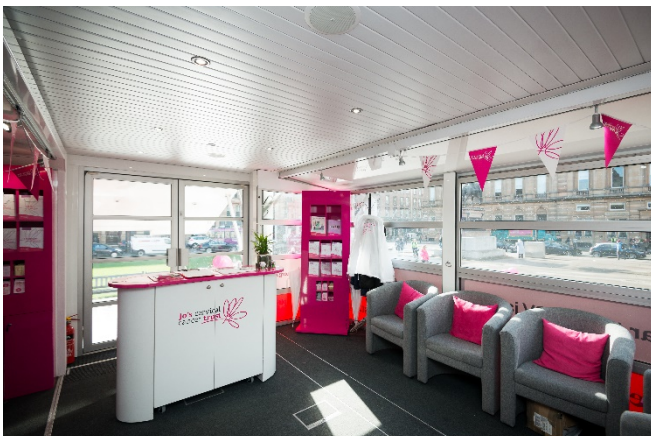


# Be Cervix Savvy Roadshow: End of Show Report



*On the road from March to July 2017*

## 1. The Be Cervix Savvy Roadshow

In the UK, over 3,000 women are diagnosed with cervical cancer each year. The NHS Cervical Screening Programme helps to reduce the risk of cervical cancer and saves 5,000 lives each year. However, attendance of this life-saving test is falling year on year and incidence of cervical cancer is worryingly high, with nine women diagnosed every day in the UK.

Knowledge and awareness of cervical cancer symptoms is poor and our research has shown that women are more likely to visit a GP about a cold than if they had gynaecological symptoms<sup>1</sup>. Our research has also shown that many women do not know how they can reduce their risk of cervical cancer or what cervical screening is.

For 25 to 29 year olds, over a quarter (26.7%) are too embarrassed to attend cervical screening (also known as a smear test) and over two thirds (70%) don't think they reduce a woman's risk of cervical cancer. For women over 50, one in three (32%) do not think cervical screening is a part of the healthy upkeep of a woman's body and almost one in four (22%) do not think they are important to have regularly. A worrying one in three (33%) women have delayed or not attended this potentially life-saving test, with an average delay of 26 months, while one in 10 (10%) women delay for over five years.

In March to July 2017, Jo's Cervical Cancer Trust ran the UK's first ever information roadshow, called 'Be Cervix Savvy'. It aimed to increase awareness by addressing the public's knowledge around the cervix, cervical screening, and cervical cancer. The Be Cervix Savvy Roadshow aimed to reach women in their local area, particularly where cervical screening attendance is low, and boost knowledge to see these numbers reduced.

The Roadshow was primarily funded by Her Majesty's Treasury's Tampon Tax Fund, awarded in 2016. Public Health England (PHE) funded an extra 10 days at the end of the Roadshow, focusing on areas with low screening coverage in the North of England.

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<sup>1</sup> Jo's Cervical Cancer Trust 2012. Cervical cancer symptoms awareness among women – an area in need of more education. Accessed December 2017: <https://www.jostrust.org.uk/about-us/our-research/symptoms-awareness>

## 1.1. Aims of the Be Cervix Savvy Roadshow

The Roadshow aimed to:

- Increase awareness of women's risk of developing cervical cancer.
- Increase awareness of cervical cancer prevention via human papillomavirus (HPV) vaccination and cervical screening attendance.
- Encourage women to be aware of cancer signs and symptoms, and to go to the doctor if they are experiencing any symptoms.
- Engage with women that prefer to get information verbally.
- Ensure that our health information is accessible and communicated accurately and consistently.
- Work in partnership with health providers (local and national), so we could work more effectively in the local community and signpost visitors to appropriate services.
- Save lives!

## 2. Getting on the road

The Roadshow was open to visitors for four days each week – usually Monday, Tuesday, Thursday and Friday, from 10am to 4pm. For the locations commissioned by PHE, only two days were spent at each location, compared to four at other localities.

A Roadshow Ambassador was recruited to help with day-to-day logistics, evaluation, health and safety, and to provide continuity for staff and volunteers during their shifts on the unit. Alongside our Ambassador, we employed a Roadshow Logistics Manager to drive the unit and set it up at new locations. At Jo's Head office, a part-time Roadshow Administrator was employed to help recruit, support and coordinate volunteers and staff. It was also their responsibility to create networks between local screening and immunisation teams and local authorities, as well as promote the Roadshow.

### 2.1. Where did we go?

The Roadshow ran in total for 66 days and travelled to 16 locations. The UK Treasury, through The Tampon Tax Fund, funded 56 days in 11 locations from Glasgow to London. PHE funded the last 10 days in North of England (Middlesbrough, Sunderland, Hull, Bradford and Knowsley). Site locations were selected by:

- reviewing cervical screening coverage figures, so that areas with poor coverage could be targeted
- analysing local data on deprivation figures
- consulting local screening and immunisation teams

- taking advice from our Roadshow supplier, who had previously run similar

<b>Funder</b>	<b>Miles</b>	<b>Week starting</b>	<b>Location</b>	<b>Cervical screening coverage</b>
Tampon Tax	3,085 miles	20 & 27 March	Glasgow	63.5%
		3 April	Newcastle & Gateshead	66.2%
		10 April	Blackburn	62.8%
		18 April	Manchester	62.6%
		24 April	Liverpool	65.0%
		1 May	Leicester	62.7%
		8 May	Birmingham	63.1%
		15 May	Cardiff	69.5%
		22 May	Bristol	76.1%
		29 May	Brighton	67.3%
		5, 12 & 19 June	London	65.7%
PHE	1,121 miles	27 & 28 June	Middlesbrough	70.7%
		29 & 3 June	Sunderland	75.5%
		3 & 4 July	Hull	73.9%
		6 & 7 July	Bradford	66.2%
		10 & 11 July	Knowsley	72.0%
<b>Roadshow</b>	<b>4,206 miles</b>	<b>66 days</b>	<b>16 locations</b>	<b>UK average: 75.5%</b>

awareness campaigns.

## 2.2. Design, branding and key health messages

The Roadshow was branded with the Jo's Cervical Cancer Trust logo and colours.



Figure 1. The Be Cervix Savvy Roadshow unit with branding.

The main considerations for the final design were:

- **Recognition of the aim.** The strapline '*Be cervix savvy. Reduce your risk of cervical cancer.*' helped visitors easily understand the Roadshow's purpose.
- **Engaging with visitors.** It included seating, information displays, access to online surveys and information, areas to talk confidentially and refreshments.
- **Inclusivity.** The external design did not include images of people, to avoid linking only one type of woman with the campaign.
- **Awareness of Jo's Cervical Cancer Trust.** As well as the main branding on the unit, bespoke hoodies for the Roadshow team and swing boards were created to instil the charity and its services into visitors' minds at every point of interaction.
- **Design of a bespoke information resource, our Be Cervix Savvy travel wallets.** The wallet covered key health messages and acted as a hook to help conversations happen.

### 2.3. The Roadshow team

It was vital that the right people were engaging with Roadshow visitors and accurately distributing verbal and written information. As well as recruiting for the role of Roadshow Ambassador, who was present for the entire tour, we needed volunteers at each location to support staff members and encourage their community to get involved.

We recruited through a number of channels, including our website, social media channels, free online recruitment sites and via healthcare professional contacts, to ensure we were reaching a diverse population.

All volunteers and staff planning to help run the Roadshow took part in training. We were able to offer it online and in-person in London and Manchester.

Training focused on:

- Key health messages around cervical cancer and ways to prevent the disease, including cervical screening and the HPV vaccine.
- Basic health promotion techniques, including how to approach members of the public
- Ways to respond to difficult people and questions.
- Keeping yourself and others safe on the Roadshow.

*“A well-structured and thoroughly engaging day. It’s my first time volunteering for anything, and I feel confident and fully prepared for the Roadshow.”  
- One example of a typical response to our volunteer training*

Overall, 100 volunteers were trained, with 12 dropping out before the Roadshow due to personal issues. The final Roadshow team was made up of:

- a Roadshow Ambassador
- a Logistics Manager, who travelled to all locations
- 15 Jo’s Cervical Cancer Trust staff members
- 88 volunteers, who joined according to the locality closest to them.

As public representatives of Jo's, as well as the funding bodies, it was important that our volunteers felt confident in their roles, remained engaged with the cause and were left with the desire and ability to go back to a similar role in possible future Roadshows. Thanks in large part to our funding, we were able to create a dynamic and effective training programme and feedback from our volunteers indicated they found it beneficial.



Figure 2. Some of the Roadshow team in Glasgow.

### 3. Roadshow outputs

Our aim was to reach a minimum of a 100 people a day and over 7,500 people throughout the Roadshow and aimed to distribute 15,000 information materials. Across the Roadshow we connected with many more people than anticipated. More details of these outputs are highlighted below.

In order to provide information to as many people as possible, we produced specifically designed travel wallets. The wallets outlined the Roadshow's key health messages and explained what to expect at cervical screening. Additionally, we gave out a range of our standard publications.

#### 3.1. Conversations

*"I got a letter [inviting me to cervical screening] recently. I'll definitely get booked in now I've seen you."*

*- A Roadshow visitor in Glasgow*

In total, we had 9,063 conversations during the Roadshow. We divided these into:

- 6,681 basic conversations – a simple conversation for less than five minutes, for example around screening invitation ages.
- 2,382 advanced conversations – a more complex conversation for more than five minutes, for example around personal barriers to screening and how to overcome them.

*"You don't know how much better I feel having spoken to you. It's like a weight has lifted. I know that I can take the first step now."*

*- A Roadshow visitor in Sunderland*

If we had an advanced conversation, we gave visitors an opportunity to complete a feedback questionnaire about what they had discussed and what action they would take as a result of meeting us on the Roadshow.

	Conversations total	Active Roadshow days	Average conversations per day	Information materials distributed
<b>Tampon Tax funded</b>	7,589	56	135	17,277
<b>PHE funded</b>	1,474	10	147	2,055
<b>Total</b>	<b>9,063</b>	<b>66</b>	<b>137</b>	<b>19,332</b>

Table 3. Be Cervix Savvy output data

### 3.2. What did people talk about?

Our research has shown that barriers to cervical screening can be split into five main themes:

- **Accessibility** – Choice of test location, finding a suitable appointment, work commitments, and lack of childcare.
- **Psychological** – Previous bad experiences resulting in fear, embarrassment, etc.
- **Literacy** – Language barriers and a low level of health literacy.
- **Physical** – A physical or learning disability, history of female genital mutilation (FGM) or sexual abuse, pregnancy, not being sexually active, and forgetting appointments.
- **Cultural** – Fatalistic and cultural views about cervical cancer risk, sex and the HPV virus, screening not being a priority, and a partner not allowing someone to attend.

#### 3.2.1 Literacy

We had numerous conversations about barriers to screening attendance, with all of the above areas being discussed. The most recorded theme was a lack of understanding of health information (low health literacy). From our conversations, it was apparent that many people did not know:

- what HPV was
- what cervical screening was looking for
- ways to make screening more comfortable
- what the process of cervical screening was.

Low health literacy was particularly concerning where it directly affected a woman's health. For example, some women told us they were not attending screening because they believed it was looking for cervical cancer, while others were not sure whether they had a full or partial hysterectomy so did not know if they needed to attend. Thanks to the Roadshow, we were able to address these myths and concerns in person, as well as signpost to appropriate services and support.



The lack of knowledge in these areas complemented the fact that information on HPV and cervical screening was among the most popular on the Roadshow.

*“There were a lot of women who said, ‘I have no symptoms so why would I go?’ They were incredibly shocked when learning about HPV and that it has no symptoms, and that nurses aren't looking for cervical cancer during screening.”*

*- A volunteer in Blackburn*

### **3.2.2 Other barriers**

Even for those women who understood the importance of cervical screening and wanted to attend, there was a struggle to get an appointment. Reasons ranged from long waiting lists at GPs, to lack of childcare, to local sexual health clinics – which could often give appointments at preferable times – no longer offering cervical screening.

*“One woman said she booked a smear but could not go due to heavy menstrual bleeding, and then was told she couldn't attend again for another three months due to an extremely long waiting list.”*

*- A volunteer in Leicester*

Many women talked to us about the psychological issues that stopped them attending. The most prevalent barrier of this kind was having had a previous bad experience of cervical screening. Anxiety, embarrassment and fear of cancer were also commonly cited reasons for not attending.

*“I was screened very quickly and not given time to be made to feel relaxed.”*

*- A Roadshow visitor in London*

The Roadshow gave us the opportunity to bust a number of myths surrounding cervical screening that created barriers, including no longer being sexually active, not having penetrative sex, and having had the HPV vaccine.

*“One lady, who was 50, hadn't ever had a smear, but thought she wasn't at risk as she hasn't ever had intercourse. However, she has engaged in genital touching. The lady was shocked to hear HPV isn't only passed through coitus and is passed through genital touching too.”*

*- A volunteer in Blackburn*

### 3.3. What information did people request?

In total, 19,332 information materials were distributed. The most popular material was the specifically designed travel wallet (13,050).

Roadshow sections	Information materials distributed
Tampon Tax funded	17,277 (11,773 travel wallets and 5,504 other materials)
Public Health England funded	2,055 (1,277 travel wallets and 778 other materials)
<b>Total</b>	<b>19,333</b> <b>(13,050 travel wallets and 6,283 other materials)</b>

Table 3. Number of information materials distributed during the Roadshow split by funder

The travel wallet contained key health information, including:

- Jo's contact details
- how to find more information and support
- details about what to expect at cervical screening
- why cervical screening is important
- our health messages for Be Cervix Savvy.

We designed it as a prompt to remind people to book their test or look out for signs of cervical cancer. It is a re-useable product that can hold bank or travel cards, meaning these health messages are communicated over a longer period. It also means the wallet has a higher reach, as many more people could see it. The wallet acted as hook to engage people in more in-depth conversations and was well received by members of the public.



Figure 3. The contents of the Be Cervix Savvy travel wallet

*“...they [women] did wish to learn more about screening, but due to language barriers we were only able to provide them with a travel wallet to help them understand what we were wanting to convey.”*

*- A volunteer in Manchester*

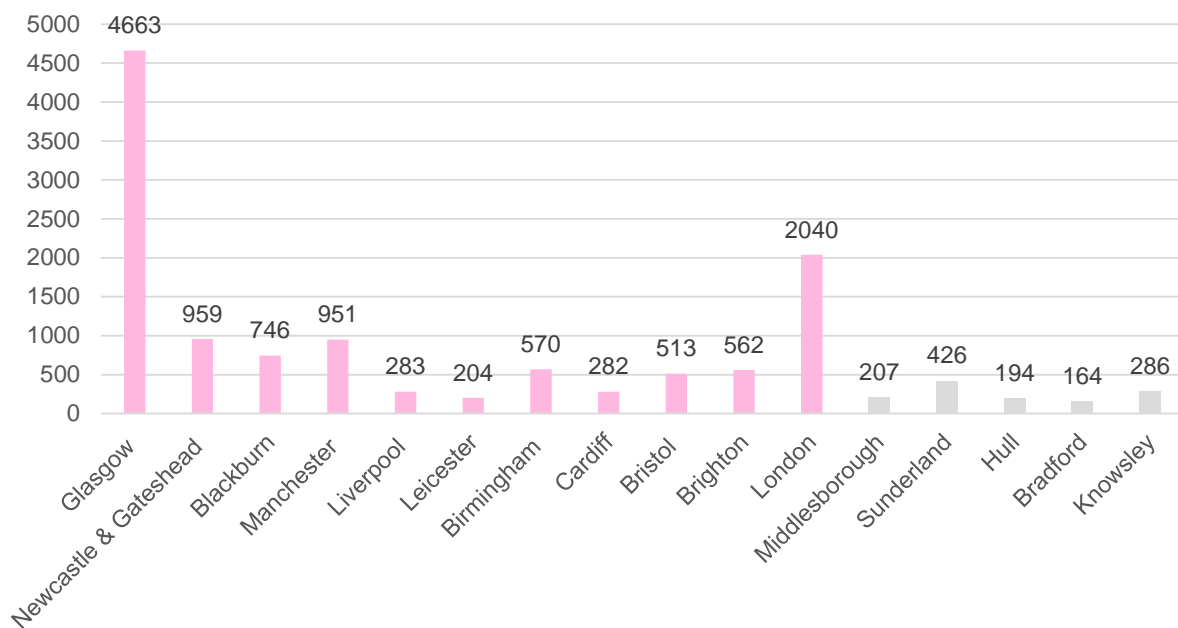


Figure 4. Travel wallets distributed across the Roadshow

Of other materials given out, 41.3% were about cervical screening (2,593), 7% about HPV vaccination and 26% about HPV (1,623).

The popularity of our HPV information is significant, as it does not align with our usual orders. HPV information tends to be among the least popular with healthcare professionals (HCPs), who make up the bulk of our information material orders. Judging by our conversations on the Roadshow, there is a gap in public knowledge around this area that HCPs aren't aware of or properly addressing. As cervical screening moves from cytology to primary HPV testing, educating and reassuring women on this topic will become an even bigger priority, demonstrating a clear need for health information interventions such as the Roadshow.

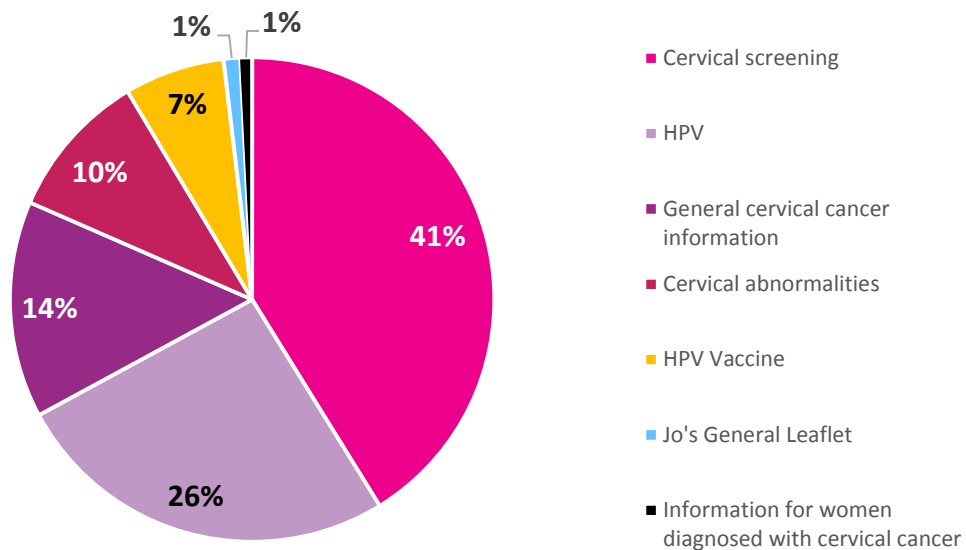


Figure 5. Percentage of total information materials distributed by topic, excluding the travel wallet

### 3.4. Who did we speak to?

If the Roadshow team had advanced conversations, they asked the visitor to complete a two-page feedback form. The aim was to understand the conversations we were having and the public's level of knowledge about cervical cancer. The feedback forms asked eight targeted questions about cervical cancer and ways to prevent it, along with demographic questions.

527 visitors provided feedback, which represents 5.8% of the total people we had conversations with. The majority were women (93%) between the ages of 25 to 49 (52.6%). Just over half (57%) were white, with 36% identifying as BAME. 14% said they had a disability.

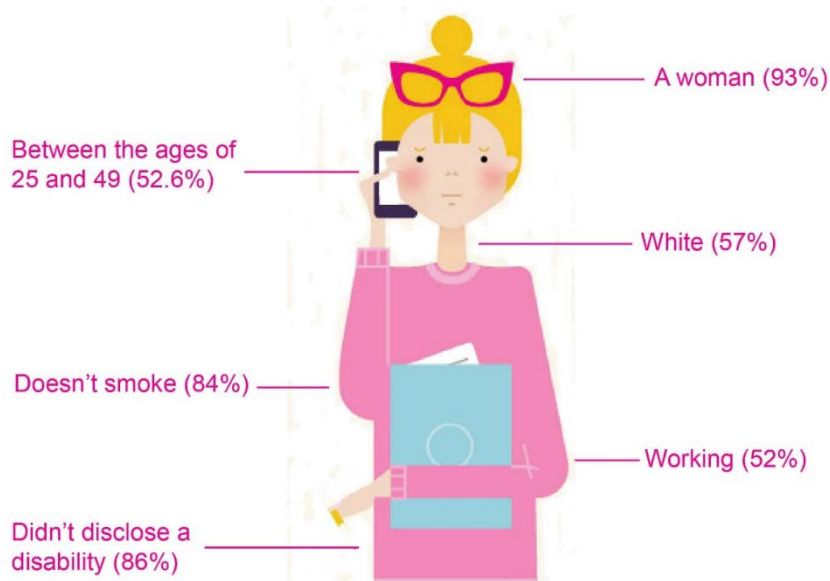


Figure 6. A typical Roadshow visitor

Although this presents a very particular image of someone who might visit the Roadshow, the most insightful conversations and feedback were, unsurprisingly, usually with and from people outside of this main demographic who did not want to complete our feedback form. These were often people traditionally from harder to engage groups, such as BAME communities, or those in higher risk groups, such as smokers.

### 3.4.1. Risk perception and knowledge

A sexually transmitted virus called the human papillomavirus (HPV) causes most cervical cancers. This common virus is passed on through genital skin-to-skin contact. Four out of five (80%) people will get it during their lifetime. Other risk factors, such as not attending cervical screening and smoking, also increase someone's risk of developing cervical cancer. However, when we asked people if they thought they were at risk of cervical cancer, only 28% said yes, 35% were unsure, and 36% said no.

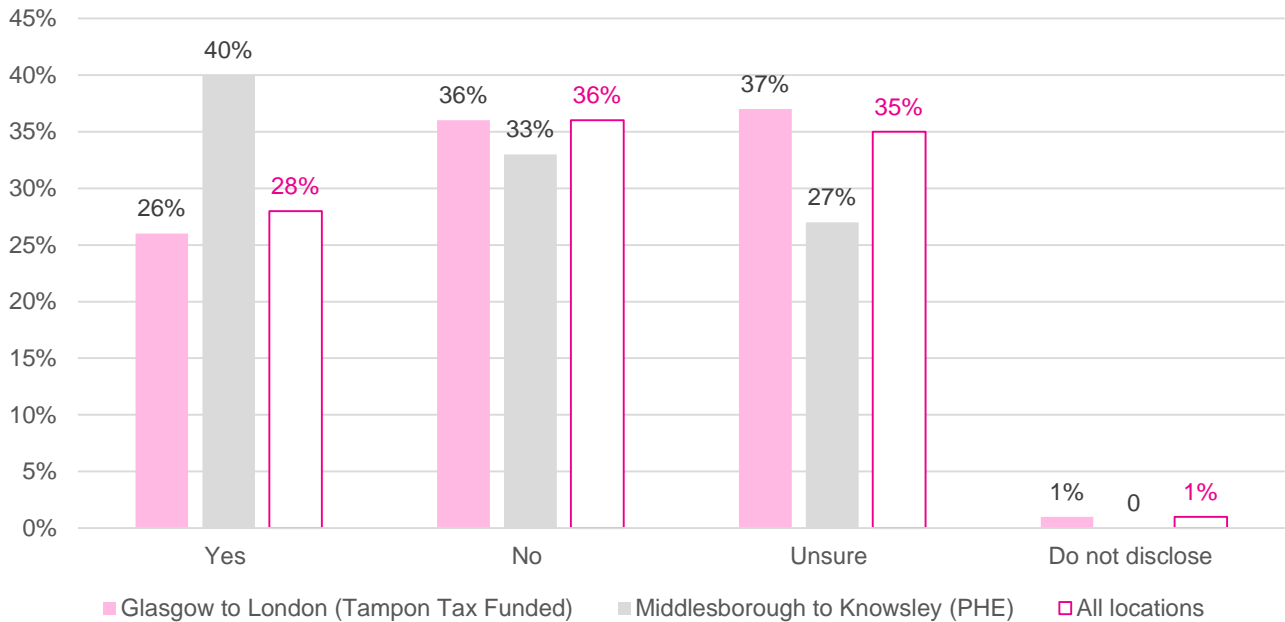


Figure 7. Answers to 'Do you think of yourself as at risk of cervical cancer?'

Significantly, just under half of 25 to 29 year olds (44.3%) and one quarter of smokers (25.6%) did not consider themselves at risk of developing cervical cancer. Added to this, 43% of people didn't know that HPV causes cervical cancer. This points to a severe lack of awareness around cervical cancer and its risk factors that our Roadshow was able to address, to help our visitors make informed choices about their health.

### 3.4.2. What did people intend to do after meeting us?

We asked people that took our survey if they intended to take any action as a result of meeting us on the Roadshow. One third (33.8%) intend to attend a screening appointment, with 17.4% intending to actively contact their GP or sexual health clinic to book an appointment. One quarter (24.7%) intend to encourage others to attend their appointment.

Just under one third (31.2%) would consider seeking advice about a sign or symptom of cervical cancer as a result of talking to our Roadshow team. 12.6% will ask a GP or school nurse about the HPV vaccine. Almost one quarter (23%) will be going to the Jo's website in search of more information or support.

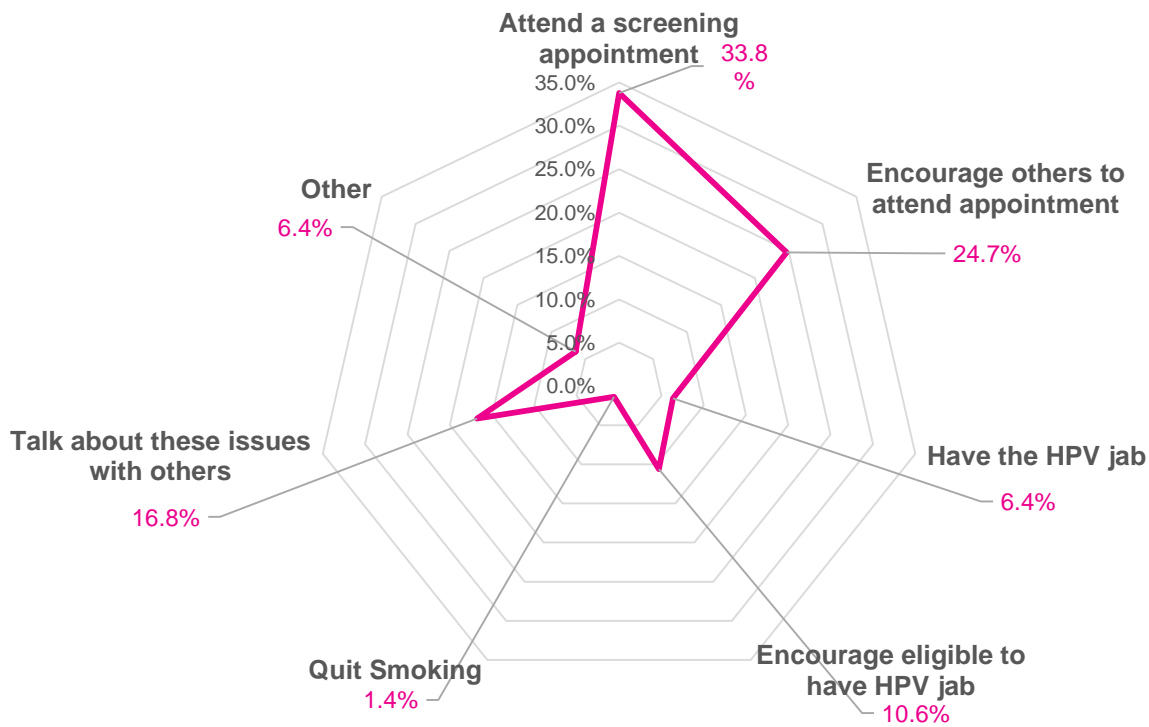


Figure 8. What people intend to do after meeting us at the Roadshow.

## 4. The impact of the Roadshow

While on the road, the branding on the Roadshow unit displayed key health messages, including signposting to Jo's. People had the opportunity to see these messages an estimated 199,785 times (Tampon tax funded – viewed 146,538 times; PHE funded – viewed 53,248 times).

While we can see that the Roadshow has influenced people's awareness of our charity, we hope to eventually see a national impact on cervical screening coverage. To monitor this, we will contact the screening programmes across the UK to ask for more data on coverage. We will collect data across the whole year, rather than focusing only on the months that the Roadshow was running, so we can ensure the health messages have a long-term impact.

### 4.1. Impact on our support services

Compared with March to July 2016, the same period in 2017 saw an increase in use across all Jo's Cervical Cancer Trust services.

#### Information material orders

We produce accredited health information on topics ranging from prevention through to a cancer diagnosis and life after. During the Roadshow, there was a 68% increase in the number of information material orders. Considering the Roadshow's aims around raising awareness and increasing knowledge of prevention, risk and causes, we can see that these conversations and health messages encouraged an increase in orders for those topics:

- HPV – 63%.
- Cervical screening – 50%.
- Cervical abnormalities – 103%.
- Cervical cancer – 70%.

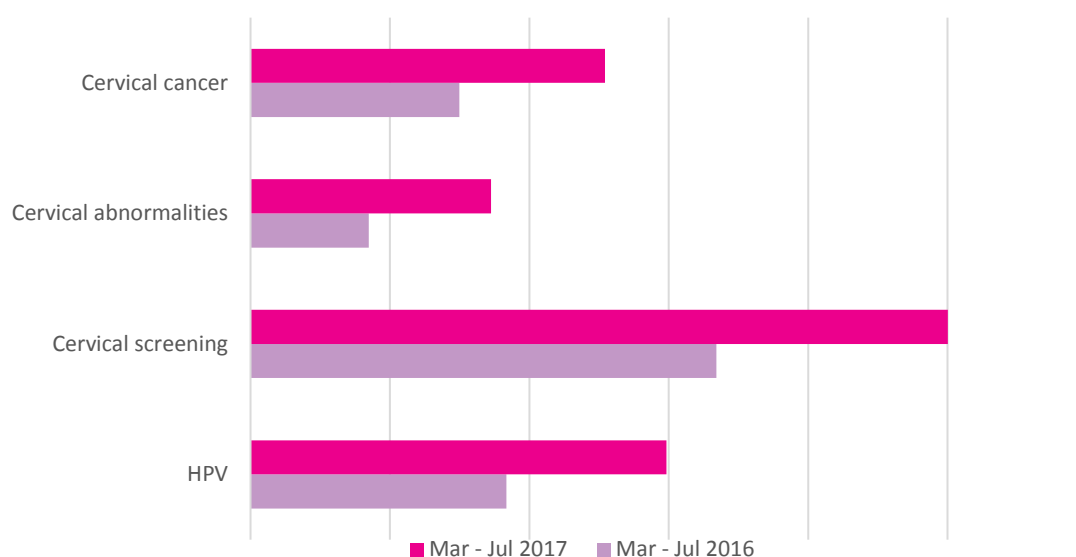


Figure 9. Comparison of information materials ordered between March to July 2016 and March to July 2017 (by topic)



While we can partly attribute this to the build up to our annual Cervical Screening Awareness Week (CSAW) in June, the exposure from the Roadshow no doubt boosted the interest in and desire for these resources to unprecedented levels.

### Helpline

Our Helpline provides a vital service to anyone affected by cervical cancer or abnormalities, as well as people who may be worried or have questions about related issues. With many women reporting that they feel isolated after a diagnosis, we offer a reassuring voice at the end of the phone.



Figure 10. A visitor to the Roadshow calling the Helpline.

During the Roadshow, there was a:

- 51% overall increase of calls.
- 27% increase in callers from a BAME background.
- 59% increase in calls from devolved UK countries.
- 72% increase in people calling about cervical screening.
- 164% increase in people calling about the HPV vaccination.

The increase in calls around cervical screening and the HPV vaccination are significant, as these were the biggest gaps in knowledge we identified during the Roadshow (see [What did people talk about?](#)). It is positive to see the immediate impact of people proactively seeking more information to help them make important health choices.

### Other services

Our Ask the Expert service saw a 19% increase in questions submitted by people from devolved UK countries and our forum had a 31% increase in registrations.

### 4.2. Roadshow website

For 11 of the 16 weeks that the Roadshow ran, the Roadshow location was one of the top three areas visiting the Roadshow website. This is a clear indicator that through campaign branding, as well as publicity around the Roadshow, we were reaching our intended audience – a reach that was crucial if people were unable to physically attend.

### 4.3. Volunteer hours

A full day was six hours. Most volunteers gave one or two days (six or 12 hours), exceeding the initial ask of a four-hour commitment.

In total, volunteers gave 860.5 hours, an average of seven hours per volunteer.

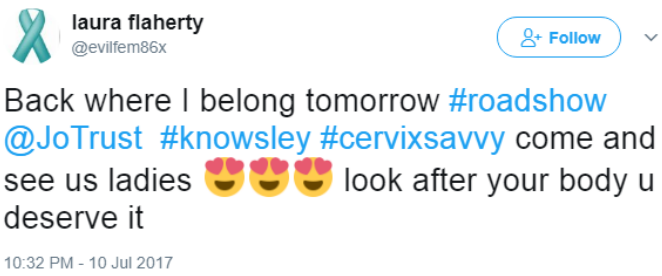


Figure 11. A tweet from Laura, one of our Roadshow volunteers.

### 4.4. Social media, press, engagement and public affairs

Prior to Roadshow visits, we contacted parliamentarians, local healthcare professionals and Clinical Commissioning Groups (CCGs), among others, in the relevant locations. Our political impact was curbed due to the snap election, but we still had 11 politicians visit the Roadshow.

As well as gaining in-person support, we aimed to increase the Roadshow's social media presence. We already have a large audience across our social media channels, meaning our Roadshow posts reached around 300,000 people overall. In total, our hashtag #BeCervixSavvy was used 356 times on Twitter.



Figure 12. A tweet from a supporter using our hashtag.

We also used local case studies across print and broadcast media, with 18 media pieces being picked up across the UK, helping our message reach an audience of around 600,000 people.

## 5. Conclusion

On average, each woman diagnosed with cervical cancer costs the NHS and the state a combined total of around £13,600 a year. That woman will also face a personal cost of around £5,800 over the course of a year, through lost income and additional spending. For some, the costs are considerably higher, often when the cancer is diagnosed at a later stage and the long term consequences of diagnoses can be far reaching, life-long and debilitating. The most effective way of reducing this cost to the NHS, state and individual is by preventing cervical cancer or diagnosing it at an early stage. We can achieve this by educating the public and healthcare professionals about the issue, as the Be Cervix Savvy Roadshow has done.



*Figure 13. A Roadshow volunteer talking with the public in Glasgow.*

The Roadshow was successful in its aim of reaching women across the UK and engaging them about risk factors and prevention of cervical cancer. The Roadshow exceeded targets around people reached and information distribution, resulting in an immediate increase in use of Jo's Cervical Cancer Trust's services.

That impact has the potential to grow even further:

- If each material is passed on to one other person, the overall potential reach of physical information increases to 38,666 people.
- If each person spoken to tells two other people about Jo's Cervical Cancer Trust or the topics discussed, the overall potential reach of verbal information increases to 27,189 people.

- If we combine press circulation reach, opportunities to see the unit, footfall (where provided), and the people we have had conversations with passing on health messages to two other people, the Roadshow’s total reach is **3,165,531 people**.

	Conversations	If each person we spoke to tells two other people	Opportunities to see the unit and key messages while it was on the road	Opportunities to see the Roadshow while in show mode	Press and social media reach
<b>Tampon Tax funded</b>	7,589	<b>22,767</b>	146,537.50	14 locations (representing 41.1% of locations) locations provided daily	<b>Press circulation: 600,000</b>
<b>Public Health England funded</b>	1,474	<b>4,422</b>	53,247.50	footfall = <b>2,038,557</b> 20 unable to give data	<b>Social media reach: 300,000</b>
<b>Total</b>	<b>9,063</b>	<b>27,189</b>	<b>199,785</b>	<b>2,038,557</b>	<b>900,000</b>

Table 4. Roadshow total reach: conversations, word of mouth, number of unit views, footfall, press circulation and social media.

As well as engaging with the public, the Roadshow offered Jo’s Cervical Cancer Trust the opportunity to connect with politicians and other stakeholders. This resulted in greater awareness of the charity and its aims, demonstrated through a commitment by several politicians to attend our Westminster and Holyrood drop-in events. In the long-term, this could help the charity affect policy around cervical cancer and prevention at a national level.

*“Women are literally dying of embarrassment.”  
- A visitor in support of the Roadshow*

Jo’s Cervical Cancer Trust is grateful to have received funding from Her Majesty’s Treasury and Public Health England because it has enabled us to work at a community-level, giving women the ability to make informed choices and spread vital, life-saving health messages to family and friends. As a result of this Roadshow, there could be a significant impact on general awareness, screening coverage, and earlier diagnosis, which could ultimately save lives. We would like to replicate this success, so are applying for further funding to repeat the Roadshow.

## Contact us

To find out more about our work and the findings in this report, contact [info@jostrust.org.uk](mailto:info@jostrust.org.uk) or call **020 3096 8100**. Jo’s Cervical Cancer Trust is based at CAN Mezzanine, 7-14 Great Dover Street, London, SE1 4YE.