

# HPV Stories



## Most of us will have HPV (human papillomavirus) in our lifetime. We're far more likely to get at least one type of HPV than to not.

It usually goes away without affecting the body and we often don't even know that we have it as it causes no symptoms. Cervical screening tests for HPV. This means some women and people with a cervix will be told they have it on their results letter. This experience can be straightforward, but we know that this isn't the case for everyone. The majority of calls to our Helpline include HPV, and we hear daily from people who experience a wide range of emotions, decisions and thought processes after being told they have HPV. For a few it can be truly life changing.

We set out to better understand the breadth of experiences through research, one-on-one interviews and focus groups. What we've discovered is set out in this report, along with recommendations to improve the diagnostic experience and the support offered afterwards. They may be just a handful of stories but they represent the views of countless women and people with a cervix.

**For some, the experience is straightforward...**

*“Once I heard a bit more about HPV, I realised this was really common and wasn't worried about that anymore.”*

*“Almost everyone has HPV so don't worry!”*

Our research found that half of those who are told they have HPV have never heard of it. This can make coping with results from the very first cervical screening extremely difficult.

“

I remember the letter said cell changes can be caused by HPV and long lasting HPV can result in cancer. The word I remember most was 'cancer'. I broke down in the living room in front of my mum.

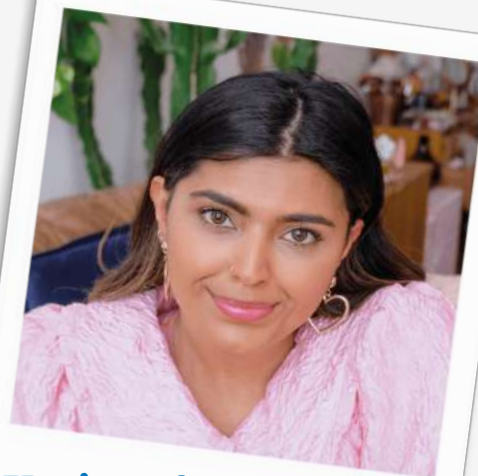
I'd never heard of HPV before that point and started googling it straight away. It said STI and I thought I'd done something wrong. Trying to explain it to people was hard as I didn't really get it and there were lots of questions, I had no idea if I'd had the vaccine or what that would have meant.”



**Antonia, 28**

“

I was really surprised to learn I had HPV. The only knowledge I had of HPV at the time was that I had had all three of my jabs at school, which I thought would completely prevent me from getting it! I was worried what it would mean, as no one had taught me about it at school and my doctor didn't tell me anything about it when I attended my smear test either. I just had to google and figure it out myself. Because I'm so open about HPV, I've taught many of my female friends about it, as they had no idea what it even was and were surprised how little they knew.”



**Kavita, 28**

“

I was very anxious and upset to learn that I was HPV positive and abnormal cells had been found. When I had these results I found little information online.

The HPV worried me. I have been with my partner for 6 years, and I'd had the HPV vaccine at school, over 10 years ago. I believe my school year was one of the first years (if not the first) to receive the HPV vaccine. I think there was a lot of misinformation given to myself and my peers at that age. We were given the impression that the HPV jab prevents you from getting HPV which could potentially lead to cervical cancer and perhaps (naively) many of us believed this to be the case. I now know this to not be the case and a part of me was confused when my letter confirmed I had HPV.

I began researching and found HPV to be very common and nothing to worry about, but I know I am not the only one who was confused. I had various girls my age reach out to me after I shared my story, surrounding my abnormal cells

and HPV. They had the same confused questions like,

"I thought the jab at school prevented us from this?" and "I'm HPV positive too, do you think that may be due to us having the vaccines when we were younger and the HPV still being in our bodies?"



**Hollie, 26**

## We want to see

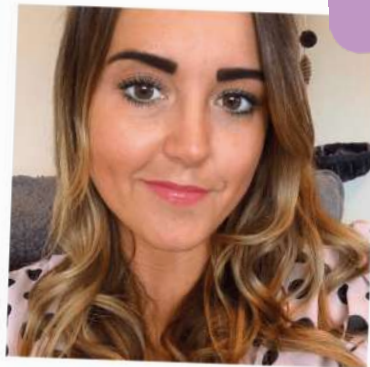
Greater education about HPV from vaccination age with its inclusion in PSHE, and/or science lessons. This will support the provision of informed consent, help tackle stigma from an early age and encourage cross-generational conversation about cervical health.



A HPV diagnosis can lead to all sorts of emotions. Our research showed that over seven in ten felt anxious about it, and almost half felt ashamed. A diagnosis often comes at a time which is already stressful, for example dealing with treatment for cell changes and fears about cancer.

“

It takes a lot for me to cry, but hearing this news made me break down in tears. The diagnosis made me feel vulnerable, and I was frightened as I thought HPV could cause complications like requiring a hysterectomy, or affect my chances of having children. I felt as though the HPV diagnosis meant part of my future had been decided for me and there was nothing I could do about it. I was gripped with fear and uncertainty of what was going on inside my body.. I carried out a Google search for 'What is HPV?' and the result read 'HPV is the most common sexually transmitted infection (STI)'. I was alarmed and confused, as I didn't understand how I could have caught an STI having been with my boyfriend for over four years.”



**Nina, 31**

### We want to see

Appropriate information and increased awareness across the life course about what HPV is, how common it is and what it means to have the virus.

“

I was totally freaked out as I'd been with the same partner for 20+ years – and I didn't really understand what it was, how I got it, or what it meant. I recognised the letters but always associated it with promiscuity and I immediately wanted to point the finger at my partner. We'd been together for 24 years. I remember saying, “but it's an STD!” and feeling dirty.”



**Lisa, 49**

Talking about a diagnosis, especially with partners and loved ones, can be hard and may mean answering tough questions. Almost half of those we surveyed were worried about telling their partner they had HPV. It can also lead to changed feelings about sex and intimacy.



**Lydia, 26**

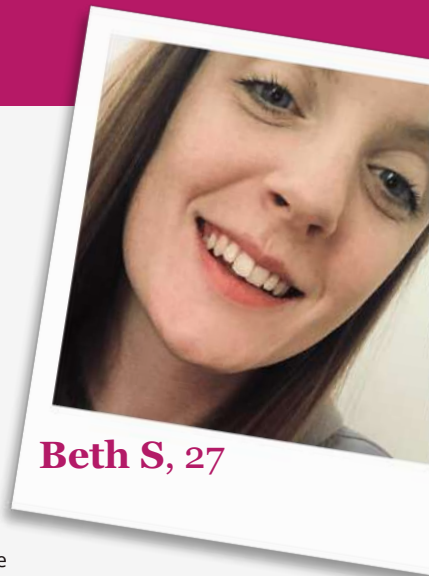
“

Talking to my partner was difficult. There was a lot of stigma and shame in my head and I didn't know how to do it. I was the first of my friends to have a smear test and I felt embarrassed to ask their advice because that meant I'd have to tell them I had HPV. I felt quite isolated and, of the few I did speak to, I got differing opinions on whether or not I needed to tell him and how to do it.”

“

For me, the whole experience was kind of strange because I'm in a same sex relationship. My immediate thought when I got the results was, am I putting someone else in danger? Am I giving this to someone else? That was really scary.

My initial thought was, someone else in this relationship has a cervix - what have I done to it? It did put a different perspective on things for me. I read all the stories about if and how you can pass on HPV to people - and there's great stories about guys and girls - but what if the other person has a cervix too?”



**Beth S, 27**

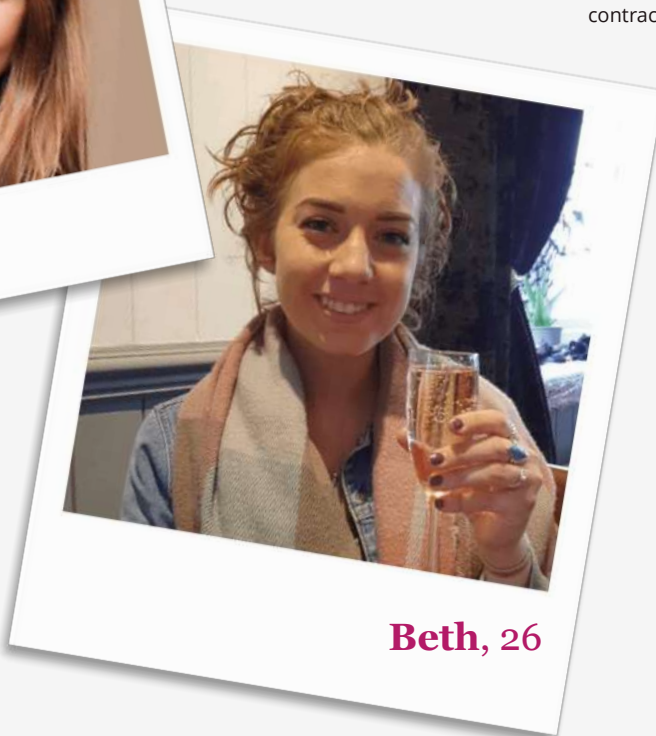
“

My mum and I have a very open and honest relationship, but when it comes to dating and sex, it is a bit trickier. She is a very devout Catholic from the Philippines and religion was a big part of life growing up. This in particular felt difficult to share. But I felt it was a health issue I wanted her to be aware of. Lo and behold, she told me she had HPV years ago too and even had been to colposcopy! I'm 30 and I never knew this about my mum! Talking about sexual issues or sexual health is not usually done in my (Asian, Filipino) family but I'm so happy my mum was open and honest with me about it, and it made me feel like I have someone to talk to about it with.

At first, it felt like a really private thing between me and my doctor but I found that once I started talking about it, people began opening up – it's a matter of starting those conversations. It's not indicative of my behaviour or lifestyle and nothing to be ashamed about. If I could do everything again, I'd speak to my mum straight away.”



**Diana, 30**



**Beth, 26**

“

I was single when I got the diagnosis, and I wondered how I could face dating again. Would I be thought of as promiscuous? Would I be seen as careless, in terms of contraception? Would it put future partners off me?

What I didn't realise was that this way of thinking was internalised slut-shaming. It was difficult to know how and when to have the conversation with a male partner, because there is so little advice out there on how to do it. My first thought was; 'what if I date someone, I pass HPV to them, we then break up and he passes HPV to another woman, and it causes her health issues?'

## We want to see

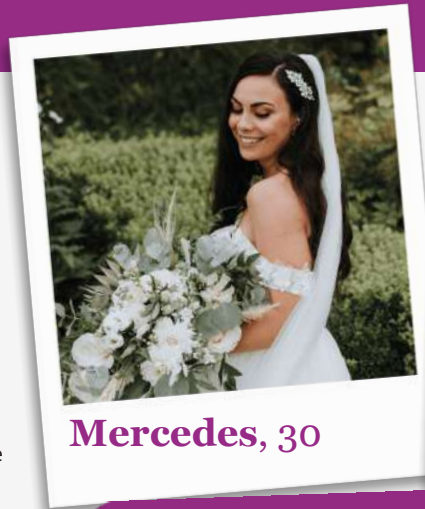
More information and resources for those who are diagnosed on what it means to have HPV, for example on how to communicate with new and current partners.

Health professionals can play an important role in increasing the understanding and supporting patients. Being aware of the different patient experiences is central to this. Over two thirds wanted information about HPV from their healthcare professional.

“

At the colposcopy, my nurse explained a bit more about HPV, and told me for the first time that condoms don't necessarily protect you. She also mentioned that the amount of partners I had or my partner had made it more likely to come into contact with HPV. This made me feel really dirty, like I'd contracted something horrible or that something was wrong with me.

I think that people should bear in mind peoples' feelings when you talk about HPV. It doesn't matter how many people you've been with, you can come into contact with HPV at any point. The number of partners isn't really relevant.



**Mercedes, 30**



**Dinah, 29**

“

Seeing HPV on a letter was scary, it was something I knew little about, so I asked my GP. They said that it was an STI and was contracted by any penetrative activity and that it can sometimes develop into precancerous cells or cancer. That was the extent of the conversation.

I'd only ever had 2 partners in my life, had always been safe and I felt like I now had a sexually transmitted disease and that I was somehow responsible for myself having cancer. It made me feel dirty and was almost worse than the cancer. I didn't know when I had contracted, and didn't know if I was at risk of passing it on or getting it again.

I'd have liked the GP to have been clearer about what HPV actually is. That actually most people will get it at some point in their life and that it will normally clear itself. That I was not responsible for what was now happening to me and that I hadn't done anything wrong.

### We want to see

Greater sharing of, and listening to, the patient experience so that healthcare professionals are equipped to deal with the wide range of questions and concerns their patients may bring.



There is a lot of stigma surrounding HPV and reports of feeling dirty and ashamed are common.

“

There is a stigma with cervical cancer that it is a sexually transmitted disease, or it might even be just because it's 'down there'. People don't always talk about cervical cancer in the same way that you might talk about breast cancer, for example.



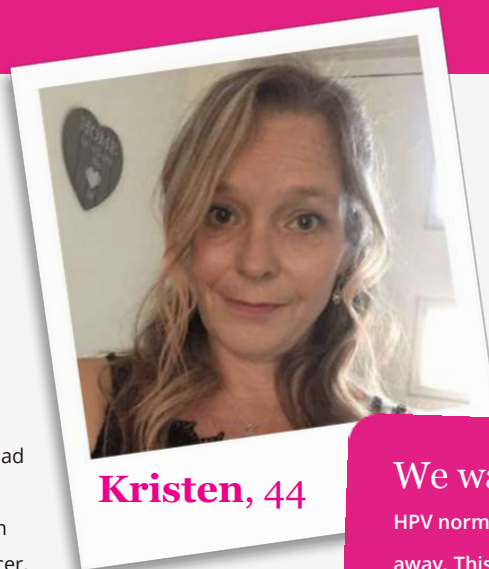
**Cassandra, 41**

My husband booked me a spa day when I went into remission. I explained to the staff that I couldn't have a certain treatment because of my cancer treatment. The woman replied 'oh you poor thing, what kind of cancer?' When I replied 'cervical', she said 'cervical - where did you get that from?' I got straight off the massage table and walked out in tears."

“

When I told my partner of my HPV diagnosis, needing his support and love, I instead heard back: "that's an STD. I've not given you that. Who gave you that?" In the back of my mind I was wondering if he had given it to me too, but the truth is I was going through the toughest time of my life... and yet my partner and I were arguing about whether one of us had cheated. It shouldn't be the case that the first time you hear about what it means to live with HPV is when you're being diagnosed with cancer, and face being blindsided by both of these things.

It would have been that bit easier if I hadn't had to contend with HPV stigma throughout my experience with cancer. It's still hard to talk about. When people ask what cancer I have it can be hard to say. If I had felt able to be open, I might have been able to talk to people who understood what I was going through and share the burden."



**Kristen, 44**

### We want to see

HPV normalised with the STI label taken away. This will remove some of the blame and shame attached to a diagnosis. Stigma can make accessing screening and receiving results far harder. HPV cannot be prevented, treated, or detected in the same way as other STIs and calling it an STI can just increase taboos and fears.

There are many gaps in the research and our understanding about HPV, which makes answering patients' questions hard. Persistency, retransmission and dormancy are just some areas where question marks still remain.

“

I've been married for 40 years and can't bear the thought of passing HPV onto my husband or asking to use a condom at this point. It means that our intimacy has totally stopped, but I just couldn't risk it.

It does make me feel vulnerable, knowing that HPV is staying in my body. What upsets me most is the lack of information. Why can't I fight it? How long have I had it? It does feel like the virus is swept under the carpet. It causes a lot of anxiety which is always in the background and, for me, is never going to go away.

I'm never going to know if I've fought it off, because I'm now too old to be invited back for smear tests. I am considering paying privately to have a HPV test. It would be a lot to do, with the cost and because where I live means travelling miles to a hospital, but for me it would be worth it for my own peace of mind.”

\* name has been changed



“

It feels a bit like a never-ending process as I've now had it for at least four years so the statistic that 9/10 people will fight off the infection within two years doesn't help me. I don't understand why I still have it, or why I'm one of those people who for some reason can't fight it off. It makes me feel like my body is letting me down.

Even though I know it's not my fault, I keep wondering whether there is something I could have done, or not done, in the past to prevent this. I have had the HPV vaccine and have used protection with all my sexual partners too which makes it harder.

I can't help feeling that I will develop cervical cancer or another HPV-related cancer at some point, just because the infection is still there and nobody can tell me when it will go away. In my opinion, there is not enough research into why some of us continue to have HPV.”

### We want to see

Investment in research around HPV to provide reassurance and answers. There are wide knowledge gaps around HPV, including why dormant HPV becomes active again, why some people clear the virus when others do not, whether couples with HPV can re-infect one another, and the merits of therapeutic HPV vaccination for those with reinfection.



If there was one thing  
that I could make sure

# Keep talking about HPV

Stay in touch by signing up to our newsletter

Get support if you have questions or worries

**Share this report**, these stories, and your own experience:



[@JoTrust](https://twitter.com/JoTrust)




[Jo's Cervical Cancer Trust](https://www.facebook.com/JoTrust)



[joscervicalcancertrust](https://www.instagram.com/joscervicalcancertrust)

#### Contact us:

#### Jo's Cervical Cancer Trust

 CAN Mezzanine,  
7-14 Great Dover Street  
London, SE1 4YR

T 020 3096 8100

W [jostrust.org.uk](https://www.jostrust.org.uk)

E [info@jostrust.org.uk](mailto:info@jostrust.org.uk)

Call our Helpline:

**0808 802 8000**

Registered in England and Wales. Company Limited by Guarantee: 7111375.  
Registered Charity No: 1133542 / SC041236.