

# Talking about HPV and cervical screening



Attending cervical screening and getting results can be difficult for some patients. As a result of HPV primary screening, more women and people with a cervix are learning that they have HPV.

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**Language is important** – it can help your patients feel at ease and reassured, or panicked and uncomfortable. There are many medical words used during appointments that can make it hard for patients to understand. It can also be intimidating, and some patients might feel embarrassed about asking questions. Some patients might have low health literacy, or English might not be their first language, meaning it can be even more difficult.

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#### **DO**

**Reassure patients that however they feel about cervical screening and HPV, it is completely normal**

No question is too big or small or strange and they are far from the only person to have asked it. At Jo's, the volume of HPV related calls to our support services has doubled since HPV primary screening has started, with many feeling anxious, confused or worried about what it means to have HPV.

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#### **DO**

**Ask open-ended questions**

Say “do you have any questions or worries?” This can provide opportunities to discuss any concerns and address any adjustments that might be needed.

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#### **DON'T**

**Say a smear test is quick and easy**

Cervical screening is often described as quick or easy when, for many patients, it can be the opposite. This can be for many reasons, including difficulty locating the cervix and needing more time to process the test. If the test is not straightforward but the patient has been told it should be, they may believe something is wrong with them and feel guilty or ashamed. Not understanding that the test isn't always easy can also impact on the patient's ability to make an informed decision.

#### **DON'T**

**Use phrases patients might not understand or that might cause alarm such as “pre-cancerous/abnormal cells/dyskaryosis/CIN/CGIN”**

Try using – “cervical cell changes” There are a few different words or phrases that are used to mean cervical cell changes. Our community told us that this was confusing and, in some cases, they felt negatively labelled because of them – for example, the use of ‘abnormal’. Their preference was that ‘cell changes’ was used as the general term, with more medical terms, such as dyskaryosis, only used along with a clear explanation.

We suggest avoiding ‘pre-cancerous’ completely, as it can inaccurately imply that all cell changes will develop into cancer. It can also sound scary for patients and cause alarm, as the focus lands on the ‘cancer’ element (not the ‘pre’).

“When I first saw on my letter that I had been diagnosed as being HPV positive, I didn't know what it was. When I Googled it, lots of places said it was a sexually transmitted infection, so I automatically thought my partner had been cheating. I knew nothing about it, and it felt dirty. No-one I spoke to had heard of it.”

## **DON'T**

### **Call HPV an STI or sexually transmitted infection**

We know that many people describe HPV as an STI, but it can create unintended stigma, fear and confusion. At Jo's, we don't classify HPV as an STI. With HPV primary screening now introduced across most of the UK, you will probably be asked about HPV frequently and more people will be hearing about it.

While HPV is usually sexually transmitted, it's not fully preventable and not treatable so it's not like any other STI. A diagnosis can bring confusion, fear and shame, and calling it an STI can increase this.

You can simply describe the virus as being 'passed on through skin-to-skin contact in the genital area'.

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## **DO**

### **Consider how to talk about HPV to patients with lower health literacy or those who have English as a second language**

You can explain it as - "a virus that can affect someone's/a woman's intimate area"

This may be the first time a patient has heard of HPV, so it is important to address any confusion or myths the patient might believe. We have written a suggestion for a simple explanation below, but remember you will need to adapt it to your patient.

"HPV is a really common virus. We can pick it up the first time we have any touching in the genital area [gesture to your lower body].

Almost everyone will get this virus at some point in their life. It can live inside or infect the vagina and cervix.

Most people can fight off the virus. But sometimes you might have a tricky strain of the virus that you cannot get rid of. This can cause problems inside the cervix/the vagina."

## **DO**

### **Acknowledge HPV is confusing**

HPV can be difficult to fully explain and understand, and you're not alone if you find it tricky. Check your patient's understanding, and let them know that it's OK to not fully understand everything the first time. Whether it's your patient or a member of staff who wants more information, you can find more support from Jo's, by calling our Helpline on 0808 802 8000.

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## **DO**

### **Avoid automatically saying "husband / boyfriend"**

TRY - "partner"

Sometimes everyone falls into a rhythm with words or phrasing, which can lead to unintentional assumptions, especially if you are seeing a lot patients back-to-back. Remember that every patient is an individual and it's best to use neutral language about partners and, if it comes up, their sex life. If you find out they have a wife, boyfriend, or something else, you can then reflect their language choice.

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## **DO**

### **Signpost to further support**

Jo's Cervical Cancer Trust has a wide range of support services to help your patients through cervical screening, their results and any diagnosis that may follow. This includes our online Forum, where they can speak to others in a similar situation, a Helpline and Ask the Expert service.