heal well and many people can hardly see the scar once it is healed.

Sometimes the doctor will need to make a vertical incision. If this happens, the doctor will explain where the scar will be and why he needs to do the operation this way. It is usually for a reason other than the cancer, such as the womb being a bit larger than normal.

In some centres, it is possible for the operation to be done using laparoscopic (keyhole) surgery. In this case, you will usually have two or three small scars either side of your tummy button at the level of your pubic hair line or slightly higher. Having laparoscopic surgery causes less blood loss, speeds up the recovery time and less pain relief is needed. If it is available at your centre, you will be offered this.

### **What will I experience straight after a radical hysterectomy?**

You will usually have a small, plastic tube (a drip) in your arm. This means that you will get the fluids you need without needing to drink.

---

<sup>69</sup> Lifetime risk estimates calculated by the Statistical Information Team at Cancer Research UK. Based on Office for National Statistics (ONS) 2016-based Life expectancies and population projections. Accessed December 2017, and Smittenaar CR, Petersen KA, Stewart K, Moitt N. Cancer Incidence and Mortality Projections in the UK Until 2035. Brit J Cancer 2016, Accessed October 2019.

A catheter (small tube) will usually be put into your bladder whilst you are asleep. This drains urine into a bag. The drip will usually be removed soon after your operation, once your body has recovered and you can drink independently. The catheter may need to stay longer, sometimes up to five days. This is to let the bladder fully recover after the surgery. Even when the catheter is removed, it is important that bladder function is measured to make sure it doesn't overflow. Sometimes it is necessary to continue catheterising the bladder to make sure it empties properly. This can be for a few weeks, or even a month or two in some cases.

In some cases, your medical team may teach you how to do intermittent self-catheterisation. This is when you insert a catheter into your own bladder at regular intervals during the day or when you need the toilet. Once all of the urine has been drained from your bladder, you remove the catheter again. This means you control emptying your bladder.

A dressing will cover your scar. You may have stitches or clips which will need to be removed usually between five and ten days after the operation. If you have had a laparoscopic procedure, the wounds are often held together with glue. This dissolves on its own and leaves a barely noticeable scar.

You may have one or more wound drains in place. Wound drains are small tubes that drain any blood or serous fluid from the scar area into a bag or bottle. This helps prevent infection and reduces bruising. These wound drains are taken out within days of the operation. You will be given painkillers to help with any discomfort that you have. This may be in the form of:

- an epidural
- a hand held pump, where you can press the button when you need more pain relief
- injections
- suppositories.

When you are able to drink, you can have oral medicines, such as tablets. The staff looking after you will talk to you about your pain relief choices before your operation.

### **Will I be able to have sex after a radical hysterectomy?**

Yes. The vaginal tissues are very stretchy, which this means that although the top part of the vagina is removed, you will be able to have penetrative sex. Most people say that they do not notice any difference. However, if you had radiotherapy, you will usually notice some changes to the vagina after treatment. The most common changes are:

- the uterus not moving during orgasm – this does not make the orgasm less pleasurable
- if the ovaries have been removed and no HRT has been taken, the vaginal tissues may feel a little dry – HRT or a vaginal lubricant should be helpful
- if the cervix has been removed, even if the ovaries remain, there may be vaginal dryness – a water-based lubricant or vaginal moisturiser should help address this.

Psycho-sexual issues, including how a woman or her partner feel about their body or sex, may affect their arousal and satisfaction with sex. If this is a problem, all women who have had treatment for cervical cancer should be able to see a psycho-sexual counsellor to discuss it. You can arrange an appointment via your GP, your hospital consultant or specialist nurse.

You can signpost to our information on sex and intimacy for more detail about possible changes to sex life: [www.jostrust.org.uk/about-cervical-cancer/moving-forward-from-a-cancer-diagnosis/sex-and-intimacy](http://www.jostrust.org.uk/about-cervical-cancer/moving-forward-from-a-cancer-diagnosis/sex-and-intimacy)

### **Will having my lymph nodes removed affect me?**

The lymphatic system is a system of thin tubes and lymph nodes that run throughout the body. These tubes are called lymph vessels or lymphatic vessels.

The lymph system is an important part of our immune system. It plays a role in:

- fighting bacteria and other infections
- destroying old or abnormal cells, such as cancer cells

Lymph nodes affected by cervical cancer are usually in the pelvis. You can't be certain that lymph nodes are not cancerous unless you remove them and look at them under the microscope.

You will likely experience some discomfort or pain after having lymph nodes removed, which will be managed by your health care team with painkillers. Your immune system is not compromised with the removal of lymph nodes.

There is a risk that you could experience some swelling in the area of one or both of your legs, called lymphoedema, after the operation.

### **What is lymphoedema?**

Lymphoedema is a condition that causes swelling in the body's tissues. It is a long-term (chronic) condition.

Lymphoedema can affect any part of the body, but usually develops in the legs after cervical cancer treatment<sup>70</sup>. It develops when the lymphatic system doesn't work properly. The lymphatic system is a network of tubes and nodes throughout the body that helps fight infection and remove excess fluid. Lymphoedema means the fluid cannot drain away and may cause build up.

It's important that lymphoedema is identified and treated as soon as possible. If it isn't treated, it can get worse.

Our key message is that lymphoedema is not dangerous, but it can be uncomfortable or painful, which can impact your quality of life<sup>71</sup>. There are ways you can reduce your risk of lymphoedema or manage the condition.

Before surgery, you may want to ask your specialist nurse what you can do to help prevent developing lymphoedema, what signs to look for and what services are available if you develop it. Your surgeon may also put a small drainage tube in place during your surgery to help reduce the build up of this fluid. The tube will be removed a few days later.

If you do develop lymphoedema, tell your GP, consultant or specialist nurse. They will confirm that it is lymphoedema and refer you to a specialist.

### **Will I develop lymphoedema?**

If you have had any lymph nodes removed, you are at risk of developing lymphoedema. Your risk increases if you have had radiotherapy to your pelvic area as well as surgery<sup>72</sup>.

We don't know exactly how many people will go on to develop lymphoedema after cancer treatment. Our key message is to speak with your healthcare team about any treatment you have and your risk of developing it, as well as ways to reduce that risk.

### **How do I reduce my risk of developing lymphoedema?**

It's not possible to completely prevent lymphoedema, but the following things may help reduce your chances of developing it.

#### Skin care

---

<sup>70</sup> Biglia N. et al, Lower Body Lymphedema in Patients with Gynecologic Cancer, Anticancer Research: International Journal of Cancer Research and Treatment, 2017.

<sup>71</sup> Dunberger G. et al, Lower limb lymphedema in gynecological cancer survivors—effect on daily life functioning, Supportive Care in Cancer, 2010.

<sup>72</sup> Tada H. et al, Risk factors for lower limb lymphedema after lymph node dissection in patients with ovarian and uterine carcinoma, BMC Cancer, 2009.

Any cuts in your skin can allow bacteria to enter your body and may quickly develop into an infection. Skin infections may damage your lymphatic system and cause lymphoedema to develop.

There are ways you can reduce your chance of skin infections, including:

- treating cuts and scratches immediately with an antiseptic cream
- using insect repellents to prevent insect bites
- moisturising your skin daily – your GP can prescribe a suitable cream
- using sun cream with a high sun protection factor (SPF) to prevent sunburn
- using anti-fungal powder to prevent fungal infections in your skin or feet if your lower limbs are affected
- cutting your nails with nail clippers instead of scissors

if you develop symptoms of a possible skin infection, such as redness and a feeling of heat in the skin, speak with your GP as soon as possible.

#### Healthy lifestyle

Making lifestyle changes may help reduce your risk of developing lymphoedema, including:

- eating a healthy, balanced diet – it is important to speak to your healthcare team about a diet that is right for you
- maintaining a healthy weight
- exercising regularly – it is important to speak to your healthcare team about what exercise is suitable for you.

#### **Are there ways to manage lymphoedema?**

- Take care of your skin. In areas where there is swelling, skin may become stretched and more fragile. Cleaning your skin and drying it gently, moisturising, and checking it for any signs of damage like redness or marks) can help look after it. Doing this can also help prevent swelling from flaring up.
- If you have lymphoedema in your legs or feet, make sure your socks and shoes fit properly and are not too tight.
- Keep physically active. It is important to speak with your healthcare team about exercise that is suitable for you.
- Wear a compression garment. This may be a tight elastic sleeve or stocking that helps to reduce and contain any swelling.

There is more detailed, reliable information at:

- The Lymphoedema Support Network (LSN) – [www.lymphoedema.org/information-and-support](http://www.lymphoedema.org/information-and-support)
- NHS – [www.nhs.uk/conditions/lymphoedema/treatment](http://www.nhs.uk/conditions/lymphoedema/treatment)

#### **What is pelvic exenteration surgery?**

A pelvic exenteration is a type of surgery for cervical cancer that has come back in the pelvic area. It is a major surgery and may only be suitable for a few women.

There are three types of pelvic exenteration:

#### Total exenteration

In this surgery, your doctor removes the:

- cervix
- womb (uterus)
- vagina
- ovaries
- bladder
- lower end of the large bowel (rectum).

#### Anterior exenteration

In this surgery, your doctor removes the:

- cervix, womb, ovaries and all or part of the vagina
- lymph nodes
- bladder.

#### Posterior exenteration

In this operation your surgeon removes the:

- cervix
- womb
- ovaries
- all or part of the vagina
- lymph nodes
- back passage (rectum)
- part of the large bowel (colon).

#### Laterally extended endopelvic resection (LEER)

Laterally extended endopelvic resection (LEER) is a new surgery and is done at very few specialist hospitals in the UK. It is a similar surgery to pelvic exenteration, but it also includes removing the pelvic side walls.

If the position or size of the cancer means you cannot have a pelvic exenteration, you may be able to have a LEER instead. Your doctor will be able to tell you if this is possible.

and if the bladder is left and the bowels and rectum are removed it is called a posterior exenteration.

Our key message is that it is important to discuss the different options with your doctor so you understand if it is suitable for you and what impact pelvic exenteration will have on your life.

#### Effects of treatment

Part of the operation involves creating one or two openings (stomas) on the abdominal wall. These are needed because the operation can involve removing the bladder, or the bowel and rectum, or both. One stoma bag collects your poo and the other collects your wee. These stomas are known as a colostomy (poo) and a urostomy (wee).

In some centres, instead of having a urostomy they may offer you a procedure called a continent urinary diversion. This is where a pouch or reservoir is made instead of an opening attached to a bag. This means you have control of when you empty your new bladder. This procedure is not offered at all cancer centres. If this option is available, your healthcare team will discuss it with you.

Before having a pelvic exenteration, you will see a nurse who specialises in the care of people with stomas (a stoma nurse). The nurse will explain all about stomas and how to look

after them. They can answer any questions you may have and will visit you after the operation to help you.

The operation may also involve making (reconstructing) a new vagina. Your healthcare team will be able to discuss this with you in detail.

### **How will pelvic exenteration surgery affect me?**

Pelvic exenteration is a major operation. Although it is hard to think about, it is important to understand that outcomes are poor<sup>73</sup> and the impact on quality of life can be huge<sup>74</sup>, both physically and psychologically. Our key message is that your healthcare team will play a vital role in helping you decide whether pelvic exenteration is right for you.

If you speak with someone who is thinking about or who has had pelvic exenteration, it is helpful to signpost them to our online forum – [www.jostrust.org.uk/forum](http://www.jostrust.org.uk/forum). They can talk with other women who have gone through pelvic exenteration and get support through their surgery and recovery. We also have a closed forum specifically for women with who are living with advanced cervical cancer.

If someone has been offered or had had pelvic exenteration surgery, please ask them to contact [support@jostrust.org.uk](mailto:support@jostrust.org.uk) We will do our best to connect them with other women who have been through this experience.

### **How does radiotherapy treat cervical cancer?**

Radiotherapy uses high energy x-rays to destroy cervical cancer cells, while doing as little damage as possible to healthy cells.

### **What is the difference between external and internal radiotherapy?**

External beam radiotherapy is a treatment where high energy x-rays are directed from a machine outside of your body at the area of your cancer. You usually have it in a hospital radiotherapy department. External beam radiotherapy is usually given in short doses on a daily basis for some weeks, with breaks at the weekend. The number of treatments you get will depend on the type and size of the cancer, and where it is.

Internal radiotherapy, also called brachytherapy, is often given after a course of external radiotherapy has been given. In brachytherapy, a controlled high dose of radiation is given directly next to the tumour. How it is given depends on whether or not you have had a hysterectomy:

- If a woman has not had a hysterectomy, a thin tube is placed into the vagina and uterus. A radioactive ball (known as a source) is then fed into the tube so that it sits next to the tumour.
- If a woman has had a hysterectomy before beginning radiotherapy, either one or two tubes are put into her vagina. The controlled dose of radiation will be given to the top of the vagina instead.

In both cases, how long you have the treatment for can vary. Your specialist nurse or clinical oncologist will give you more information about your treatment.

---

<sup>73</sup> Katory M. et al, Short- and long-term outcomes following pelvic exenteration for gynaecological and colorectal cancers: A 9 year consecutive single-centre cohort study, *International Journal of Surgery*, 2017.

<sup>74</sup> Kolomainen D. F. and Barton D. P.J., Pelvic exenteration for recurrent gynaecological cancer after radiotherapy, *The Obstetrician & Gynaecologist*, 2017.

### **I have been advised to have pelvic radiotherapy treatment for cervical cancer. Why haven't I been offered a hysterectomy?**

Sometimes radiotherapy can be more effective than surgery. Whether surgery or radiotherapy is offered depends on the size and extent of the cancer.

Remember, your healthcare team will have advised what they believe is best for you based on their knowledge of your situation and cervical cancer. But if you want a second opinion, you can ask for it.

### **Are there side effects after radiotherapy?**

Every treatment has potential side effects or impacts. The technology used for radiotherapy improved, so treatment is more precise and there are less side effects than there used to be.

The most common effects affect the vagina, bowel and bladder, and bones. The walls of the vagina may become more fragile, bringing the blood vessels closer to the surface. This can cause bleeding, the vaginal tissues to become drier and less stretchy, and, sometimes, the walls of the vagina to stick together. The radiotherapy team can give you advice about using vaginal dilators and lube (lubricants) to help prevent or minimise these effects.

You can keep having sex during and after treatment. If sex feels uncomfortable, speak to your specialist nurse or radiographer for advice and support.

Psycho-sexual issues, including how you or a partner feel about your body or sex, may affect arousal and satisfaction with sex. If this is a problem, all women who have had a treatment for a cervical cancer should be able to see a psycho-sexual counsellor to discuss it further. You can arrange an appointment via your GP, your hospital consultant or specialist nurse.

You can signpost to our information on sex and intimacy for more detail about possible changes to sex life: [www.jostrust.org.uk/about-cervical-cancer/moving-forward-from-a-cancer-diagnosis/sex-and-intimacy](http://www.jostrust.org.uk/about-cervical-cancer/moving-forward-from-a-cancer-diagnosis/sex-and-intimacy)

### **My doctor said that I will have radiotherapy and chemotherapy. Does this mean my cancer is very advanced?**

Not necessarily. Chemotherapy and radiotherapy (known as chemoradiation or chemoradiotherapy) are often used for advanced cancer, but increasingly chemoradiation is being used for early cancer too. Sometimes, the chemotherapy appears to sensitise the cells, making the radiotherapy more effective.

Remember, your doctor is the best person to talk to about how advanced the cancer is, as they know your full medical history.

### **Is chemotherapy ever used on its own to treat cervical cancer?**

Yes, it can be used on its own. Sometimes this is because the cancer is advanced or it has come back. Sometimes it is used before another treatment, such as radiotherapy, is started.

Bevacizumab, sometimes called Avastin<sup>®</sup>, is a different kind of drug treatment that is sometimes used to treat women who have recurrent or advanced stage cervical cancer. It does not cure cervical cancer, but may be given to try to extend a person's life. Bevacizumab is given through a drip, like chemotherapy. Usually, it can be given for up to and no more than 10 cycles. Your oncologist will tell you if this treatment is suitable for the stage and type of the cancer.

# Glossary

## A

**Abdomen:** Also called the stomach or tummy. The area between the chest and the pelvis.

**Abnormal cells:** Cells that change in a way that they shouldn't or 'go wrong'. They are sometimes called abnormalities. In our information, we use the term 'cell changes'.

**Abnormalities:** See abnormal cells.

**Acetic Acid:** Acetic acid is used as a wash in colposcopy, to remove mucous from the surface of the cervix. It is also used as a test (3% to 5%) to highlight abnormal areas in the cervix.

**Adenocarcinoma:** A type of cancer that forms in gland cells. In the cervix, these are the cells inside the cervical canal.

**Adenocarcinoma in situ (AIS):** Changes in the gland cells inside the cervical canal. Also known as cervical glandular intraepithelial neoplasia (CGIN). This is not cancer.

**Adenosquamous cancer:** A type of cancer that forms across 2 types of cells, squamous and gland.

**Adhesion:** Fibrous scar tissue that is formed inside the body. Adhesions are usually caused by trauma to tissue. This can happen due to cervical cancer treatment, including surgery and radiotherapy. They are a common cause of pelvic pain. They can attach organs to each other inside the pelvis, or to the pelvic wall.

**Anaesthetic:** Medicine that stops you feeling anything during treatment. Local anaesthetic numbs a specific part of your body. General anaesthetic sends you to sleep.

**Anaemia:** A condition caused by heavy blood loss, excessive red blood cell destruction, or a deficiency in the production of red blood cells. It causes a low red blood cell count, which leads to extreme tiredness.

**Anticonvulsants:** Drugs used to treat epilepsy, which have also been found to have an effect on the body's ability to perceive pain.

**Atypical:** Atypical means abnormal or irregular.

**Autoimmune disorders:** When immune cells attack the body's own cells by mistake. Examples of autoimmune disorders include Type 1 diabetes mellitus, celiac disease and rheumatoid arthritis.

**Avastin:** A cancer treatment drug, also known as bevacizumab. In cervical cancer, it is a life-extending drug.

## B

**Back pain:** Pain felt in the lower or upper back. There are many causes of back pain.

**Benign:** Something which is **not life threatening or cancerous**. A benign tumour does not invade surrounding tissue or spread to other parts of the body. Benign tumours can cause

problems if they are large, or if they obstruct the bowel or other organs. Benign tumours can also be 'pre-malignant', which means they have the potential to turn into malignant tumours.

**Biopsy:** The removal of a sample of tissue for purposes of diagnosis. For further staging and the maturity of cells within your cervix, the cells from the layer beneath the surface of your cervix will need to be analysed; this is achieved by taking a small sample called a biopsy. This biopsy is then sent to a laboratory to be analysed.

**Bone density:** The measurement of how strong (dense) a person's bones are, in their body. If a person's bones become weak, and lose density, this can lead to them becoming brittle and easily broken. This condition is called osteoporosis.

**Borderline screening (smear):** A borderline screening means that there is a slight abnormality of the cells of unknown significance.

**Bowel:** The section of the digestive system that runs from the stomach to the rectum (anus). It is also known as the intestine. The small bowel and the large bowel are the small intestine and large intestine, respectively. The bowel works by digesting and then absorbing the nutrients from the food we eat, then by making poo (also called faeces or stool).

**Bowel resection:** Surgery to remove a blockage from the bowel. The procedure removes the portion of the bowel where the obstruction is located. Complications of a bowel resection include perforation, the formation of adhesions, and the possibility of a colostomy.

## C

**Carbon dioxide:** A gas known as CO<sub>2</sub>, which is produced during the breathing process. During a laparoscopy, CO<sub>2</sub> is pumped into the abdomen, to enlarge it, and move the wall of the abdomen away from the internal organs, to allow the surgeon to get at them.

**Carcinoma:** A type of cancer that starts in cells that make up the skin or the tissue that lines organs.

**Cervical canal:** A narrow passage that goes up from the cervix into the womb. Also called the endocervical canal.

**Cervical cancer:** A cancer that develops in the cervix.

Cervical dysplasia – Another name for cell changes in the cervix.

**Cauterisation:** The removal or destruction of the tissue with a laser or an electrical current. This can help with heavy bleeding and removal of endometriosis deposits.

**Cell changes (abnormal cells):** Changes to the cells of the cervix caused by high-risk HPV. Sometimes called abnormalities.

**Cervical dysplasia:** Cervical dysplasia is the presence of abnormal cells on the surface of the area known as the cervix. It is important to note that dysplasia is not cancer but if it is left untreated may develop at a future time into cervical cancer. Dysplasia can be graded into mild, moderate and severe.

**Cervical erosion (ectropion):** Cervical ectropion is where there are harmless changes in the neck of the womb (cervix). It's the most common cause of bleeding during the later stages of pregnancy.

**Cervical intraepithelial neoplasia (CIN):** A condition where there are cell changes (abnormal cells) affecting the outer surface of the cervix. It is numbered 1, 2 or 3, to show how advanced the cell changes are. CIN is not cancer.

**Cervical glandular intraepithelial neoplasia (CGIN):** A condition where there are cell changes (abnormal cells) inside the cervical canal. CGIN is not cancer.

**Cervical mucus:** A normal fluid or mucus produced by the cervix. Also known as vaginal discharge.

**Cervical screening:** A free test to check your cervix is healthy and that you don't have HPV. Also called a smear test. **Cervix:** The bottom, narrow part of the womb (uterus) that joins to the top of the vagina. The opening of the cervix is called the os. The cervical os allows menstrual blood to flow out from the vagina during menstruation.

**Chemotherapy:** Treatment that destroys cancer cells using anti-cancer drugs.

**Clinical nurse specialist (CNS):** A registered nurse specialising in a particular area, such as gynaecological cancers. They may provide services like psychological support and symptom control.

**Clinical trial:** Compares the effects of one treatment with another or no treatment.

**Clitoris:** The clitoris is a small organ under a fold of skin at the top of the vulva. The external part is about the size of a pea. When stimulated during sexual arousal it will swell with blood and can produce feelings of sexual pleasure.

**Coagulation:** The application of a hot probe to the cervix, which burns away and removes the abnormal cervical cells (see treatment of abnormal cervical cells section on website)

**Colposcope:** A colposcope is a large, electric microscope that magnifies the surface of the cervix 10 to 40 times its normal size. A bright light on the end of the colposcope makes it possible for the colposcopist to examine your cervix and help identify areas on the surface that show abnormalities.

**Colposcopist:** A colposcopist is a nurse or a doctor who has undergone specialist training and assessment for colposcopy examinations and treatments.

**Complementary therapies:** Sometimes used alongside conventional medical treatments to improve quality of life.

**CTCR-CE 01:** Dynamic contrast enhanced MRI in combination with tumour molecular profiling as predictors of radiation response in cervix cancer.

**Cul-de-sac:** The area between the uterus (womb) and the rectum. It is also known as the Pouch of Douglas.

**Cutaneous pain:** Pain that is normally connected to tissue damage – for example, bruises, burns, fractures. It is usually short-term pain in that when the tissue heals, the pain usually stops. An exception to this is arthritis pain. This pain responds well to treatment with painkillers.

**CXII:** Phase II study of weekly neoadjuvant chemotherapy followed by radical chemoradiation for locally advanced cervical cancer.

**Cystoscopy:** A procedure where the bladder is examined using a small telescope inserted through the urethra (tube where urine passes from the bladder to outside the body).

**Cytologist:** Laboratory professionals who study cells.

**Cytology:** The study of individual cells of the body.

## D

**Diagnosis:** The process of naming the condition or illness that someone has.

**Disease:** Illness or sickness that usually has typical symptoms.

**Diathermy:** Diathermy is the use of high frequency electric current to produce heat.

**Dysmenorrhea:** Painful periods.

**Dyspareunia:** Painful sex.

**Dyskaryosis:** Cells that look abnormal. You may get this result after cervical screening (a smear test). It isn't cancer and usually means you need more tests to find out if you need monitoring or treatment. Sometimes called dysplasia.

## E

**Ectocervix:** A layer of skin-like cells on the outer surface of the cervix.

**Ectopic pregnancy:** When a fertilised egg stays in the fallopian tube and starts to develop instead of travelling into the uterus (womb). This can be dangerous and even life-threatening if left untreated.

**Ectropion (cervical erosion):** Cervical ectropion is where there are harmless changes in the neck of the womb (cervix). It's the most common cause of bleeding during the later stages of pregnancy.

**Endocervical canal:** A narrow passage that goes up from the cervix into the womb. Also called the cervical canal. **Endocervix:** Glandular cells lining the inside of the cervix.

**Endometriosis:** A condition where cells like the ones found in the lining of the uterus (womb), grow elsewhere outside the uterus.

**Endoscopy:** A procedure where an optic instrument, such as a laparoscope, is inserted into the body allowing a doctor to visualise the internal organs and cavities of the body.

**Epithelium:** Epithelium is a thin layer of tightly packed cells which line internal cavities, ducts and organs. It also covers exposed bodily surfaces.

**EUA:** Examination under anaesthetic

**Excision:** The removal of tissue during surgery, using a tool such as a laser.

## F

**Fallopian tube:** A tube that lies between the ovary and the uterus and transports the eggs to the uterus. A woman has two fallopian tubes.

**Fatigue:** Extreme tiredness. It can come on quickly, or be a chronic condition.

**Fibroid (leiomyoma):** A benign tumour of the uterus (womb).

**Follicles:** Areas in the ovary, filled with fluid, containing the eggs that are released during ovulation.

## G

**Genitals:** In women, this is the skin around the bottom (anus), the vulva, including the labia and clitoris, the vagina, and the cervix. In men, this is the skin around the bottom, the urethra, scrotum, penis, testicles and prostate.

**Genital warts:** A common sexually transmitted infection caused by HPV.

**Glandular cells:** A type of cell found in the cervix. Involved in the menstrual (period) cycle and producing vaginal discharge.

**Grade or Grading:** The grade of cervical cancer gives an idea of how quickly it might grow. The grade of cell changes (abnormal cells) show how deep into the cervix they go.

**Gynaecology:** A specialised area of cancer care focusing on the diagnosis and treatment of cancers affecting women's reproductive organs.

**Gynaecologist or Gynaecologist:** A surgeon specialising in cancers affecting women's reproductive organs. Your GP may refer you to a gynaecologist to investigate symptoms.

## H

**Histology:** Histology is the study of the structure of tissues under a microscope.

**Hormone:** A chemical substance released inside the body that controls and maintains the activity of cells or organs.

**Hormone replacement therapy (HRT):** A treatment used to relieve symptoms of the menopause by replacing hormones, like oestrogen and progesterone. It may be prescribed after treatment that can trigger the menopause, such as a hysterectomy or chemoradiation.

**Human papillomavirus (HPV):** A very common virus that most people will have and get rid of at some point during their lives, a bit like cold. There are over 200 types, and a few are linked to cancer.

**Hysterectomy:** The removal of the uterus from the body during surgery. Hysterectomy can be done with or without removing the ovaries depending on the advice of your consultant, according to how extensive your cancer is. Hysterectomy is irreversible.

**Hysteroscopy:** A procedure in which the doctor examines the inside of the uterus (womb) under anaesthetic, by inserting an instrument (hysteroscope) into the uterus. Minor surgery, such as the removal of a polyp, can be done at the same time.

## I

**Immune system:** Our body's defence system against infection or illness. It may become weaker because of conditions or diseases that attack it, like HIV, or some treatments, like chemotherapy.

**Incidence:** The number of newly cases of an illness.

**Incision:** A cut made into the body, by a doctor during a surgical procedure.

**Incurable:** A term used for cancer that cannot be cured. People may still be able to live with the cancer for a long time and have treatment for any symptoms.

**In Vitro Fertilisation (IVF):** Literally means "in glass". Fertilisation takes place outside the body in a small glass dish.

**Infertility:** The inability to have children or the inability to carry a pregnancy to a live birth; if a couple has had a year of regular, unprotected sex and the woman doesn't become pregnant, then it is also classed as infertility. Infertility, if not caused by treatment for cervical cancer, should be investigated by a doctor.

**Inflammation:** A way in which the body reacts to infection, irritation or other injuries. Inflammation causes swelling and pain.

**Informed consent:** A contractual agreement between a healthcare professional and a patient, where the patient understands and agrees to any treatment or surgery and the implications and risks involved and what it is trying to achieve. This agreement should be based upon clear and accurate information being provided to them by the healthcare professional.

**Internal exam:** Also known as a vaginal examination. The patient lies on a couch and sometimes the feet are put in stirrups. The doctor or nurse then inserts fingers into the vagina and also presses on the abdomen to feel the pelvic organs. The patient and the doctor/nurse both have the right to a chaperone for this examination.

**Intrauterine:** Inside the uterus (womb), the opposite of extrauterine – outside the uterus.

**Invasive disease:** Sometimes used to describe cancer.

**Iodine solution:** Lugol's iodine, also known as Lugol's solution is named after French physician J.G.A. Lugol and is often used as an antiseptic and disinfectant. It is used in colposcopy usually in combination with acetic acid to facilitate the identification of changes in cells in the cervix.

**IUD (Intrauterine Device):** A device placed into the uterus to prevent pregnancy.

**Irritable Bowel Syndrome (IBS):** A disorder of the bowel causing bloating, cramps, spasm, constipation and diarrhoea.

## L

**Laparoscope:** An instrument, like a small telescope with a light on the end, used to look at the inside of the pelvis, during a laparoscopy.

**Leiomyoma:** The medical term for fibroids

**Lesion:** A small area of abnormal tissue – can be caused by endometriosis, other diseases or injury.

**LLETZ:** Stands for 'large loop excision of the transformation zone'. The most common treatment for cell changes (abnormal cells) that uses a thin wire loop to remove the affected area of the cervix. Sometimes used to treat early stage cervical cancer. Also called a loop electrosurgical procedure (LEEP), a loop diathermy or simply a loop.

**Laparoscopy:** Together with other procedures, laparoscopy is sometimes used when diagnosing cervical cancer. Usually done under general anaesthetic, a small telescope with a light on the end (the laparoscope) is inserted into the pelvis through the navel (belly button). The laparoscope usually has a camera to transmit the images to a video monitor, which the surgeon uses to look inside the body. Carbon dioxide gas is used to extend the abdomen, to give the surgeon room to see the organs. The surgeon can move the laparoscope around the abdomen to see if any organs other than the cervix have been affected. They may make another small cut to insert surgical instruments to treat endometriosis, remove lymph nodes in the abdomen or they may remove a small piece of tissue to be examined at a later stage, this is known as a biopsy. After the procedure, the gas is removed.

**Laparotomy:** Open abdominal surgery. A laparotomy is a major operation, which involves a cut into the abdomen. Laparotomy carries greater risks and has a longer recovery time.

**Lymphoedema:** A long-term condition that causes swelling in the body's tissues. It usually affects the arms or legs.

## M

**Malignant:** Cancers that can grow and spread to other parts of the body.

**Menopause:** When a woman's ovaries stop functioning and her period stops. This can be artificially induced through drugs, hysterectomy or chemotherapy and radiation, or it can happen naturally.

**Menorrhagia:** Heavy periods.

**Menstruation:** The monthly cycle where the body prepares for pregnancy. Every month a woman's body goes through hormonal changes. Hormones are naturally released which cause the lining of the uterus to increase in preparation for a fertilised egg. If pregnancy does not occur, this lining will break down and bleed – this is then released from the body as a period.

**Metastasis or Metastatic:** Cancer that has spread from 1 part of the body to another. This usually happens through the lymphatic system or bloodstream. Also called secondary cancer.**Miscarriage:** Spontaneous loss of a foetus from the uterus.

**Mortality:** Another word for death. It's usually used when talking about the number of people who have died from an illness ('mortality rate').

**Multidisciplinary team (MDT):** Members of different hospital departments who meet to discuss the treatment plan for individual patients.

## N

**Nausea:** Feeling sick or queasy and needing to vomit.

**Navel:** The belly button, otherwise known as the umbilicus.

**Neurectomy:** The removal of a nerve can be done to help relieve pain.

**Neuropathic pain:** Pain caused by damage to the nervous system, which affects its ability to perceive pain. This pain is usually chronic and lasts longer than the time taken for damaged tissue to heal. It can be treated with pain modifiers such as anti-depressants or anti-convulsants.

## O

**Obstetrician:** A gynaecologist who specialises in delivering babies and monitoring pregnancies.

**Obstruction:** When something is blocked (obstructed) e.g. the bowel.

**Oestrogen:** The female sex hormone produced in the ovary. It is produced in response to hormones (FSH and LH) released from the pituitary gland and controls the female sex characteristics, for example, breasts. It is responsible for the growth of eggs and uterus lining.

**Oligomenorrhea:** Irregular periods

**Oncologist:** A doctor who specialises in treating cancer.

**Oncology:** The study of cancer.

**Oophorectomy:** The removal of one or both of the ovaries. When both ovaries are removed, the surgical procedure is called “bilateral oophorectomy”, whereas the removal of one ovary is called “unilateral oophorectomy”. When both ovaries are removed, a woman will experience an instant and irreversible menopause, and will be unable to have children. In this instance, women will need to take some form of hormone replacement therapy (HRT), as the oestrogen produced by the ovaries is responsible for stopping the bones from thinning.

**Os:** The small opening in the cervix. The cervical os allows menstrual blood to flow out from the vagina during menstruation.

**Osteoporosis:** A disease where the bones lose density, become thin and brittle and break easily. Having osteoporosis makes a person more likely to break their bones frequently and they take longer to heal. It can also lead to changes in posture.

**Ovaries:** Ovaries are a pair of organs (each about the size of an almond) in a woman's pelvis. They produce follicles from which eggs develop and when fertilised mean a woman is pregnant.

**Ovarian cyst:** A growth in or on the ovary filled with fluid. Called an endometrioma when caused by endometriosis and filled with dark, old blood.

**Ovarian Hyperstimulation Syndrome:** A side effect of fertility treatments that stimulate the ovaries to produce follicles (eggs). It can be life threatening. It occurs when too many follicles (with eggs) are produced.

**Ovarian failure:** When the ovary no longer response to the hormone FSH and produces follicles (with eggs) – either because it is damaged or hasn't formed properly. This can be spotted by a blood test in which the FSH in the blood is raised.

**Ovarian transposition:** Ovarian transposition is a surgical manoeuvre used to protect ovarian function before delivery of doses of radiotherapy. Laparoscopic techniques can be used to move the ovaries outside of the radiation field.

**Ovulate / ovulation:** When the egg is ripe and is released from the ovary. The follicle surrounding it breaks open and it will travel into the fallopian tube, to wait for fertilisation. If the egg then becomes fertilised it will travel into the uterus and implant.

## P

**Pain:** The body's reaction to damage or injury. It is subjective and everybody has different tolerances of pain. It is a message that travels through the nerves into the brain and is there as a defence mechanism – to alert us to when something has happened to us. It can range from mild discomfort to agony. Pain can be classified as acute or chronic; pain is usually defined as 'chronic' when it lasts 6 months or longer.

Definitions of pain include cutaneous, neuropathic, chronic and visceral (coming from the organs).

**Palliative care:** Care that treats the symptoms of cancer but is not aimed at curing cancer.

**Pathologist:** A doctor who understands and diagnoses the changes caused by illness in the body's cells and tissues.

**Pathology:** The study of disease/illness.

**Pelvic Inflammatory Disease (PID):** A 'catch-all' description for an infection in the pelvic area (around the fallopian tubes, ovaries etc). It can be caused by various bacteria – including developing from the sexually transmitted disease, Chlamydia. It can lead to damage of the pelvic organs, cause ectopic pregnancies, other complications and eventually cause infertility if serious or left untreated.

**Pelvis:** The lower area of the body between the stomach and thighs.

**Peritoneum:** The thin tissue that covers the walls of the pelvis and abdomen on the inside, as well as the pelvic organs.

**Physiotherapist:** A specialist healthcare professional who treats patients with exercises, activities and physical manipulation. Physiotherapists treat muscles and joint problems. They can be seen privately or under the NHS (with a referral from your GP).

**Pituitary gland:** The area of the brain that acts as the 'control centre'. It controls all hormonal functions, including reproductive organs.

**Polycystic Ovarian Syndrome (PCOS):** A condition found in women caused by the excessive production of male sex hormones (androgens). It results in the presence of small cysts in the ovaries. Though PCOS can appear without any symptoms, some of the symptoms are irregular periods, excessive weight gain, acne, and excessive hair growth. It has been linked to problems with insulin and is sometimes treated with insulin medication.

**Polyp:** A polyp is a small growth of tissue (a tumour) inside the body. They can be benign or malignant.

**Pouch of Douglas:** The area between the uterus (womb) and the rectum (bottom). Another name for this is "Rectouterine pouch".

**Pregnancy:** The state of carrying a developing embryo or foetus within the female body. This condition can be indicated by positive results on an over-the-counter urine test, and confirmed through a blood test, ultrasound, detection of foetal heartbeat, or an X-ray. Pregnancy lasts for about nine months, measured from the date of the woman's last menstrual period (LMP). It is conventionally divided into three trimesters, each roughly three months long.

**Premature menopause:** Menopause that occurs naturally before the age of 40. Also known as premature ovarian failure.

**Premature ovarian failure:** A condition where the ovary runs out of follicles before the normal age associated with menopause.

**Presacral neurectomy:** A surgical procedure in which nerves at the back of the uterus are severed in an attempt to eliminate or reduce pain.

**Progesterone:** A female hormone and the principal progestational hormone that is made mainly by the corpus luteum in the ovary and by the placenta. Progesterone prepares the lining (endometrium) of the uterus (the womb) to receive and sustain the fertilized egg and so permits pregnancy.

**Progestogens:** Naturally occurring substances that shrink endometrial tissue; they are used as an endometriosis treatment but can have severe side effects.

**Prognosis:** A prediction of the likely or expected development of an illness.

**Puberty:** The time of life when the body begins making adult levels of sex hormones (oestrogen or testosterone) and the youngster takes on adult body characteristics: developing breasts, growing a beard, pubic hair, and auxiliary hair; attaining sexual maturity.

## R

**Radiographer:** A healthcare professional specialising in the imaging of human anatomy for the diagnosis and treatment of pathology.

**Radiologist:** A doctor specialising in diagnosing and treating illness using medical imaging techniques, such as x-rays.

**Radiotherapy:** Treatment that uses high energy x-rays to destroy cancer cells.

**Rectum:** The last 6 to 8 inches of the large intestine. The rectum stores solid waste until it leaves the body through the anus.

**Recurrence:** When a condition or cancer comes back.

**Remission:** When the signs or symptoms of a cancer are reduced, or the cancer can no longer be detected.

**Reproductive age:** From first period until the onset of menopause; all the years a woman is able to conceive a child.

**Resection:** Surgical excision (removal by cutting) of a portion of an organ or other structure.

**Risk factor:** Anything that increases the likelihood of developing an illness.

## S

**Salpingectomy:** Surgical removal of the fallopian tube.

**Schiller Test:** The Schiller Test is a test in which an iodine solution (either Lugol's or Schiller's) is applied to the cervix. The iodine colours healthy cells brown; abnormal cells can remain unstained, usually appearing white or yellow.

**Secondary cervical cancer:** Cancer that has spread from the cervix to another part of the body.

**Side effects:** Problems that happen when treatment affects healthy tissues in the body.

**Sigmoidoscopy:** Inspection of the sigmoid colon through a telescope inserted through the back passage.

**SLIPER:** Development of an integrated clinical assessment strategy for women receiving pelvic radiotherapy.

**Small cell cervical cancer:** A rare and aggressive type of cervical cancer. Also called small cell neuroendocrine carcinoma.

**Smear test:** Another name for cervical screening.

**Speculum:** A speculum is an instrument used to hold open the vaginal canal in order to view and examine the cervix.

**Surgery:** The word “surgery” has multiple meanings. It is the branch of medicine concerned with diseases and conditions which require or are amenable to operative procedures. Surgery is the work done by a surgeon. A surgery in England (and some other countries) is a physician’s or dentist’s office.

**Symptoms:** Any subjective evidence of disease. Lower back pain and fatigue are all examples of symptoms. They are sensations only the patient can perceive. In contrast, a sign is objective evidence of disease. Bleeding in between periods or after sexual intercourse can be signs. It is evident to the patient, doctor, nurse and other observers.

## T

**Terminal:** Used to describe cancer that has reached a point where it is likely to result in death.

**Testosterone:** The male hormone responsible for the formation of secondary sex characteristics and for supporting the sex drive. Testosterone is also necessary for spermatogenesis.

**Tissue:** Tissue is a broad term that is applied to any group of cells that perform specific functions.

**Transformation zone:** An area of the cervix around the opening (os) that leads to the cervical canal. During cervical screening, samples are usually taken from this area. The transformation zone isn’t always in the same place – in younger women, it is usually on the outer surface of the cervix, and in older women it may be higher up in the cervical canal.

**Transvaginal surgery:** surgery where the incision is inside the vagina; transvaginal surgery may be used for surgery that affects the bladder such as stress incontinence.

**Transvaginal ultrasonography:** Ultrasonography which sends into the pelvic cavity and receives ultrasonic waves through the vagina by using a probe placed inside the vagina.

**Tumour:** A tumour is an abnormal mass of tissue that results from excessive cell division that is uncontrolled and progressive, also called a neoplasm. Tumours perform no useful body function and may either be benign or malignant.

**Ultrasound:** High-frequency sound waves. Ultrasound waves can be bounced off of tissues using special devices. The echoes are then converted into a picture called a sonogram. Ultrasound imaging, referred to as ultrasonography, allows physicians and patients to get an inside view of soft tissues and body cavities, without using invasive techniques.

**Uterosacral ligaments:** Ligaments attaching the lower part of the uterus to the sacral bone.

## V

**Vaccine:** An injection (jab or jag) that aims to protect against illness.

**Vagina:** The muscular canal extending from the cervix to the outside of the body. It is usually six to seven inches in length, and its walls are lined with mucus membrane. It includes two vault-like structures – the anterior (front) vaginal fornix and the posterior (rear) vaginal fornix. The cervix protrudes slightly into the vagina. It is through a tiny hole in the cervix (the os) that sperm makes their way toward the internal reproductive organs. The vagina also includes numerous tiny glands that make the vaginal secretions.

**Vault smear:** A vault smear is similar to a cervical screening test, except that the cell samples are taken from the vagina. It is sometimes called a vaginal smear. Some treatments that remove or damage the cervix, like a hysterectomy or pelvic radiotherapy, may mean a doctor suggests someone has a vault smear after.

**Vulva:** The vulva is the area surrounding the opening of the vagina. It includes the inner and outer vaginal lips (the labia) and the clitoris.

## W

**Womb:** The womb (uterus) is an organ in a woman's lower stomach, between the bladder and rectum. It is hollow and shaped a bit like a pear. The cervix is at the bottom part of the womb – the narrow part. The broader, upper part is called the corpus. The corpus is made up of two layers of tissue.