Annual review 2016.
4,059 new Forum users,
#SmearForSmear,
£650,000 grant,
£1.07m raised, 1.2m website users, directly supported 7,200 women, 1,479 ‘Ask the Expert’ submissions, 1,107 Helpline calls, 1,921,925 Forum visits, 3,758 EasyRead booklets ordered
"Jo’s has been my sanity and sanctuary. The information provided, combined with your Forum, has been the biggest comfort in the world. I felt too shy to ask my own questions or strike up conversation but found that most of my questions and concerns were asked, and answered, by women far braver than me. I cannot begin to tell you how vital Jo’s has been to me during such a turbulent time."

– Support services user
Introduction

From Robert Music, Chief Executive and Clodagh Ward, Chair

The last year was one of many pluses for the charity. We directly supported over 7,200 people, this is more than at any time during our history and a 13% increase on the year before. Our reputation, campaigning and influencing position have gone from strength to strength and our reach and impact have continued to grow.

All of us at Jo’s passionately believe that cervical cancer can be eradicated and are committed to ensuring that until that day comes, no woman should face a diagnosis without the support they need. During the year we got even closer to our vision and have started work on a new five year strategic plan. We hope this plan will provide a platform and foundation for significant growth across all areas of our work, which in turn will see the charity have a wider and deeper impact than ever before.

This is increasingly urgent as we are seeing continued drops in the numbers of women attending cervical screening and worryingly high incidence of cervical cancer. Through our research we know the barriers to women attending screening are broad and throughout the year we will be focused on gaining an even deeper understanding of the barriers faced by different groups of women, and working to tackle them both at a local and national level. We know that accessibility stops many women from attending and this will be a key policy strand of our work in 2017.

We were delighted to receive a multi-year grant of £650,000 from the Tampon Tax Fund to launch our ‘Eradicate Cervical Cancer’ campaign which will see the charity begin a new large scale project across the UK. Through targeted outreach programmes, we will engage with the hardest to reach communities to support access to cervical screening, increase symptom awareness and offer support to those who need it.

We both want to say thank you for the extraordinary passion and commitment of our staff, volunteers and supporters, without whom we would not have achieved what we have and plan to do in the future.
1.2m website users
12,273 comments on our Forum
£878,319 spent on charitable objectives
£1.07m raised
1,107 Helpline calls
£650,000 awarded from the Tampon Tax Fund
226,388 printed materials distributed
333 Jo’s voices members
Supported over 7,200 women directly
Support at every step

Sadly every year in the UK over 3,000 women are diagnosed with cervical cancer and a further 220,000 are told they have a cervical abnormality which may require treatment. We want to be there for every woman who has questions, feels alone, or needs support and in 2015-16 we were there for more than ever before.

Our Helpline was open for longer enabling us to take 30% more calls than the year before, a total of 1,107 calls. Through our new Callback service we followed up with 198 callers two weeks after their initial call providing extra support at a time when they needed it the most. 91% said the call was helpful, 95% said it gave them confidence in their situation, 90% would recommend the Helpline and 68% sounded less anxious after the call.

We responded to 1,479 Ask the Expert submissions, providing hundreds of women with access to experts across all areas of cervical cancer.

61 support group meetings provided women living with or beyond cervical cancer the opportunity to meet others in their own community and 81% of attendees reported feeling less isolated, 73% said they had made new friends and 86% said the group helped them overcome difficulties resulting from treatment. Our patient information event Let’s Meet provided a further opportunity for women to meet others and attend workshops on topics covering changes to fertility, sex and intimacy and pelvic radiation disease.

We gained 4,059 new users to our Forum, with 12,273 comments and a massive 1,921,925 visits. Our Forum provides an invaluable informative and supportive lifeline to thousands of women allowing instant access to a large and welcoming online community.

We distributed over 226,388 printed materials to organisations including hospitals, GP surgeries and workplaces, an increase of 16% from the previous year. Over 10,000 more materials were downloaded digitally. This has provided thousands of women with information about the support we provide and the information they need to make fully informed decisions about their health.

“Leaving feeling so positive and ready to move on in my own journey and my support of others”

– Let’s Meet attendee
Every woman deserves the best care possible

We want every woman affected by cervical cancer to have the best care, support and treatment possible and our research enables us to better understand and identify areas in which improvements are needed.

Through our report ‘Cervical cancer stories’, we were able to highlight the different experiences of cervical cancer patients from diagnosis through treatment and life after. The report followed in depth interviews with 35 women.

Less than half of the women surveyed felt they received a consistent level of care, with many reporting not being provided much needed support to cope with the side effects of treatment, this includes impact on mental health, intimacy and relationships with children. Clinical Nurse Specialists (CNSs) are invaluable to patients, however almost half wished they had more contact with theirs citing nurses being rushed, overworked or not wanting to ‘bother’ them.

Our report was launched with 20 recommendations calling for:

- The psychological and emotional needs of patients to be addressed throughout treatment and after care, with signposting to appropriate services and organisations
- Patients to be introduced to their CNS as soon as possible ensuring patients understand the support a CNS can offer especially if CNS contact is patient led
- A collaborative project to design a care model to provide all the extra support women with cervical cancer require focussing on the long term consequences of treatment

The report has enabled us to raise our concerns with health care professionals, health policy leads and parliament and will remain a key tool for 2016-17 activity.

“There was no support after you get the all clear. There is no emotional support. I see on the forums a lot that people think they should be happy as they have got rid of cancer but that’s not how it feels.”

– Age 25, Stage 2b2
The long term impact of cervical cancer treatments

The long term physical and psychological impacts of cervical cancer are often underreported and greatly underestimated by the state and healthcare systems. These may include: changes to or loss of fertility; bowel, bladder and vaginal changes; lymphoedema; changes to sexual function and the impact on work life. In 2015 we set out on a research project to fully ascertain the long term impacts on women treated for cervical cancer and identify gaps in the provision of long term care.

More than 800 women were surveyed highlighting extremely differing experiences, needs and gaps in care and support. Many of the women surveyed reported feeling unable to raise or discuss these issues with their healthcare professionals.

“Sometimes it is difficult to know what to do. I have at times dreaded getting out of bed, there seems to be so many things: aches, pains. I can’t keep going to the doctors. I think is the cancer back or is it my age.”

– Survey respondent

“If you don’t want to talk to your partner or family go on to [the] Jo’s website, there are loads of other women in your position. You will instantly feel so much better, as there will be someone who has been through it and done it, or someone who is just at the same stage as you. Even if you don’t want to talk to someone face-to-face, just that online chat or chat over the phone is really important.”

– Emma
The work of Jo’s Cervical Cancer Trust is instrumental to ensuring women affected by cervical cancer have the care and support they need at every stage of their journey and through their research they have highlighted some of the most pressing issues faced by women with cervical cancer in the UK.

The report ‘Cervical cancer stories’ drew attention to the value of the work done by our clinical nurse specialist colleagues in supporting women through this journey and it is essential that all women with cervical cancer have the benefit of this close supportive relationship.”

– Dr Andy Nordin, President of the British Gynaecological Cancer Society

“Katherine

My CNS was able to answer all the questions I had; she was super important to me. She made this whole process so much more manageable, always responding to my needs. She was also the one who first mentioned Jo’s to me and they have been a huge support since.”

– Katherine
Preventing cervical cancer

Cervical cancer is a largely preventable disease with HPV vaccination and cervical screening providing a high degree of protection against it.

We want to ensure that every woman knows the steps she can take to reduce her risk of cervical cancer. This includes being symptom aware and fully understanding the role of cervical screening in preventing the disease.

Currently in the UK more than one in four women don’t attend cervical screening when invited. Reversing this trend is one of our biggest challenges.

**Cervical Cancer Prevention Week**

We saw a 122% increase in material orders making January our busiest month ever. Over 100,000 materials were sent out and displayed in workplaces, waiting rooms, receptions and handed out to members of the public. Through our materials alone, we were able to reach over 155,000 people with potentially lifesaving messages of cervical cancer prevention.

“We walked around Eccles town centre wearing pink and handed out the leaflets, whilst having conversations with 125 women on the importance of taking up their cervical screening.”

“Throughout our trust we organised ‘manned’ information stands...we handed out lots of information re both cervical cancer and cervical screening. We received positive feedback from members of the public. People approached staff and requested smears to be taken on the day. One woman had not had a smear for 20 years!”

“I posted the posters to all the GP practices in the Western Isles so they could display them in waiting rooms. I also plan to send them out to the local halls and meeting places in the Western Isles over the next few months.”
Patients find [the materials] extremely useful and yours is the main website I direct them to for further information and support as it is so user friendly and easy to understand the content.”

– Health care professional
25-29 year olds
Our award winning cervical screening awareness campaign #SmearForSmear reached millions of women in 2016, with the simple message ‘Attend your smear test, reduce your risk of cervical cancer’.

524 pieces of UK media coverage reported on our findings that 3.7 million women across the UK had never attended or were not up to date with their cervical screening.

105 celebrities including supermodel Cara Delevingne joined the campaign posting #SmearForSmear selfies on social media and helping share the campaign message.

The highest number of visitors ever to our website was recorded with a 24% increase on traffic from the year before, our support services saw record numbers of users and most importantly women across the country told us the campaign encouraged them to attend screening.

Women over 50
A survey with social networking site for the over 50s Gransnet, found one in three women do not think screening is part of the healthy upkeep of a woman’s body, almost one in four do not think it is important to have regularly and one in three had delayed or not attended screening. One in ten women admitted delaying for over five years.

During Cervical Screening Awareness Week we set out to change the misconception that it is less important for women over 50 to attend screening and increase awareness of the risks of not attending.

We focused on publications targeting women over 50 and reached almost 72 million people through 73 news articles. As a result, we saw 41,163 visits to our website, a 50% increase on the same week in 2015, enabling thousands of women to access information which may encourage them to attend a test that could save their life. 55 MPs and Assembly Members including Nicky Morgan, Jane Ellison and Paula Sherriff joined us in raising awareness on social media, tabling parliamentary questions and issuing local news stories increasing our voice and the profile of screening.

1 in 3 women do not think screening is part of the healthy upkeep of a woman’s body
3.7 million women across the UK had never attended or were not up to date with cervical screening.

105 celebrities and influencers

200% increase in Ask the Expert submissions

#SmearForSmear®

524 pieces of media coverage

24% increase in web traffic

193% increase in Helpline calls
Hard to reach groups

During 2015-16 our film ‘Your Guide to Cervical Screening (smear test)’ was watched over 16,000 times. Meaning thousands of women were able to better understand the role of cervical screening in preventing cancer and fully understand what will happen during the test, potentially reducing anxiety or concerns. To reach even more women we invested in translating the film into eight different languages: Arabic, Bengali (Standard and Sylheti), Chinese Mandarin, Hindi, Polish, Tamil and Urdu.

Just 20% of women with a learning disability attend cervical screening, so reaching this group of women is another priority area for the charity. During the year we reached 3,841 women with our targeted film ‘The Smear Test Film’ (compared to 2,867 in 2014-15) and sent out 3,758 copies of our EasyRead booklet.

68.2% of those who used the resource to talk about screening with women with a learning disability said it increased understanding and all rated the resource as excellent.

In 2016 we received an award by the Quality in Care Programme, in the ‘Prevention and Early Diagnosis’ category, for our targeted health information resources for women with a learning disability, further evidence of the quality of our materials and their role in increasing knowledge of cervical cancer prevention.

We are regularly invited to deliver training and outreach to women in hard to reach communities providing opportunities to deliver targeted health messages:

“It’s really good and helpful for me because I learnt more. Before I didn’t know that much, now I have attended this session I have an idea of how important it is to check cancer”

“I will] Raise awareness to female friends that may not have had talks”

“I am now confident to talk about the cervical cancer to the community”
Employers making their employees’ health a priority

Our research has shown that over a third of women that work and have missed or delayed screening find it difficult to leave work to attend appointments, with many choosing to take holiday or feeling too embarrassed to talk to their employer. To tackle this we launched Time to Test, a campaign encouraging employers to raise awareness of cervical cancer and ensure female employees can have the time to attend cervical screening if they are unable to get an appointment outside of working hours. Workplaces large and small, spanning all industries, have signed up pledging to raise awareness and as a result hundreds of women will have one less barrier to accessing potentially life saving cervical screening.

We decided to join the Time to Test campaign as we were supporting Jo’s Cervical Cancer Trust through a 24 hour 3 peaks challenge. Valspar are all about people so as a company with a younger workforce, many of whom are female, our employees health is very important to us. We have raised £10,000 towards our challenge, which has been great in bringing our employees together. One of our team has a friend who has also been affected by cervical cancer and she was blown away by the support she received from Jo’s. When we were asked to choose a charity to fundraise for, Jo’s was the obvious choice.”

— Andy, Valspar
Influencing change

We saw a high level of activity in all four UK parliaments and positive meetings with the English and Scottish Health Ministers to discuss our concerns over rising cancer incidence and falling screening attendance.

Our manifestos for the elections in Scotland, Wales and Northern Ireland in May 2016 prioritised activity to increase uptake of cervical screening. Over 50 candidates recognised the importance of our policy asks and pledged their support to raise awareness of this potentially life saving test and increase accessibility for women.

Toolkits sent out ahead of Cervical Cancer Prevention Week resulted in parliamentarians and assembly members across the four nations joining us to raise awareness of prevention, in particular cervical screening. In addition to speaking out on social media and in the press, 26 questions and four Early Day Motions were tabled across the House of Commons, Scottish Parliament, Welsh Assembly and Northern Ireland Assembly. The week was also highlighted in a plenary session of the Welsh Assembly. During Cervical Screening Awareness Week we targeted MPs residing in areas with the lowest cervical screening uptake amongst the over 50s. Our efforts prompted the tabling of 29 questions, and mentions in two plenary sessions of the Welsh Assembly, with inquiries on screening made to both the Welsh First Minister and the Cabinet Secretary for Health, Well-being and Sport. 60 parliamentarians and assembly members also showed their support on social media. These activities, alongside our ongoing parliamentary outreach have significantly helped to increase awareness of the charity, the need for investment in cervical cancer prevention and the experience of cervical cancer patients both during and after treatment.

People reached through bus ad campaign

106,000

We sit on a wide range of committees and work with policy makers across the UK to improve outcomes for cervical cancer patients and improve prevention. Through our partnerships we are able to reach even more women with much needed information and support. One example is a partnership with the Merseyside 2 Year Cancer Plan which resulted in...
activities including a roundtable in Liverpool engaging MPs and health influencers, and an advertising campaign with St Helens council that saw adverts on 133 buses promoting cervical screening during April. The campaign reached an estimated 106,000 people with over 845,000 impacts and saw a 48% increase in visitors to our website from Liverpool.

We were also delighted to be included in the new NHS cervical screening booklets issued along with screening invitations in England and Scotland. This means even more women are aware of how our free support services are there to alleviate concerns and provide support.
Our vision is a future where cervical cancer is a thing of the past

Every year over 3,000 women are given a life changing cervical cancer diagnosis and many, many more are living with the long term physical and emotional side effects of treatment and diagnosis.

The HPV vaccination programme was introduced into schools in 2008 and since then girls have been provided the opportunity to protect themselves from the two high-risk types of HPV that cause at least 70% of all cervical cancers. We know that this will have a huge impact on incidence of cervical cancer and get us closer to our end goal of eradicating mortality and diagnosis from the disease.

Until we get to that day, we need to see increased early diagnosis and greater numbers of women getting the vital support and information they need. There are far too many women facing isolation, uncertainty and suffering in silence during an enormously traumatic experience. We will continue to champion the needs of women affected by cervical cancer and abnormalities to ensure they receive the highest quality treatment and care possible, which in turn will provide huge savings to the individual as well as financial savings to the NHS and state.

To achieve our vision, we need to ensure more women understand how they can protect themselves from cervical cancer.

“Jo’s Cervical Cancer Trust are a key partner for Public Health England. Their insight and expertise, combined with their valuable perspective as the only cervical cancer patient body, is extremely important to us. They are a key player in cervical cancer prevention and are not afraid to speak up or even challenge us to ensure the cervical screening programme, in particular, is fit for purpose. I look forward to continue working with them over the coming years.”

– Dr Anne Mackie, Director of Screening, Public Health England
Eradicate cervical cancer campaign

In March 2016 we were awarded a £650,000 grant from the Tampon Tax Fund enabling us to start a bold, targeted three year campaign focusing on four key underrepresented groups: women from Black, Asian and minority ethnic communities, those from disadvantaged communities, women aged 25-29 and women over 50.

Two Outreach Coordinators, based in London and Manchester where attendance is low, will be working at a local level to engage directly with women and health professionals to deliver education, create opportunities to increase awareness of prevention and recruit volunteers to help deliver key health messages.

We will be launching the first ever cervical cancer prevention roadshow which will see an information unit travelling to 11 UK cities over 14 weeks from Spring 2017 providing support and information to women across the country on all aspects of cervical cancer including how they can look after their own health and reduce their risk of the disease.

The grant has also funded new targeted information for women at the first age of screening and women over 50.

We anticipate this campaign will reach thousands of women over the three year period and provide a model for future projects and programmes.
Investing in our volunteers

We couldn’t do what we do without our incredible volunteers. From answering calls on our Helpline to helping out in the office to joining our cheer squad at fundraising events, their help is instrumental.

The insight provided by our patient group Jo’s Voices is invaluable to ensuring the content we create, campaigns we run and services we offer are as engaging and useful as possible. We were thrilled to welcome 60 new members during the year bringing the total up to over 330.

Our volunteers donate vast amounts of time and energy to support others and the value of our current volunteers is over £100,000, the equivalent of at least three full time staff positions. It is through their dedication and commitment that we have been able to grow our services to the extent that we have throughout the year.

Current volunteer value exceeds £100,000

We would like to take this opportunity to say a huge thank you to each and every one of you!
Our fantastic fundraisers

Our vital work wouldn’t be possible without the generosity of our supporters and for the second year in a row, and the second time in our history, we reached over £1 million in income, raising £1,067,521. The additional £650,000 grant from the Tampon Tax Fund secured during the year will be utilised from 2016-17 over a period of three years.

An amazing 350 individuals put on events and took up challenges in support of Jo’s during the year. This included 10 runners taking on the gruelling London Marathon raising an impressive £48,000, Pelican Feminine Healthcare Limited raised £5,000 through their sale of speculums bringing their total raised for Jo’s over five years to an incredible £53,476.25, two cyclists covering the length of New Zealand and a ladies rugby team choosing us as their Charity of the Year and raising over £2,000. Each and every fundraiser has enabled us to ensure less women face cervical cancer alone and increase the reach of our awareness campaigns.

Through the Women V Cancer cycle series women undertake incredible cycling challenges while raising funds for Jo’s, Breast Cancer Care and Ovarian Cancer Action. Last year the events were more successful than ever and included a cycle event across Tanzania raising £197,000 for each charity and 3,000 women cycling through London through the night. The 100km Ride the Night event became the biggest women’s night time cycle event in the UK raising £783,944.31 net profit which was split between each charity. The funds raised by these incredible women continue to be transformational in terms of what we have been able to achieve.

£28,000 was raised across our annual Step’s for Jo’s events in London, Manchester and Ayrshire. Families, friends and women who have had personal experience of cervical cancer or abnormalities put on their trainers and joined us to take steps towards a future free from cervical cancer.

In 2016 one of our supporters, Ted Tugwell who started The Angela Tugwell Tribute Fund in 2014, became the biggest individual fundraiser in the charity’s history raising over £100,000!
Where we raise and spend our money

Income for 2015-16 was £1,067,221, slightly lower than the 2014-15 (£1,120,165), with expenditure in 2015-16 at £1,059,904 compared to £992,008 in 2014-15, resulting in a surplus of £7,317. Charitable expenditure increased by £44,609 in 2015-16 to £878,319 (£833,710 in 2014-15). This is the highest level of charitable expenditure in the charity’s history, with additional funds primarily spent towards our Information, Education and Prevention programmes.

How we raise our money

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<th>Source</th>
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<tr>
<td>Raising funds</td>
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Total: £1,067,220

How we spend our money

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Total: £1,059,904
Jo’s has been a great source of support to me during what has been a very difficult time. I want every woman affected to know about the incredible support and information they offer.”

– Roz