

“Revealing the true
cost of cervical
cancer...”

BEHIND THE SCREEN

Jo Salter

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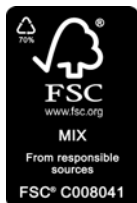
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All errors and omissions remain those of the authors alone.

Jo Salter
June 2014

Foreword

The UK is fortunate to have a cervical screening programme that can significantly reduce incidence of cervical cancer. In 1999, when Jo's Cervical Cancer Trust (the UK's only dedicated cervical cancer charity) was established uptake of the programme in many parts of the UK was at around 83 per cent. Fifteen years on this figure has dropped to an average of 78.5 per cent, which for much of the UK is the lowest during that period. This in itself is a concern but with the latest statistics for cervical cancer incidence showing that in parts of the UK they are at the highest level since 1999 there is a very real worry we will continue to see many more women diagnosed and die from what is a largely preventable disease.

Cervical cancer affects women both young and older. It is the most common cancer in women under 35 years, and its incidence in 60–64-year-olds in parts of the UK is higher than it was 15 years ago. From previous research commissioned by the charity we know that there is a range of barriers to uptake of cervical screening. Until these barriers are addressed we are concerned that screening rates will continue to fall and incidence will rise further. To tackle this we feel there is a need for greater resourcing given to cervical cancer prevention campaigns at both local and national level.

The results in this Demos report clearly highlight the urgent need to find ways to encourage more women to attend screening. If we make the necessary small investment now we could not only save millions of pounds for the state in both the short and long term but also save many more women from losing their fertility, bladder and bowel function, prevent the onset of early menopause, stop the significant reduction in their quality of life, and ultimately save lives.

Foreword

We sincerely hope all policy and health influencers start to make cervical cancer prevention a greater priority. If the recommendations in this report can be taken forward, we may start to see a future where cervical cancer becomes a disease of the past.

Robert Music
Chief Executive, Jo's Cervical Cancer Trust

Executive summary

This report follows on from Demos' previous work exploring the financial impact of a cancer diagnosis, and what steps can be taken to reduce the financial burden to individuals and their families.¹ In this new report, we explore in detail the financial impact of cervical cancer, looking at its impact not just on individuals but also on the NHS and state more widely. Around 3,000 women are diagnosed with cervical cancer every year, and in women under 35, it is the most common form of cancer in the UK. It is also unique among cancers in that it is largely preventable. In the UK, preventing cervical cancer is the function of the NHS Cervical Cancer Screening Programmes in each of the devolved regions.

But screening does not have the take-up that it should – and in the past ten years there has been a long, slow decline in screening coverage (the number of women being regularly screened). In England, after peaking at around 82 per cent in the late 1990s, rates are now hovering just above 78 per cent. Between 2012 and 2013, coverage fell from 78.6 per cent to 78.3 per cent.² In Scotland, Wales and Northern Ireland, uptake is very similar.

This has serious implications for cervical cancer diagnosis rates and mortality, and subsequently also financial implications for the state, the NHS and individual women and their families. In this report, Demos has looked at how raising screening coverage from its current level to 80 per cent, 85 per cent or even 100 per cent would affect cancer incidence and costs, as well as what would happen if screening coverage continued to decline to 70 per cent of all eligible women.

How to reverse this worrying fall in screening rates across all age groups, but particularly among the age groups receiving their first screening invitation (25–29) and older women, where

screening frequency changes to every five years (50–64), remains a huge challenge for the screening programmes. The reasons behind the steady decrease in the number of women attending for regular screening since the late 1990s remain contentious, with the current government facing criticism that restrictive GP opening hours are to blame by preventing women from making convenient appointment times.³ The Government is now planning to pilot seven-day working in 1,000 GP practices, but the British Medical Association last month warned that GP surgeries are already operating at full capacity, with demand rising and no additional funding to help cope with it. Without ‘sustained investment’, GP practices will simply not be in a position to expand their working hours.⁴

As we argue in this report, falling screening rates are likely to be due to a combination of reasons – a mix of inconvenience, embarrassment, poor awareness of what screening is for and misunderstanding the risks of developing cervical cancer. Demographic changes over the past 15 or so years may also be playing a part in the falling numbers – particularly an ageing population, with many more women over 50, and larger numbers of immigrant women, both of which pose a particular challenge in screening uptake. All of these reasons will need to be tackled if this alarming trend is to be reversed. In the concluding chapter of this report we provide some suggestions on how this might be achieved, bringing together the insights we have drawn from a series of expert interviews and a comprehensive literature review of international approaches to this issue. Before presenting these conclusions and recommendations, we provide a comprehensive analysis of the costs of a cervical cancer diagnosis to individuals and their families, the NHS and state more widely, before calculating how these costs would fall if screening were improved.

We found that the NHS currently spends around £21 million a year treating cervical cancer, while the state loses £9 million in tax revenue from women and their partners who stop work as a result of cervical cancer, and women who die from cervical cancer. Women diagnosed with cervical cancer faced a combined financial loss of £14 million a year – £5,844, on average, for each woman diagnosed (table 1).

Table 1 **The costs per year to the NHS, state and women of treating cervical cancer in England**

	Cost per person	Total cost
NHS	£9,233	£21,126,025
State	£4,365	£9,372,848
Individual women	£5,844	£14,198,904

Our research also shows that much of this expense comes from more advanced cervical cancer – as this tends to be more expensive to treat, causes more disruption to women’s working lives (and subsequently more loss of income), and results in more additional spending by women and their families. In the process of testing for and treating pre-cancerous cervical cell changes, regular cervical screening also makes it more likely that any cervical cancers that are present will be picked up at a comparatively early stage. Therefore increasing cervical screening has the overall effect of cutting the number of costly, late-stage cancers diagnosed, and therefore brings down costs to the NHS, state and women themselves.

Our modelling suggests that this is the case – as table 2 shows, raising screening rates leads to an overall reduction in cost to all three parties.

Table 2 shows that with 100 per cent coverage of screening, costs to the NHS would almost halve, costs to the state would fall by a third, and total costs to women diagnosed with cervical cancer would fall by around 40 per cent.

Conversely, if screening rates were to fall to 70 per cent nationally, annual costs to the NHS would increase by £6.5 million – to £27,585,702 per year. Costs to the state would increase by £800,000 to £10,181,045 a year. And women themselves would face huge combined additional costs of £1.4 million – costing them £15,569,784 each year altogether.

The clearest route to achieving these savings is by boosting uptake of cervical screening. We therefore conclude by offering a set of recommendations for a renewed and concerted effort to

Table 2 **The relationship between the screening rate for cervical cancer in England and the annual costs to the NHS, state and individuals**

Screening rate	Direct cost to the NHS	Cost to state	Cost to individuals
78.3% (current)	£21,126,025	£9,372,848	£14,198,904
80%	£19,676,164	£8,856,686	£13,225,896
85%	£17,661,640	£8,071,090	£11,946,600
100%	£12,111,586	£6,137,306	£8,634,672
70%	£27,585,702	£10,181,045	£15,569,784

increase the number of women regularly attending screening by removing some of the practical, psychological and emotional barriers to screening.

We recommend changes to GP surgeries' working practices, enabling them to play a more proactive role in boosting screening, by offering 'on the spot' testing capabilities, out-of-hours drop-in sessions specifically for screening, and giving every woman the choice of a female clinician to carry out the procedure. These changes have potential cost implications for GP surgeries, many of which are already operating at bursting point. We suggest offsetting these costs by offering GPs financial incentives for increasing their local screening rates.

The message to women about the importance of regular cervical screening needs to present the risks of cervical cancer clearly (as there is perceived to be a strong tendency, particularly among younger women, to underestimate the health risks of neglecting screening), and aim to normalise screening as healthy, preventive behaviour. This will be better achieved if the message comes from a credible source, which is why we recommend a 'mums and daughters' campaign, where young women reaching screening age and their mothers (generally in their 50s and 60s) remind and encourage each other to attend screening. We also recommend that 'cervical cancer ambassadors' – young, female celebrities with wide appeal – should help raise awareness, and

dispel some of the embarrassment associated with cervical screening. It is vitally important that Public Health England includes cervical cancer in any subsequent Be Clear on Cancer campaigns, so that women are alert to the signs and symptoms of cervical cancer.

Finally, the nature of the test itself (which requires a doctor or nurse to take a swab directly from the surface of the cervix) will always remain problematic in the minds of most women, and can be painful in older, postmenopausal women. Other countries have invested in piloting alternative screening methods, including self-testing, and urine testing. We recommend that the UK follows their lead, and looks into whether these methods could potentially be used in future for mass screening, beginning with higher-risk groups, who have defaulted from the screening programme.

These measures, taken together, tackle head-on some of the obstacles that keep women from attending screening regularly. By making screening more convenient and flexible, more appealing to women, and presenting it as a routine, healthy, normal behaviour, we hope that these suggestions will pave the way to more women opting in to the screening programme, more cancers being averted, and more lives saved.

Introduction

What is cervical cancer?

Cervical cancer is the most common form of cancer among women under 35 in the UK, and the twelfth most common cancer among women in the UK as a whole. Every year, there are around 3,000 new cases of cervical cancer diagnosed in the UK, and around 970 women die of the disease.⁵

Cervical cancer affects the neck of the womb – and is especially common in younger women of reproductive age (there is a spike in incidence between the ages of 30 and 34⁶). It is caused in virtually all (99.7 per cent) cases by infection with the human papillomavirus (HPV) – a sexually transmitted infection that causes mutations in the cells of the cervix, which can lead to cancer. Women with the disease often display no symptoms until the cancer reaches a comparatively advanced stage, at which point more intensive treatment may be required and survival rates are significantly reduced.

And yet cervical cancer is one of the only cancers that can be prevented – as it can be detected and treated in the pre-cancerous stage. The presence of either cervical cell abnormalities, or the presence of HPV, can act as a precursor for cervical cancer, and tests for either can allow a woman to be treated before cancer has a chance to develop. If cervical cancer does develop, as long as it is caught and treated at an early enough stage, treatment is relatively straightforward, and survival rates are good. Cervical cancers diagnosed at stage 1a – the earliest possible stage (see chapter 1 for an explanation of cervical cancer staging) – have a cure rate of between 95 per cent and 99 per cent. However, once the cancer spreads, the prognosis quickly deteriorates. Only 20 per cent of women diagnosed with a stage 4 cancer survive for more than five years.⁷

Cervical cancer is therefore a prime candidate for early intervention – and one does exist, in the form of the NHS Cervical Screening Programme, introduced in 1988. The Programme invites all women between the ages of 25 and 64 for regular screening tests, which look for pre-cancerous abnormalities in the cervix. If these are found, they are removed, and a case of cervical cancer could have been prevented. In the 20 years following its introduction, cervical cancer incidence fell by over a third – from 15.0 to 9.8 cases per 100,000 women.⁸

Yet cervical screening suffers from similar problems to other early intervention measures in public health: it requires pro-activity on behalf of the public to avoid an intangible, future ill, but may involve inconvenience, discomfort and embarrassment for those being screened in the short term. Healthcare providers therefore need to work doubly hard to ensure that people take advantage of preventive measures on offer.

Coverage of cervical screening – the number of women regularly attending a screening appointment – peaked at around 82 per cent in the late 1990s, and is now on the wane. The proportion of eligible women screened at least once in the past five years fell from 78.6 per cent in 2010/11 to 78.3 per cent in 2011/12.

This is a worrying trend: fewer women being screened means that more cancers that could be prevented will not be, and so the number of women being diagnosed with cervical cancer will rise. This is already beginning to happen – except for 2009 (when many more women were diagnosed in the wake of Jade Goody's death from cervical cancer), incidence in 2011 (3,067 cases) was the highest it has been in the UK since 1999 (when 3,276 women were diagnosed). As cervical cancer is often symptomless in its early stages, it is also likely that many more cancers will go unnoticed until they reach a more advanced stage, where survival rates are lower.

Despite the overwhelming evidence of the benefits of cervical screening, it appears that women are still discouraged by the inconvenience and embarrassment of the screening test – a survey by Jo's Cervical Cancer Trust found a quarter of women put off screening because of embarrassment, while 35 per cent

agreed they would attend if GP appointments could be more flexible⁹. Ethnic minority women, women from more disadvantaged communities and older women all have persistently lower rates of cervical screening than average. It is clear, then, that to reverse this downward trend in screening rates, awareness of the importance of screening needs to be raised and steps need to be taken to make it easier, more convenient and less awkward for women to undergo a smear test. This, invariably, will cost money. In this report, we tackle this issue head-on by demonstrating the financial implications of cervical cancer and show, clearly, how increased investment not just saves lives, but makes sound financial sense.

In our report *Paying the Price* Demos highlighted the under-recognised financial side-effects of cancer – income lost during time off work or having to stop work altogether, and extra costs accrued in the course of treatment and recovery, which can include higher bills, additional travel costs, replacement clothing and medical costs.¹⁰ We argued that cancer is viewed primarily as a healthcare issue, but following fantastic improvements in diagnosis, treatment and survival rates, wider socio-economic issues are also becoming apparent. People who have survived cancer are increasingly returning to work, having families and carrying on with their lives, but they also have to recover from the drastic financial loss experienced during illness and treatment (estimated by Macmillan Cancer Support to be on average £570 a month) as well as make a physical recovery. Banks, insurers, employers and people surviving cancer themselves all need to adapt to the new reality of cancer survival.

This is especially true for those who have had cervical cancer, given the preventable nature of the illness, and the high survival rates for early stage cancers. Early stage cancers and pre-cancers can be treated quite quickly and easily with surgery (chemotherapy and radiotherapy, and more debilitating surgeries tend only to be used for more advanced cancers), so a woman can be back on her feet reasonably quickly and financial effects will be minimal.

Preventing cervical cancer, or diagnosing and treating it at an earlier stage, therefore, is likely to be cheaper for the woman

involved, allowing her to get on with her life much more easily post-recovery. It also delivers cost savings to the NHS, through less costly treatment, and to society in general, through keeping more women healthy and either in work or caring for their families.

In this report, we are aiming to demonstrate:

- the cost savings that the NHS can achieve by increasing screening rates to 80 per cent, 85 per cent or even 100 per cent of all eligible women; these savings are likely to more than offset the extra spend required to boost uptake
- to women themselves how some of the costs associated with cervical cancer can be minimised or avoided altogether by ensuring that cervical cancer is either prevented entirely or picked up at the earliest possible stage through regular screening.

Methodology

A more detailed methodology can be found in the methodological appendix to this report (page 97).

Demos carried out semi-structured interviews with ten specialists working in the fields of cervical cancer screening and treatment, which explored their perceptions of the links between changes in cervical cancer screening rates, stage of diagnosis, and the costs of illness to the NHS and the individual. We then looked at the costs of cervical cancer in three broad categories: costs to the NHS (chapter 2), costs to the state (chapter 2) and costs to the individual (chapter 3).

To model the costs to individuals and the state (through loss of tax revenue when people stop work), we surveyed 182 clients of Jo's Cervical Cancer Trust, all of whom had previously been (or were currently being) treated for cervical cancer. The survey asked women who had been diagnosed at different stages and ages what extra costs and loss of income they had experienced post-diagnosis.

The team at the Centre for Cancer Prevention, Wolfson Institute of Preventive Medicine, Queen Mary University of London provided data on cervical cancer incidence and mortality

in England, and a breakdown of the treatment given to women according to their age and stage of diagnosis. More limited data (without the treatment information) were provided for Scotland, Wales and Northern Ireland. Using these data, we modelled what would happen to cervical cancer incidence and mortality in the three countries if cervical screening coverage was increased to 80 per cent, 85 per cent and 100 per cent nationally. We also modelled the implications of screening coverage falling to 70 per cent.

For England, we were also able to attribute costs to the treatments received by women at different stages and ages, using unit costs from *NHS Reference Costs 2012–13*.¹¹ This allowed us to compare the overall cost to the NHS of treating cervical cancer currently, and in each of the four screening scenarios.

To calculate the costs to the state, we looked at the loss of tax income to the state when somebody stops work altogether, or reduces their working hours – both of which were reported by women in our survey. We based our calculations on somebody earning the median salary, and where women switched from full-time to part-time work when they reduced their working hours.

Finally, we interviewed three women who had been treated for cervical cancer; their stories about how cervical cancer affected them financially appear throughout this report, to illustrate the costs associated with different cancer experiences.

1 The cervical screening landscape

Cervical cancer is one of the very few cancers that is almost wholly preventable, as it can be picked up at the pre-cancerous stage and treated before the cancer has a chance to develop. Since 1988, the NHS Cervical Screening Programme has existed to screen women for pre-cancerous changes to the cervix, and refer them to appropriate treatment. Women are invited to be screened at regular intervals between the ages of 25 and 64 (in all of the UK except Scotland, which will switch to the same system in 2015). The introduction of the Cervical Screening Programme has had a profound impact on the number of cervical cancers diagnosed and the number of women dying of cervical cancer. Between 1989 and 2009, incidence rates fell by a third, while mortality fell by 60 per cent.¹²

And yet screening remains optional – women are invited to be screened, rather than required to. Many women ignore their invitations, or delay making an appointment. Surveys by Jo’s Cervical Cancer Trust find that on average women delay their screening by 15 months after being sent an invitation, rising to 33 months for the 60–64s.¹³ As a result, the Cervical Screening Programme cannot be as effective as it would otherwise be at preventing cases of cervical cancer.

What is cervical screening?

Unlike breast or bowel cancer screening, cervical screening is not looking for the presence of cancer itself. Instead, the aim of the programme is to prevent cancer from developing in the first place by detecting changes to the cells of the cervix that, if left, could develop into cancer. If these cells are found, they can be quickly and easily removed and the cancer is avoided. Research by the Wolfson Institute of Preventive Medicine published in

Table 3 **Cervical screening intervals in the UK**

England	Women aged 25–49, every 3 years Women aged 50–64, every 5 years Women aged 65+, only invited if had a previously abnormal result, or not attended since age of 50
Wales	Same as in England
Northern Ireland	Same as in England
Scotland	Women aged 20–60, every 3 years (set to change in 2015 to be the same as in the other three countries)

2003 estimated that screening at regular three-yearly intervals prevents 8 out of 10 cancers from developing.¹⁴ Regular screening is therefore the best way of avoiding cervical cancer.

The Cervical Screening Programme invites women from the age of 25 (currently 20 in Scotland) to make a cervical screening appointment with their GP or nurse. Women are routinely invited back at regular intervals, depending on their age and the country they live in (table 3).

At a cervical screening appointment, a sample of cells is taken from the surface of the cervix using a brush or swab, which is inserted into the vagina. This sample is then held in preservative liquid to be sent to a laboratory for analysis, called cytology. At cytology, scientists look to see if there are any changes to the cells of the cervix that may lead to cervical cancer. If these cells are found, a woman is referred on for further examination of the cervix (colposcopy) and treatment, if required.

However, the presence of cervical abnormalities on its own is not sufficient for cervical cancer to develop – mutations in the cells of the cervix are relatively common, especially in younger women, and most are completely benign. This can result in many more women being referred to colposcopy than necessary, causing a lot of stress and anxiety for the women concerned, and inefficient use of NHS time and resources. As a result, between 2008 and 2012, human papillomavirus (HPV) triage was rolled

out across the Screening Programme in England and Northern Ireland. HPV triage is explained in more detail in the box below; essentially it means that only women who show signs of cervical abnormality *and* test positive for HPV are referred to colposcopy for further diagnosis and/or treatment.

The presence of HPV increases the risk of developing cervical cancer, and is considered to be the cause of almost all (99.7 per cent) instances of the disease. It is a sexually transmitted infection, and is extremely common – most people, male and female, who are sexually active contract the virus at some point, but usually experience no symptoms, and in most cases the virus clears up on its own.

In a further development to the Screening Programme in England, since 2008, girls in year 8 (ages 12–13) are now routinely offered HPV vaccination, which protects against 70 per cent of all cervical cancers.¹⁵ Because the vaccination is not 100 per cent effective, NHS guidance is for vaccinated women to continue to be screened regularly. It will be a few more years before the first wave of vaccinated women are screened, and it remains to be seen what impact vaccination will have on cervical cancer rates (and indeed, on take-up of invitations for screening).

Box 1

Cervical screening definitions

Colposcopy *A detailed examination of the surface of the cervix, using a colposcope – a lighted microscope. A colposcopy is used to investigate any abnormalities that have been picked up by cervical screening. A biopsy (removal of small amounts of cells or tissue) may also be carried out for further testing and diagnosis of cervical cancer.*

Cytology *The process of analysing cervical samples on stained slides in a laboratory, to look for signs of cell abnormality.*

HPV testing *Tests for the presence of the human papillomavirus (HPV). Most cases of HPV are harmless, and clear up on their own, but some types can cause cervical abnormalities, which if left untreated can develop into cervical*

cancer.¹⁶ HPV testing has two main uses in the screening and treatment of the disease:

- 1 **HPV triage** *If low-grade abnormalities are detected in a sample, HPV testing can be carried out on the same sample. Only women who test positive for HPV are referred on to colposcopy, as without the presence of HPV, it is extremely unlikely that the abnormalities will develop into cancer. A negative HPV test is considered to be a negative screening result, and there is no need for further treatment. This process helps prioritise women who need treatment most, without putting women who do not need treatment through unnecessary anxiety. (HPV triage is currently used in England, Wales and Northern Ireland, but not Scotland.)*
- 2 **Test of cure** *A follow-up HPV test is carried out six months after treatment for cervical abnormalities. If the test is positive, the woman is invited back for colposcopy to see if more treatment is needed. If the test is negative, the woman can return to routine screening.¹⁷ (Test of cure is currently used in England, Scotland and Northern Ireland; Wales is set to introduce it soon.)*

Liquid-based cytology *Introduced in 2008, using liquid-based cytology, samples of cervical cells are preserved in liquid for analysis in a laboratory, rather than smearing the cells straight onto a slide (the traditional ‘pap smear’).*

Cervical screening has two main effects – it allows more cancers to be prevented, by catching abnormal cells at a pre-cancerous stage, and it allows cancers that do develop in between screening appointments to be picked up at an earlier stage, when they are more easily treatable, and survival rates are much higher.

Cancers, including cervical cancer, are diagnosed at different stages, depending on things like the size of the primary tumour and how far the cancer has spread into other parts of the body. These are the stages for cervical cancers, which we refer to throughout this report:

- *Stage 1* Cancer is still contained within the cervix, and has not spread to other parts of the body. These stage is often subdivided further into stage 1a and 1b, depending on the size of the tumour.
- *Stage 2* Cancer has spread into the surrounding tissue.
- *Stage 3* Cancer has spread into the lower section of the vagina and/or pelvic wall, and may cause kidney problems by blocking the ureters (the tubes that drain the kidneys).
- *Stage 4* Cancer has spread to the bowel, bladder or other organs.

Nearly all the work of the screening programme is preventing cancers and, in a very small minority of cases, picking up early stage cancers. Women diagnosed with more advanced stage cancers do not tend to have come through the screening programme, hence their cancer being diagnosed so late. An audit of invasive cervical cancer by the NHS in 2012 showed that 55 per cent of women aged 50–64 with a fully invasive (stage 1b+) cervical cancer had not been screened for at least seven years before their diagnosis, compared with 17 per cent of a control population of the same age group.¹⁸ This was borne out by medical practitioners whom we spoke to during our research. Andy Nordin, a consultant gynaecologist in Kent, and Chair of the National Cancer Intelligence Network Gynaecological Clinical Reference Group, said that in his working life:

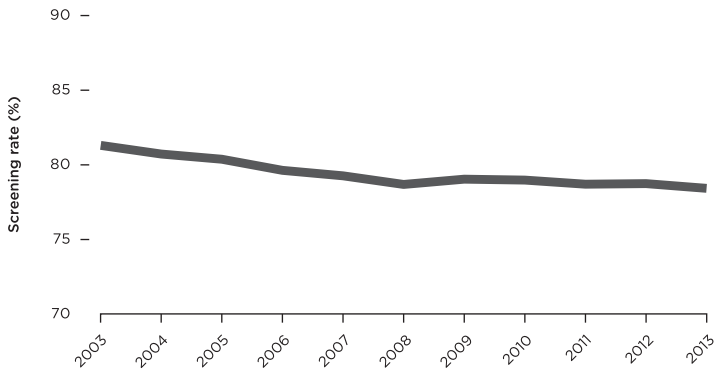
We see, usually, between 32 and 34 cancers a year and about a third of them are advanced stage, and those woman are almost universally defaulters from the screening programme, they are almost always advanced stage.

Our survey of 182 women who had had cervical cancer also confirmed this trend – more of those who reported diagnosis in later stages said this diagnosis had been made not through screening but after a GP appointment made once they had experienced symptoms.

Uptake of screening

In spite of the benefits of cervical screening, the proportion of women between 25 and 64 who have attended a screening

Figure 1 **The five-year cervical screening rate of women aged 25–64 in England, 2003–2013**



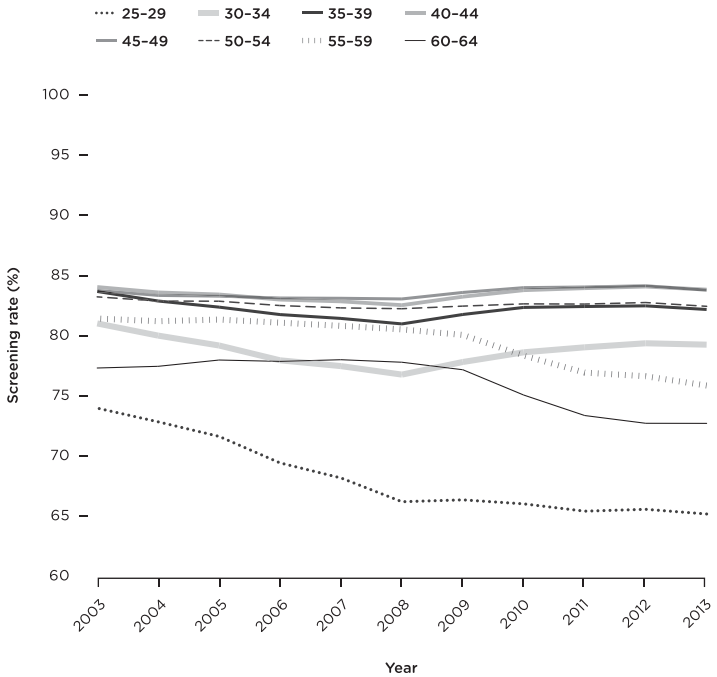
Source: NHS Cervical Screening Programme, *Annual Review 2012*¹⁹

appointment in the past five years has hovered stubbornly at around 78 per cent after peaking at around 82 per cent in the late 1990s, and is now gradually falling. Between 2012 and 2013, coverage in England fell from 78.6 per cent to 78.3 per cent (figure 1).

This downward trend has been particularly pronounced among the youngest and the oldest groups of women eligible for screening. Between 1995 and 2008, coverage of women aged 25–29 being regularly screened fell from 67 per cent to 59 per cent. Numbers of women in this age group attending screening picked up after 2008, following the death of TV celebrity Jade Goody, which particularly resonated with this age group. More recent years have seen coverage in this group start to dip again, and it remains low compared with other age groups (figure 2).

At the other end of the age range, the tailing off in the number of women in their 50s and 60s attending a regular screening appointment (every five years for this group) is also a cause for concern. Julietta Patnick, Director of the NHS Cancer Screening Programmes, explained:

Figure 2 Coverage of cervical screening in England by age group, 2003-2013



The younger women are just not coming into the [cervical screening] programme until they're older, and the older women don't want to be screened because the test does get very uncomfortable... And if you have not had a new partner for a long time or you have been twenty times already, that is when people stop.

Research from Jo's Cervical Cancer Trust similarly found that women of this age did not perceive cervical screening to be relevant to them – a third (31 per cent) of women aged 50–70 surveyed by the charity did not consider screening necessary for all women, rising to 67 per cent of women who had never been screened.²⁰ Yet as women (and men) stay sexually active for

longer, and more women in their 50s and 60s are starting new relationships and having multiple sexual partners at an older age, the risk of acquiring STIs – including the HPV virus – is growing among this age group, making screening more relevant, not less.²¹

The experts we consulted in our research consistently highlighted several demographic factors in addition to age, which are commonly associated with low take-up of cervical screening: ethnicity and indicators associated with low socio-economic status.

Ethnicity

Research by Jo's Cervical Cancer Trust showed that women from ethnic minorities were less likely to view cervical screening as a necessary health check than white British women, and tended to have lower awareness about their risk of cervical cancer. In the same survey, 23 per cent of black and minority-ethnic women said that they had never attended a screening appointment, compared with 14 per cent of white British women.²² This number is even higher among first generation immigrant women – in a study of South Asian women, a third of those who had been born overseas had never been screened.²³

One study identified cultural taboos to do with talking about cancer (particularly in some African communities), religious and cultural beliefs about women's bodies (for example, the Muslim belief that only a woman's husband may see her naked), a preference for traditional medicines, language barriers and poor literacy as playing a part in the low take-up of screening among ethnic minority women.²⁴

Deprivation

Incidence of cervical cancer and cervical cancer deaths tend to be higher in more disadvantaged areas, and this has been linked to lower uptake of cervical screening.²⁵ The 2012 *Profile of Cervical Cancer in England* showed that the average incidence of cervical cancer in the 30 most deprived primary care trust (PCT) areas

was 10.4 per 100,000 female population, compared with 7.8 in the 30 most affluent PCT areas.²⁶

More economically disadvantaged areas are also associated with some of the risk factors of cervical cancer, including smoking, and girls having sex from an earlier age (increasing their risk of contracting the HPV virus, and thus cervical cancer). They are also likely to contain disproportionate numbers of immigrant women, who have not been screened in their home country, and (as described above) are also less likely to engage with the NHS Cervical Screening Programme.

Why do more women not get screened?

Currently, around 1 in 5 women of screening age are not being screened regularly, and this number is growing. Turning this trend around requires some knowledge of what is stopping these women from attending screening – what are their feelings about screening? How important do they consider it? What barriers get in the way of them making an appointment? Some of these factors are discussed above for particular groups of women who tend to have lower engagement with cervical screening, but there are other more widespread disincentives.

In the introduction we refer to recent polling by Jo's Cervical Cancer Trust, which highlights embarrassment and inconvenience as two drivers for poor take-up of screening. In 2012, Shropshire PCT and Telford and Wrekin NHS trusts explored these drivers in more depth, and carried out joint research into the motivations of young women who had refused an invitation to attend screening.²⁷ They identified four broad categories of reasons for not attending screening, in the existing literature (table 4).

The precise interplay of these factors is different for different women. There is some suggestion that practical and organisational issues are more likely to stop younger women from attending screening, while older women are more likely to be held back by their negative feelings about the screening process.

Table 4 **Reasons why women do not attend screening for cervical cancer**

Emotional and personal reasons	Practical and organisational reasons	Knowledge and awareness	Demographics
Fear	Not being able to arrange screening at a convenient time and place, because of work, childcare or transport	Lack of knowledge about screening process, purpose and benefits	Ethnicity
Embarrassment Previous negative experience of screening or gynaecological examination	Preference for a female GP or practice nurse to carry out the procedure	Lack of awareness that screening prevents cancer	Lower educational attainment
Past experience of sexual abuse		Fear of what the results of screening might show	From more deprived background

Among the 188 women surveyed by Shropshire PCT and Telford and Wrekin NHS, the most common reasons given by women for not attending screening were:

- embarrassment (35 per cent)
- being too busy or not having time (17 per cent)
- the test being painful (15 per cent)

There was a feeling among expert interviewees that women's understanding of what cervical screening is actually for is very low – Dr Tracie Miles, a lead gynaecological oncology nurse specialist in Bath, said that women often think of it as 'the cancer test'. As a result, women may be more scared to get screened, if they think that the purpose of the test is to tell them whether or not they have cancer.

Peter Sasieni, Professor of Biostatistics and Cancer Epidemiology at the Wolfson Institute of Preventive Medicine, Queen Mary University of London, said that women may also

feel that they do not need to go for screening, because they do not feel unwell:

People think that they go for screening if they have a symptom; that's not the point of screening. The information needs to be communicated that you don't know that everything is fine, because what we're looking for has no symptoms and that's why the screening test is so perfect because it can find [signs of pre-cancer] at a point when they can be treated. And so that's the point of the screening. I wonder whether the public don't quite understand what screening is, they might think it is a test that people have when they are not feeling good.

Other reasons given included difficulty getting time off work, not being sexually active, and worry about what the test results might show. Several people mentioned that they were discouraged from having the test by their GP or nurse – particularly gay and bisexual women, and women who had never had sex – leaving them confused about whether or not they were supposed to be screened. The reasons given show a mix of personal and emotional, practical and knowledge barriers to screening – with women's personal feelings about screening perhaps the most frequent issue.

Tracie Miles identified a further practical barrier to screening, which can be very off-putting to women, and that is not being able to make an appointment. In her own experience, admin staff often cannot keep up with the number of calls from women trying to make appointments, and some women may eventually give up trying. As Tracie said: 'Whether I'm a young woman or an older woman – if the phone is never picked up, I might not try again.'

However, as Peter Sasiemi pointed out, these reasons alone are not enough to explain the falling numbers:

Of course no one loves [having cervical screening], but it hasn't got worse, you know, and if anything, the nurses who are doing screening have been much better trained than the people who were doing screening 10, 15 years ago. That training might even include, you know, trying to relax someone and talking to them to make sure the experience is as easy as

possible... So what's changed and why is presumably much more sort of sociology or psychology.

Estimating risk

The reasons given in our expert interviews for why women might not attend screening were very similar to those mentioned above. Interviewees also made a more fundamental point – that people estimate and respond to risk, which makes it less likely that we will take preventive measures that are in our own long-term best interests.

Andy Nordin suggested that the high profile of cervical screening may have become a victim of its own success – and that as a result women have become complacent about cervical cancer, believing that it has been ‘sorted’. This is a particular risk for the cohort of women who have been vaccinated against HPV, who are now beginning to reach screening age. The HPV vaccination only offers 70 per cent protection against cervical cancer, and so these women still need to attend screening, but they may feel that because they have been vaccinated, they are now ‘immune’ to cervical cancer, and so opt out of screening, exacerbating the existing downward trend.

Professor Henry Kitchener, Chair of the Advisory Committee on Cervical Screening, argued that this feeling of ‘invulnerability’, in younger women especially, is already to blame for a large number of women not attending screening: ‘I think that for young people, a very low sense of vulnerability is one. Young people don’t believe that their health is at risk.’

These issues are all associated with knowledge, awareness and relevance. A woman may know that cervical screening exists, and that it saves thousands of lives by preventing cervical cancer, and yet she may drastically underestimate her own risk of being diagnosed with the disease, and feel that – for her – screening is unnecessary, as she is ‘not the kind of person’ who might get cervical cancer.

Conclusion

Cervical screening is the most powerful preventive measure in use against cervical cancer today. The fact that cervical cancer – unlike many other cancers – can be detected while it is still in the pre-cancerous stage provides a unique opportunity to save thousands of women’s lives, and help thousands more avoid the trauma of undergoing intensive treatment.

Yet, persuading more women of the value of cervical screening is not a simple process. Even spreading the message that cervical screening saves lives is unlikely to be enough, if there are additional emotional and practical barriers. For example, in the Shropshire PCT and Telford and Wrekin NHS survey, 93 per cent of women were aware of cervical screening, and 82 per cent were aware that cervical cancer could be prevented through screening – and this was among a sample of younger women of whom 60 per cent had never had a smear test.²⁸ In this case, lack of awareness was clearly not the problem. Recognising that there are multiple barriers to cervical screening, and attempting to remove as many of these as possible will be key to boosting uptake.

We return to how this may be done in chapter 4. First, we explore some of the financial costs associated with cervical cancer – to the state, the NHS more specifically, and individual women and their families. We then go on to model the level of cost savings that could be achieved if screening rates improved – showing that increased investment in boosting our dwindling screening rates is not only medically sound, but would also prove highly cost-effective.

2 Costs to the NHS and the state

Treating cervical cancer obviously has a cost to the NHS. Different treatment options are available, depending on variables such as the age of the woman and whether she has any previous history of cervical cancer. Some procedures may make it difficult or impossible for a woman to have children in the future, and so younger women may try to choose treatments that preserve fertility.

Yet the major factor that influences the treatment given is the stage of diagnosis – women diagnosed at a later stage tend to receive more intensive treatment than women whose cancer is detected and treated very early on. The more intensive treatment is, the more expensive it tends to be.

Table 5 shows average NHS costs in 2012/13 for different treatments of cervical cancer. As precise treatment costs vary widely (eg by whether the procedure is inpatient or outpatient, how long the course of radiotherapy or chemotherapy needs to be and so on), we have attempted to average top and bottom-estimate costs to give a sense of scale between less intrusive procedures more commonly used in stage 1a cancers (eg cone biopsy) and those needed for advanced cancer – eg a ‘radical hysterectomy’ combined with follow-up chemotherapy and/or radiotherapy. The numbered notes in the table explain how we estimated an average cost in each case.

Using the number of cases of cervical cancer reported in 2011, and the known treatment given to women at different ages and cancer stages, it is possible to calculate the total cost of treating all cervical cancers in 2011. This adds up to over £21 million (£21,126,025) spent by the NHS in one year on the treatments listed in table 5. Our calculations are based on 2,288 reported cases in England between the ages of 25 and 79, which

Table 5 **The cost to the NHS in 2012/13 of different treatments for cervical cancer²⁹**

Treatment	Description	Unit cost
Cone biopsy or large loop excision of the transformation zone	Both procedures remove abnormal cells from the cervix	£465.25 ³⁰
Trachelectomy	Surgery to remove the cervix that allows preservation of fertility - used especially to treat cervical cancer in younger women who may want to go on to have children	£5,485.67 ³¹
Simple hysterectomy	Removal of all or part of the cervix and uterus	£1,230
Radical hysterectomy	Complete removal of the cervix, uterus, ovaries and associated lymph nodes	£3,937.50 ³²
Radiotherapy	Use of ionising radiation to kill and control the growth of cancerous cells; delivered in short daily treatments 5 times a week for around 6 weeks	£19,078.50 ³³
Chemotherapy	Killing cancerous cells by targeting cells in the body that divide rapidly; chemotherapy drugs are most commonly delivered using an intravenous drip; a course of chemotherapy lasts for approximately 6 rounds, at 3-4 week intervals	£5,089.17
Radiotherapy or chemotherapy (radio-chemotherapy or chemoradiation)	Chemotherapy and radiotherapy together	£24,167.67
Hysterectomy and radiotherapy	Hysterectomy followed by a course of radiotherapy	£21,662.25 ³⁴
Hysterectomy and chemotherapy	Hysterectomy followed by a course of chemotherapy	£7,672.92
Hysterectomy, radiotherapy and chemotherapy	Hysterectomy followed by radiotherapy and chemotherapy together	£26,751.42

gives an average cost per person to the NHS of roughly £9,233 a year.

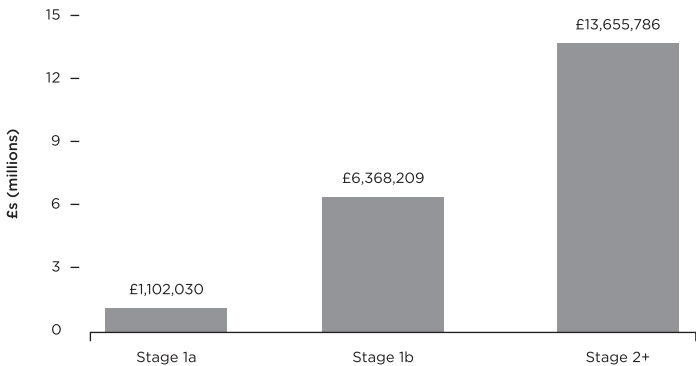
It is likely that the actual costs of treatment are significantly higher than this – as the unit costs we have used in our calculations only include direct treatment costs (the costs of the medication and medical expertise involved in the procedure itself), rather than costs of follow-up or nursing care. We have also excluded palliative care from our calculations, though for a proportion of women – particularly older women diagnosed with more advanced cancers – there may be no effective treatment, and palliative care may be the only course of action.

The £9,233 average cost per person clearly masks considerable variation, particularly according to stage of diagnosis. Women in the very early stages of cervical cancer can commonly be treated with less expensive procedures. For a stage 1a diagnosis, the most common treatments are a cone biopsy or loop excision or a simple hysterectomy – the two least expensive options.

In contrast, women diagnosed at a more advanced stage (stage 2 or above) tend to require more expensive procedures. The combination of chemotherapy and radiotherapy (also known as chemoradiation), for example, has been proven to be particularly effective at treating more advanced cervical cancers. At a cost of over £24,000 per person, it is the second most expensive treatment option. Only 0.6 per cent of women aged under 40 whose cancer was diagnosed at stage 1a received chemoradiation, compared with almost 70 per cent of the same age group who were diagnosed at stage 2 or above. Radiotherapy on its own is also much more commonly used for treating more advanced cancers – particularly in women aged over 65. Radiotherapy was the second most common form of treatment, after chemoradiation, for women in this age group diagnosed with a stage 1b cancer or above.

As a result, the NHS currently spends over 12 times as much on treating cervical cancers diagnosed at stage 2 and above as it does on treating stage 1a cancers. Figure 3 shows the relative costs of treatment at the different stages.

Figure 3 **Cost to NHS of all cancers diagnosed in England in 2011, by stage**



We know (from the data modelled by Queen Mary University of London) that in England in 2011, of the 2,288 total cancers diagnosed in the 25–79 age group, broadly equal numbers of stage 1a (799), stage 1b (780) and stage 2 and above (709) cancers were diagnosed. Therefore the approximate annual per person cost to the NHS of different stages of diagnosis is £1,379 for stage 1a cancers, £8,164 for stage 1b cancers and £19,261 per person for cancers diagnosed at stage 2 or above.

The cheapest possible outcome for the NHS is for as many cervical cancers as possible to be diagnosed while they are still at stage 1a. However, at this stage, cervical cancer is largely symptomless (it is not until later stages that symptoms such as vaginal bleeding and pain occur), and so the only way to detect it is if it is picked up by screening, or in the course of another procedure (eg during childbirth).

Better still is for cases of cervical cancer to be prevented altogether, by being picked up through screening at the pre-cancerous stage. In this chapter, we have only looked at the costs of treating cancers once they have been diagnosed. The cost of treating pre-cancerous cervical abnormalities detected through screening – usually involving laser treatment or cauterisation – is

included in the overall cost of the screening service, and so cannot be separated out and calculated. The programme screens over 3 million women a year, at a cost of £175 million, equating to a cost of roughly £58 per woman.³⁵

Costs to the state - reduced employment

As well as the costs of NHS treatment, there is an additional cost to the state when people stop working or work less because of ill health. As Julie's story below shows, often it is not just the woman diagnosed whose working life is affected – her partner or another family member may also need to take time off work or stop working to care for their loved one.

Case study 1 Julie - changes to working lives

Julie was 31 when she was diagnosed with stage 2b cervical cancer in April 2011. The cancer was discovered following the birth of her second child. She was referred straight to oncology and began chemotherapy at the end of May, together with a course of radiotherapy (chemoradiation).

As she was already planning to take maternity leave at the time she was diagnosed, Julie did not need any additional time off work, and consequently her income did not suffer. During her treatment, Julie's mother took time off work to help her care for her newborn baby, so her partner was able to continue working. When her maternity leave ended, Julie took additional annual leave from her job to give herself longer to recover.

Julie reported that the main costs of her diagnosis were related to using up her annual leave during recovery, plus petrol, parking and childcare costs:

The main thing for us was [that] after using up the annual leave... there was nothing else left for the year. But also we had to pay for parking as well and obviously we were going to the hospital every day for five weeks and some days we were there from literally 9 till 5 and we had to pay for parking every time we

were there... it was probably only about £100. A couple of times the radiotherapy machine broke down so we had to drive up to [another] hospital for the treatment, so obviously that was petrol and childcare.

Julie estimates that the total personal cost she incurred as a result of her diagnosis and treatment was between £200 and £300 as a result of paying for petrol, parking and additional childcare when her mother was not available. She feels that, overall, she was quite fortunate financially – ‘luckily we were able to scrape by with my partner’s wage and my maternity pay’.

Julie was also lucky to have support from her mother, who was able to help with childcare so that her partner could continue working, and that her cancer came at a time when she was already planning to take time off work. In other circumstances, her costs could have been significantly higher, with both her and her partner potentially needing to stop work and losing income as a result, making them less able to absorb the costs of petrol and parking. They would also have had to spend more on childcare during Julie’s hospital appointments.

Source: Demos interview, names changed

Of course, not everyone is as lucky as Julie. In the course of this research, Demos surveyed 182 women who had been treated for cervical cancer, asking them how their (and their partner’s) working patterns had changed during and after diagnosis and treatment. All but three of the women surveyed had had to make some adjustments to their working patterns – taking time off work, reducing the number of hours worked, or stopping work altogether. In 37 per cent of cases, women told us that they found it ‘quite difficult’ or ‘very difficult’ to make these changes to their working hours.

Although most women who take time off work during treatment for cervical cancer return as soon as they have recovered, where women need to reduce their hours or stop work permanently, it has an impact on state revenue because of lost

Table 6 **Loss in weekly earnings, salary, income tax and NICs when women reduce their working hours or cease working because they have cervical cancer, 2013**

	Median gross weekly earnings	Equivalent salary for full-time employee	Income tax paid per year	NICs paid per year
Full time	£517	£26,884	£3,377	£2,271
Part time	£160	£8,320	£0	£44

income tax and National Insurance contributions (NICs). We have estimated this loss in table 6, basing our estimates for how much revenue the state loses for every woman who has to stop work or reduce her hours on median earnings in the UK as of April 2013.³⁶ Table 6 shows the loss in weekly earnings, equivalent full-time salary, income tax and NICs when women need to reduce their working hours or cease working because they have cervical cancer.³⁷

Altogether, somebody working full time and earning a median wage pays £5,648 to the Treasury each year, while somebody working part time pays only £44 a year (as they are not earning enough to pay income tax). Therefore, when somebody working full time stops work, the state loses £5,648 of income. When somebody switches from full-time to part-time hours, it loses almost as much – £5,604.

Out of 107 women in our sample who were in work at the time of their diagnosis (84 per cent of all women who gave their employment status), 29 women reported that they (or their partner) had stopped working altogether as a result of cancer, and another 48 had reduced their hours. Just from our small sample of 182 women, this represents a combined loss to the Exchequer of £432,784 over the course of a year.

There were 2,288 women aged 25–79 diagnosed with cervical cancer in England in 2011, of whom around 590 die of their illness. As was highlighted by experts in Demos research

interviews, a high proportion of women who die from cervical cancer have children. This has a huge emotional cost, and may result in the remaining parent or a grandparent giving up work to look after them. We have therefore estimated the cost to the state of the death of a working mother as 150 per cent of the tax paid on a median salary, to take into account the lost earning capacity of the remaining partner.

Box 2 Lost tax revenue as a result to reduced work, or death, from cervical cancer

2,288 - 590 = 1,698 women surviving cervical cancer every year

84 per cent of these are in work = 1,426

29/107 (27%) stopped work = 385

48/107 (45%) reduced hours = 642

$385 \times 5,648 = \text{£}2,174,480$

$642 \times 5,604 = \text{£}3,597,768$

Total lost in income tax and NICs from women working less = $\text{£}5,772,248$

Assuming 84% of women who die each year from cervical cancer (590) are also in work = 496 working women dying of cervical cancer each year

57% of working women were mothers (in our survey), therefore:

= 283 working mothers

= 213 working non-mothers

die each year

$213 \times 5,648 = \text{£}1,203,024$

$283 \times (5,648 \div 1.5) = \text{£}2,397,576$

Total loss from death = $\text{£}3,600,600$

Total loss to state = $\text{£}9,372,848$

Therefore, women who have to stop work, reduce their working hours or die each year cost the state over £9 million a year purely in their lost tax contributions and in some cases those of their families. That amounts to a cost of around £4,097 per woman diagnosed. In calculating these costs, we have used the employment rate of women in our survey sample (84 per cent) rather than the national rate (67 per cent³⁸), as women diagnosed with cervical cancer are disproportionately likely to be of working age. In chapter 4 we provide top and bottom estimates for this lost revenue based on the average employment rate and the higher rate reported in our survey.

This estimate is understandably somewhat rough – we base the losses on median incomes, for example, and do not attempt to model a lifetime cost of unemployment – rather provide just a ‘snapshot’ cost of one year. Dr Simon Leeson, a consultant gynaecological oncologist for NHS Wales, pointed out that the loss of income (and therefore tax income to the state) is higher over the course of a lifetime for women who are diagnosed with cervical cancer at a younger age and have most of their working life ahead of them: ‘If you’re potentially a woman who may lose a lifetime of income, then that’s a bigger impact at the beginning of one’s life than it is at the end.’

We also only consider lost revenue to the state, and do not factor in additional costs to the state of unemployment. For example, women with cervical cancer and undergoing treatment will most likely be eligible for Employment and Support Allowance (ESA) on the grounds of long-term illness or disability. If all of the women who stopped work as a result of cervical cancer were entitled to claim ESA, and assuming the distribution between the Work Related Activity Group (WRAG) and Support Group (the two rates at which ESA is paid) were the same as national averages,³⁹ this would be an additional cost to the state of around £1.7 million (£1,661,222). Furthermore, there is a range of other benefits that a woman might be entitled to (eg housing benefit, council tax reduction, child tax credit), all of which would increase the cost to the state.

Box 3 **Calculating the cost of ESA in one year**

For all women giving up work because of illness: 13 weeks' assessment for ESA × £71.70 = £932

For 45% of women 39 weeks × £106.50 (Support Group) = £4,154

For 54%⁴⁰ of women 39 weeks × £100.15 (WRAG) = £3,906

(£932 × 338⁴¹) + (£4,154 × 152) + (£3,906 × 183) = £1,661,222

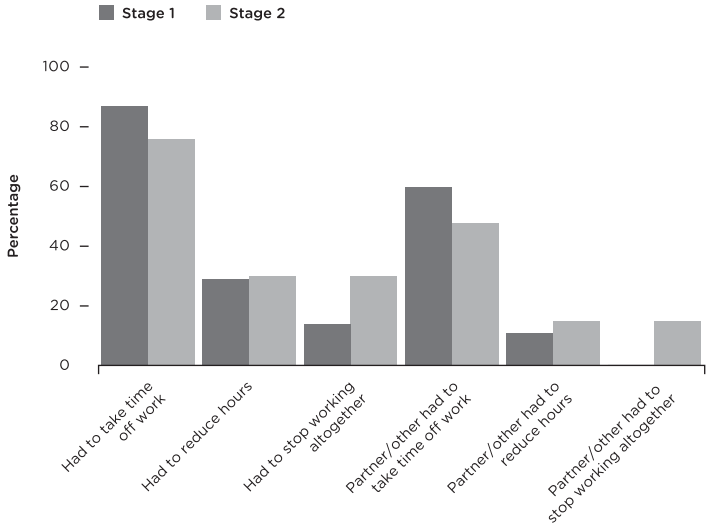
From our survey, it was clear that whether or not women or their partners had to take time off work or give up work completely was linked to the stage at which their cancer was diagnosed. Women who were diagnosed with a stage 1 cervical cancer were slightly more likely than those with more advanced cervical cancers to take time off work (and their partners were more likely to take time off work), but it was far more common for women and their partners to stop work altogether in the case of stage 2 cancers (30 per cent, compared with 14 per cent of women with a stage 1 diagnosis). The number of women whose cancer was diagnosed at stage 3 or 4 in our sample was too small to make an accurate comparison, but of those eight women, seven had to take time off work, one had to reduce her working hours, and five eventually had to stop working altogether. In three instances, a partner had to take time off work, and in two instances, a partner had to reduce working hours (figure 4).

The costs of lost tax take and NICs associated with unemployment is therefore higher on average for women diagnosed at stage 2 and above than for those diagnosed at stage 1.

Conclusion

Overall, the state spends around £21 million a year treating cervical cancer through the NHS, and loses around £10 million in lost tax revenue – a total cost of over £30 million a year. Most

Figure 4 **Actions respondents had to take as a result of having cervical cancer, by stage of diagnosis**



of this cost comes from women diagnosed at stage 2 or above, whose treatment costs are higher, and who are much more likely to stop working following treatment.

Yet it is clearly not just the state that is worse off as a result of cervical cancer – women diagnosed with the disease are also likely to find themselves spending more and earning less, at least temporarily. In some cases, the effects can be more long term – as is seen by women stopping work completely after they have been diagnosed. Some women find the financial consequences of cervical cancer last long after their recovery.

3 How much does cervical cancer cost patients?

The impact that cancer can have on a person's health is well recognised. When they imagine what cancer is like, most people think of the physical condition, the pain, the gruelling treatment, the likely prognosis, and the emotional turmoil for them and their loved ones. Few people's minds jump immediately to their bank balance. And yet the costs incurred during treatment – hospital parking charges, higher energy bills, replacement clothing, dressing and medications following surgery – as well as the potential loss of income from stopping work or reducing hours – all add up. The fact that this additional financial burden comes at a time when people already have enough to worry about makes its impact on wellbeing all the more concerning. As one expert we spoke to described it:

It's the bit that's not very sexy about cancer. None of it's sexy, but it's the bit that people sort of don't seem to think about. They think about the sorrow and the fear of it coming back, though actually the everyday nuts and bolts of not being able to cope financially is massive and it just knocks people sideways.

Research by Macmillan Cancer Support shows that 4 in 5 people who are diagnosed with cancer incur additional costs of some kind (including loss of income) as a result of their illness, to the tune of £570 a month on average.⁴² Lost income comprises the bulk of this figure (experienced by 30 per cent of people surveyed, at an average loss of £860 per month), while the most common loss came from extra travel costs to and from outpatient appointments (incurred by 71 per cent of people, at an average cost of £143 per month). Other sources of financial strain included:

How much does cervical cancer cost patients?

- additional day-to-day living costs – with the largest proportion of this coming from higher energy bills and paying for help around the home and garden
- clothing, equipment and home modifications
- other healthcare costs
- costs associated with inpatient appointments

Many of these costs are not specific to cancer, but there are several features of the disease that make it especially expensive – the frequency of chemotherapy and radiotherapy treatment, requiring regular travel; the specialist nature of some treatments, which may not be available in smaller local hospitals and so requires people to travel longer distances; the side-effects of chemotherapy and radiotherapy, which can include tiredness, weight loss or gain, and sensitivity to the cold. These all result in additional spending – on petrol and car parking, childcare, help with cooking and cleaning, replacement or additional clothing, and heating the home.

Some of these costs hit women diagnosed with cervical cancer particularly hard – the most common age for a woman to be diagnosed with cervical cancer is in her late 20s and early 30s, an age at which women are quite likely to have young children. Among women surveyed by Demos for this project who had been treated for cervical cancer, 58 per cent had children, and of those women, around a third (34 per cent) had at least one child under the age of 8. This makes it all the more likely that they will need to spend money on childcare at some point during their treatment and recovery.

Several of the experts interviewed in the course of this research also pointed out that at this age, women have their greatest earning potential ahead of them, and may be working hard to forge a career or build up experience. This makes it a particularly disruptive stage at which to have to take time off work.

Costs of cervical cancer

The Macmillan research covers all cancers, but cervical cancer is likely to come with its own set of costs. In addition to loss of

income and travel costs, experts in the field of cancer screening and gynaecological cancer interviewed by Demos for this research highlighted some costs they had identified particularly among women with cervical cancer:

- replacing a mattress, if a woman is bleeding heavily after surgery
- replacing a washing machine, if she is washing clothes very frequently
- replacing clothes that no longer fit
- wigs
- childcare (although not specific to cervical cancer, as a women's cancer that affects younger women – who may have young children – childcare costs are likely to be disproportionately high compared to other cancers)

Dr Tracie Miles told us that she often sees relationships fall apart because of cervical cancer, and this can carry additional costs (eg moving to a new home, divorce proceedings, and the additional costs associated with single parenthood, where children are involved):

About 20 per cent of our women will break up with their partners after treatment. They'll get through treatment and then they'll get into post-treatment and they look back and say, 'God, what did I just go through?' and they start readjusting their lives, and those 20 per cent who were all really unhappy in their relationships end them.

Although surviving cervical cancer (or any type of cancer) causes many women to reassess their priorities in life, the stress of coping with illness can have a negative impact on the mental health of some women, who may suffer from depression or anxiety that keeps them from returning to work, leaving them on a much reduced income.

To gather more detail about the ways in which women are affected financially by a cervical cancer diagnosis, Demos surveyed 182 women who had received treatment for cervical cancer. Of this sample:

How much does cervical cancer cost patients?

- Almost half (49 per cent) were first diagnosed between the ages of 25 and 34
- 84 per cent had attended their first screening before the age of 29 (53 per cent had attended before the age of 25, before the minimum age for screening was raised from 20 in 2003).
- 59 per cent were diagnosed with a stage 1 cancer and 33 per cent with a stage 2 cancer – the remaining 10 women were either diagnosed at stage 3 or 4 or were unsure.
- 46 per cent had their cancer detected through screening – this figure rose to 55 per cent among women diagnosed while their cancer was still at stage 1, and fell to 34 per cent of women diagnosed at stage 2, and 25 per cent at stage 3.
- The majority (71 per cent) were diagnosed more than a year ago.
- 83 per cent were now cancer-free.

Additional costs

We asked women to report any additional spending in two categories – items relating specifically to their cancer diagnosis (things that they would not otherwise have spent money on – see box below), and daily living expenses that they would have spent money on anyway, but where costs increased as a consequence of a cancer diagnosis (eg energy bills, toiletries).

Box 4 **Cancer-related costs**

These are the additional costs that may arise for those who have cancer, which Demos asked women about in our survey:

- *food and drink for specialist diets or dietary supplements*
- *public or private transport to and from appointments*
- *hospital car parking charges*
- *inpatient hospital stays*
- *specialist equipment*
- *specialist, additional and differently sized clothing*
- *prescription medicines or medical products*
- *non-prescription medicines or medical products*
- *natural or homeopathic medicines*

- *medical insurance*
- *childcare (during treatment or because of illness or side-effects)*
- *nursing or personal care at home*
- *complementary and alternative therapy sessions*
- *other therapy sessions (eg physiotherapy, occupational therapy, psychotherapy or counselling)*
- *doctors' fees*
- *paid help around the house (eg gardening, cleaning, DIY)*

Most women incurred at least some cancer-related expenditure – only 10 women out of the 112 who provided cost data said they had not spent anything on any of the costs listed above. On average, each woman who did spend extra spent £389 per month on cancer-related costs. The biggest single cost was childcare – costing £263 a month on average to the 14 per cent of women who paid for this during treatment and recovery. Other areas of high cost included medical insurance (£255 a month on average) and paying for help around the home (£246). Specialist equipment, inpatient hospital stays, doctors' fees and specialist food and drink all cost women more than £100 a month on average. Table 7 gives the details of these figures.

Some costs were more common than others. Echoing the Macmillan findings above, the most frequently reported costs in our survey were private travel to and from appointments, and hospital car parking charges (reported by 66 per cent and 59 per cent of women, respectively). Other commonly reported costs were specialist foods and dietary supplements (49 per cent) and non-prescription medicines and medical products like dressings, creams and painkillers (48 per cent):

Recovery from side-effects is expensive, whether it is booking things then not [being] able to go, to booking high quality to get a seat etc or to avoid queues. It all costs extra, holiday insurance, taxi instead of public transport, buying smaller clothes, getting clothes altered, going to private therapists, ie, nutritionist, dealing with urge incontinence, assistance with laundry, etc etc.

Woman diagnosed at stage 2, now in remission

Table 7 **The monthly expenses of women with cervical cancer**

Cost type	Average	Women incurring this cost (%)
Childcare (during treatment or because of illness or side-effects)	£263	14
Medical insurance	£255	22
Paid help around the house (excluding childcare, including for example gardening, cleaning, DIY)	£246	14
Specialist equipment	£142	12
Inpatient hospital stays	£128	25
Doctors' fees	£128	5
Food and drink for special diets or dietary supplements	£109	49
Prescription medicines or medical products	£96	24
Private transport to and from appointments	£94	66
Complementary and alternative therapy sessions (eg aromatherapy, acupuncture, massage, yoga)	£82	34
Other therapy sessions (eg physiotherapy, OT, psychotherapy or counselling)	£73	23
Specialist, additional or differently sized clothing	£73	44
Public transport to and from appointments	£66	35
Hospital car parking charges	£64	59
Non-prescription medicines or medical products (eg dressings, over-the-counter medicines, skin creams)	£62	48
Natural or homeopathic medicines	£62	26

Macmillan Cancer Support has previously highlighted car parking charges as a huge issue for cancer patients.⁴³ They surveyed hospital trusts and found that the average daily cost of hospital parking ranged from £4.26 in the north east of England to £11.85 in London.

Specialist food and food supplements stands out as an item of spending that was both reasonably common, with half of

women spending extra on it, and relatively high cost (£109 a month), so the fact that so many women are spending so much money on this is surprising and alarming. Treatment for cancer can cause changes to sense of taste, nausea and loss of appetite – so it may be that women are buying nutritional drinks and milkshakes during a time when they do not particularly feel like eating. These are fairly expensive, and may explain the high amount spent on them monthly.

Higher living costs

In addition to the cost of items relating specifically to their cancer, many women found that they were spending more money on general day-to-day living costs – particularly energy bills, which increased by £24 a month on average. For women receiving chemotherapy or radiotherapy, this may be the result of feeling the cold more, and so leaving the heating on for longer. For others, it is simply a result of being at home during the day when they would not normally be. Similarly, women may spend more money on staying in touch with friends and family by phone or e-mail, or on books, films and digital TV to provide entertainment and distraction:

The main costs I incurred [were] buying new clothing for the hospital and afterwards as I was a bigger size. Heating costs increased and general utility bills as I was at home more often. I had to go back to work after six weeks as my sick pay ran out and I couldn't afford to take any more time off, although I could have done with more time to recover.

Woman diagnosed at stage 2, now in remission

Table 8 lists the main types of expenses on which women with cervical cancer are likely to spend more than they would if they did not have cancer, and their average increase in spending each month.

As well as the physical effects of cervical cancer, the emotional impact can take a financial toll too, as Alice's story demonstrates.

Table 8 **Average monthly expenses of women with cervical cancer additional to their regular expenses**

Cost type	Average increase in spending per month
Energy bills	£24
Toiletries and beauty products	£17
Phone and internet bills	£16
Home entertainment (TV, books, music, films, games)	£14
Hobbies and leisure activities	£12
Days out	£12
Household items (eg cleaning products)	£10
Average increase per cost	£15
Total additional costs	£105

Case study 2 Alice – the emotional impact of cervical cancer

Alice had a colposcopy following an abnormal screening test in 2011, which confirmed the presence of stage 1a cancer. Because the cancer was still contained within the cervix, doctors were able to perform a loop excision there and then – by the time she received her colposcopy results, the cancer had already been removed: ‘I had the colposcopy on the day and then two weeks later when I got the results they told me it was cancer and that it had all been taken away.’

Alice started a new job three days after her treatment, and immediately had to take time off work for follow-up hospital appointments; she lied to her new employers about the reason for being absent from work, as she felt awkward talking to them about her cancer:

I was quite unlucky because I had my colposcopy and treatment on the Friday and I started my new job on the Monday in a really small company that was run by three men, so obviously I didn’t really want to tell them unless I had to what I was going through because it was a little bit embarrassing.

Although Alice was able to take time off for her appointments, her mood suffered and she was unable to work

effectively because of anxiety, which went undiagnosed for around a year and a half. As she had felt uncomfortable telling her colleagues about her cancer, she was unable to explain why she was struggling, and subsequently lost her job after five months:

The problem I had was... really putting my effort into the job, because it was a sales job and you have to be quite happy and carefree to sell, and it really affected my mood afterwards – there was a lot of anxiety so I couldn't do my job to my full potential and I couldn't explain to them why.

Alice lost her income, which was around £15,000 pa, though she was quickly able to move into a new job working for her dad, and so did not notice a long-term drop in her income. Other costs associated with her diagnosis were relatively low – mostly petrol and car parking during hospital visits.

A lot of the anxiety and emotional strain that Alice experienced after her diagnosis was about her ability to have children in the future, as she was still in her 20s when she was diagnosed. The doctors had told her that it would be possible for her to conceive, but that she was at increased risk of miscarriage and pre-term labour, which she was very upset about.

Source: Demos interview, names changed

The higher costs of living with advanced cancer

Analysing our survey data, we found that women who had been diagnosed at a more advanced stage reported significantly higher costs on average than those who had been diagnosed at an earlier stage:

- Those diagnosed at stage 1 reported on average £340 per month cancer-related costs.
- Those diagnosed at stage 2 reported on average £427 per month cancer-related costs.

- Those diagnosed at stage 3 reported on average £850 per month cancer-related costs (though these figures should be used with caution as they come from a very small sample of six).

The highest costs reported (£3,000 a month) were by a self-employed woman with two young children, who was diagnosed at stage 3 after being taken to A&E. She underwent a hysterectomy and received chemoradiation. After her diagnosis, she had to stop work altogether, while her partner had to take time off and then reduce his hours. Their additional costs were so high because they needed childcare and help around the home. She explained in her survey response:

Having two very young children when diagnosed and no family near had a massive effect on our finances as we had to pay for emergency and longer term child care over a period longer than my initial treatment. After-effects of radiotherapy [have] increased the need for holiday care and activities to occupy my children, when I am incapable of caring for them.

Table 9 shows the average monthly costs incurred for stage 1 and 2 cancers, with the proportion of women reporting them. Costs for stage 3 are included for comparison, though these are drawn from a very small sample size of six.

Very broadly, both the additional costs of cancer and the frequency with which they are experienced tend to increase with stage of diagnosis. The most dramatic increases in costs between stages 1 and 2 occur for specialist food and drink, equipment and replacement clothing – suggesting that stage 2 cancers had a more profound impact on a woman's appetite, weight and daily life.

Women diagnosed at the more advanced stages of cervical cancer also spent more on day-to-day living costs, such as energy bills and toiletries. Women diagnosed at stages 2 and 3 spent on average £112 extra each month, compared with the £105 per month extra average spend across the whole sample. Women diagnosed at stage 1 spent £91 extra.

Table 9 **Average monthly costs incurred by women with stage 1 and stage 2 cervical cancer, and for a small sample of women with stage 3 cancer**

Cost type	Stage 1 Cost	(%)	Stage 2 Cost	(%)	Stage 3 Cost
Food and drink for special diets or dietary supplements	£80	38	£129	53	£117
Public transport to and from appointments	£69	23	£79	37	£50
Private transport to and from appointments	£65	55	£68	62	£150
Hospital car parking charges	£56	55	£61	43	£75
Inpatient hospital stays	£104	15	£79	21	£200
Specialist equipment	£50	1	£125	12	£250
Specialist, additional or differently sized clothing	£58	30	£93	43	£67
Prescription medicines or medical products	£50	18	£64	25	£175
Non-prescription medicines or medical products (eg dressings, over-the-counter medicines, skin creams)	£54	31	£56	53	£75
Natural or homeopathic medicines	£54	16	£81	25	£50
Medical insurance	£114	14	£150	21	£500
Childcare (during treatment or because of illness or side-effects)	£88	10	£100	9	£600
Complementary and alternative therapy sessions (eg aromatherapy, acupuncture, massage, yoga)	£65	22	£82	34	£100
Other therapy sessions (eg physiotherapy, OT, psychotherapy or counselling)	£127	16	£93	21	£0
Doctors' fees	£133	1	£250	3	£0
Paid help around the house (excluding childcare, including, for example; gardening, cleaning, DIY)	£150	11	£88	12	£500

