

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

BEHIND THE SCREEN

Jo Salter

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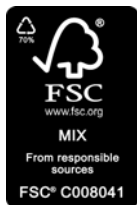
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Contents

| | |
|--|-----|
| Acknowledgements | 7 |
| Foreword | 9 |
| Executive summary | 11 |
| Introduction | 17 |
| 1 The cervical screening landscape | 23 |
| 2 Costs to the NHS and the state | 37 |
| 3 How much does cervical cancer cost patients? | 49 |
| 4 What happens to costs if screening rates change? | 67 |
| 5 Reducing the costs of cervical cancer: conclusions and recommendations | 83 |
| Methodological appendix | 97 |
| Notes | 103 |
| References | 111 |

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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:

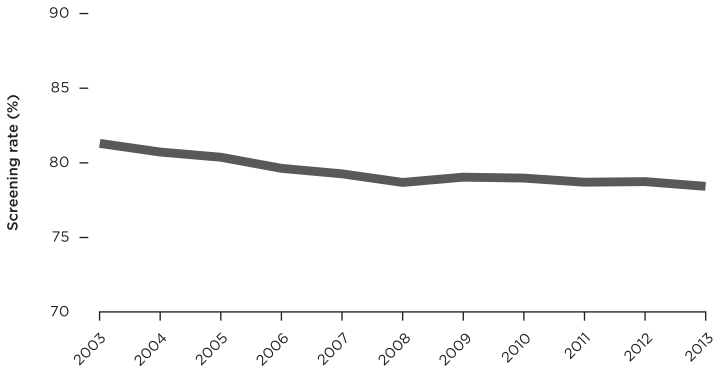
We see, usually, between 32 and 34 cancers a year and about a third of them are advanced stage, and those woman are almost universally defaulters from the screening programme, they are almost always advanced stage.

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**



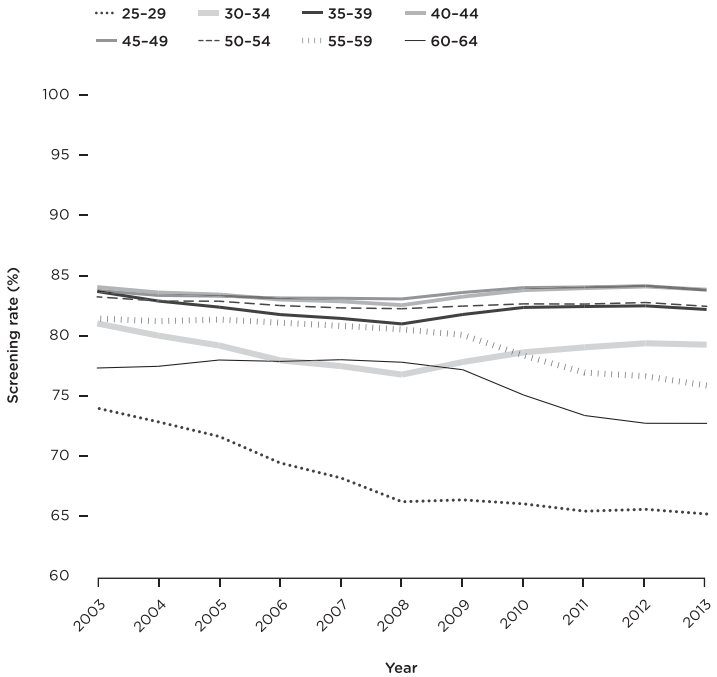
Source: NHS Cervical Screening Programme, *Annual Review 2012*¹⁹

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.

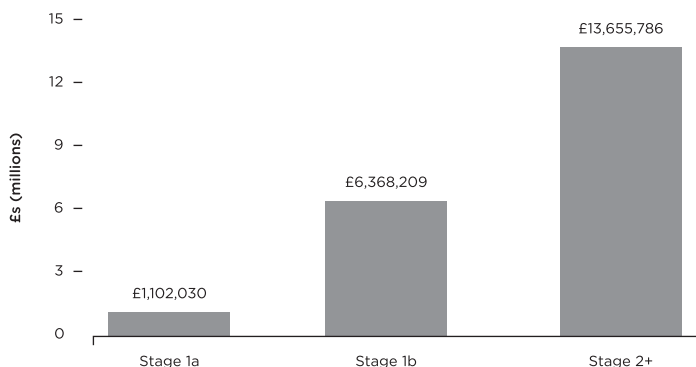
It is likely that the actual costs of treatment are significantly higher than this – as the unit costs we have used in our calculations only include direct treatment costs (the costs of the medication and medical expertise involved in the procedure itself), rather than costs of follow-up or nursing care. 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

$(£932 \times 338^{41}) + (£4,154 \times 152) + (£3,906 \times 183) = £1,661,222$

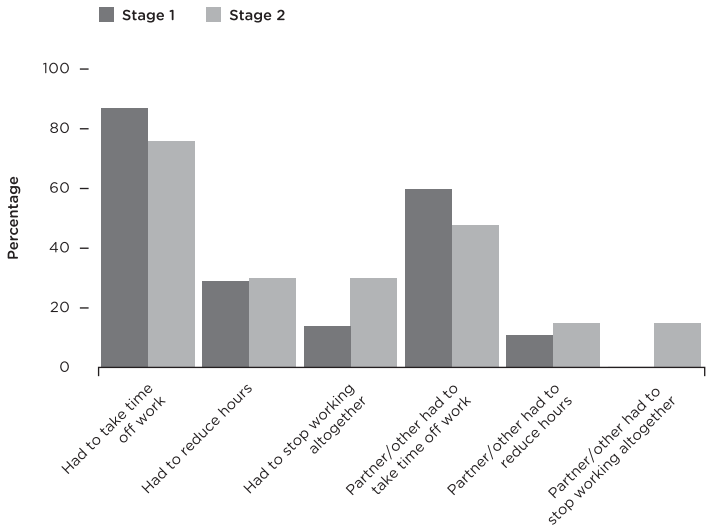
From our survey, it was clear that whether or not women or their partners had to take time off work or give up work completely was linked to the stage at which their cancer was diagnosed. Women who were diagnosed with a stage 1 cervical cancer were slightly more likely than those with more advanced cervical 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:

- 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 |

Changes in income

Being self-employed I had to stop work altogether and was unable to find someone to fill my place. I lost approximately 75 per cent of my clients – they never came back when I started work again. It has taken nearly three years to build back my practice.

Woman diagnosed at stage 2, in remission

Almost all of the women who reported their working status said that they were in work at the time they were diagnosed – 61 per cent were working full time, 17 per cent were working part time and 6 per cent were self-employed. According to our survey,

- 87 per cent had to take time off work
- 31 per cent had to reduce their working hours
- 22 per cent had to stop working altogether
- 46 per cent said their partner had to take time off work
- 13 per cent said their partner had to reduce their hours
- 6 per cent said their partner had to stop working altogether

Almost all of the women surveyed reported having to make adjustments to either their, or their partner's, working hours – either stopping work (temporarily or permanently) or reducing the number of hours worked. Two women said that their partners had had to increase their working hours – in both cases, these were self-employed women who had to stop work altogether, with the consequence that their partners had to increase their hours to make up the lost income. 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.

We asked women to estimate their total household income before and after diagnosis with cervical cancer, in order to ascertain the extent of long-term income loss as a result of cervical cancer. Comparing income before and after, we found that income loss across the sample as a whole – between the time of diagnosis and the present – was negligible.

Although income change across the whole sample was negligible, this average masks some wide variations in the experiences of individual women. The vast majority of women in

Table 10 **Change to mean weekly income for women with cervical cancer, by stage of cancer diagnosis**

| Cancer stage ⁴⁴ | Mean income before diagnosis | Mean income after diagnosis | Income change |
|----------------------------|------------------------------|-----------------------------|---------------|
| 1 | £729 | £800 | +£71 |
| 2 | £720 | £646 | -£74 |
| 3 | £825 | £685 | -£140 |

our sample (83 per cent) were now cancer-free, and several years had passed since the diagnosis for many of them. The original diagnosis for 18 per cent (almost 1 in 5) of our sample was more than five years ago, and for 43 per cent (more than 2 in 5 women), it had been more than two years since they were originally diagnosed. Thus many women who had reduced their working hours on diagnosis, or stopped working temporarily, were very likely to have returned to full-time work, maybe received a pay rise or had been promoted. Through natural career progression, their incomes were now higher than at the time of their diagnosis.

At the other end of the scale, 22 per cent of women in our sample who were working at the time of their diagnosis had to stop working altogether, and 5 per cent of women had a partner or other family member stop working altogether to care for them. The mean income loss for this group was substantial – dropping from £800 a week before diagnosis (£41,600) to £585 afterwards (£30,400) – a substantial drop of £215 a week. In one extreme case, both the woman herself and her partner or another member of her family had had to stop working, resulting in a drop in income of approximately £575 a week (£29,900 a year).

As discussed in the previous chapter, there is a clear link between changing working patterns and stage of diagnosis, with a knock-on effect on income. Those in the latter group of women who had to stop working altogether, post-diagnosis, and experienced loss of income as a result, were disproportionately more likely to have been diagnosed at stage 2 or later (see figure 4).

Table 10 shows the change in average weekly income for women following diagnosis with cervical cancer, by stage of

Box 5

The total financial burden of cervical cancer per month

Combining all of the additional costs, and taking into account changes in income post-recovery, the average financial burden facing women diagnosed with cervical cancer adds up to £487 a month (figure 5) – or £5,844 over the course of a year:

| | |
|------------------------------------|-------|
| Cancer-related costs | -£389 |
| Additional costs of daily living | -£105 |
| Change in income | +£7 |
| | |
| Overall financial burden per month | -£487 |

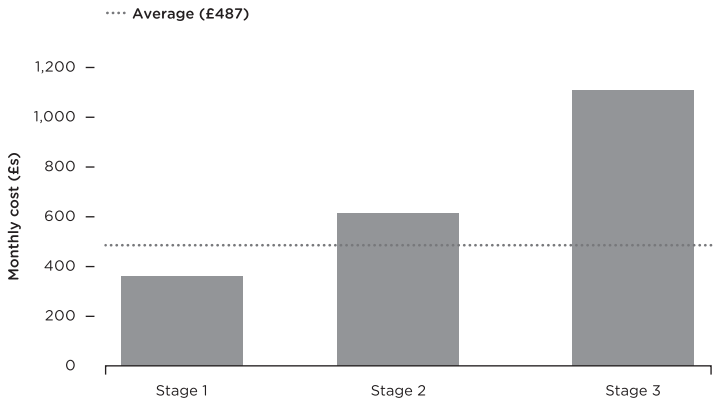
This picture is slightly brighter for women diagnosed at stage 1, and bleaker for women whose cancer has progressed to stage 2 or 3.

| | |
|------------------------------------|-------|
| Stage 1 | |
| Cancer-related costs | -£340 |
| Additional costs of daily living | -£91 |
| Change in income | +£71 |
| | |
| Overall financial burden per month | -£360 |

| | |
|------------------------------------|-------|
| Stage 2 | |
| Cancer-related costs | -£427 |
| Additional costs of daily living | -£112 |
| Change in income | -£74 |
| | |
| Overall financial burden per month | -£613 |

| | |
|------------------------------------|---------|
| Stage 3 | |
| Cancer-related costs | -£850 |
| Additional costs of daily living | -£112 |
| Change in income | -£140 |
| | |
| Overall financial burden per month | -£1,102 |

Figure 5 **The total monthly costs of women with cervical cancer, by stage**



diagnosis. As many more women were diagnosed at stage 1 than at stage 2 or 3, the overall effect is an insignificant change in income across the whole sample – though it is clear that women diagnosed at stage 1 were the most likely to have experienced a modest increase in income post-diagnosis, while women diagnosed after this stage were much more likely to see their income fall, and by a larger amount on average, as the cancer progressed.

Figure 5 shows the total monthly costs of women who have cervical cancer, by stage.

Factoring in the different numbers of women being diagnosed at different stages in England currently (see table 11 in chapter 4), and the varying financial impact according to stage, we have calculated that the total financial burden of cervical cancer to all women diagnosed in England in 2011 is around £14 million (£14,198,904).

The higher financial burden faced by women with more advanced cervical cancer is most likely a result of the more intensive treatment received for later stage cancer, and the longer recovery time required. Those diagnosed at a more advanced stage were more likely than those diagnosed at an early stage to

receive more intensive treatments, with a longer recovery time, and more likely to be treated with chemotherapy or radiotherapy (or both). Of the 27 per cent of women who reported that their energy bills had increased following their diagnosis, a disproportionate number had received chemoradiation (41 per cent of all those who had undergone chemoradiation were in this group).

This level of treatment is likely to cause more disruption to a woman's working life, leading to her spending a longer period out of work, potentially forcing her to change jobs once she has recovered – perhaps taking a lower-paid job with fewer hours than she had before – and reducing her opportunities for career progression. In contrast, women diagnosed and treated at stage 1 faced minimal disruption – in some cases taking a week or even less off work after treatment – and were able to resume their natural career progression very quickly, as Lisa's story illustrates.

Case study 3 Lisa – a quick recovery

Lisa was in her 30s when she was diagnosed with stage 1b cervical cancer in April 2012, following an abnormal screening result. As her cancer was still at an early stage, she was advised to have a trachelectomy (surgery which removes the cervix and part of the vagina, while leaving the uterus intact), so that she would still be able to have children in the future. The trachelectomy was performed in late May, and Lisa took a week and a half off work to recover.

Lisa's recovery was fairly rapid – she was up and moving after about 5–7 days, and was 'back to 95 per cent capacity' within a month of her treatment. As she works from home, she was able to start working again while she was still recovering – something that she chose to do as soon as she could, for psychological reasons rather than financial ones: 'I felt it was necessary to get back to work as quickly as possible. I have no family in this country at all, so it was helpful to focus on work rather than cancer.'

As a result of her quick treatment and recovery, Lisa's additional costs were minimal. She estimated that she spent around £100 over the course of a year on petrol and car parking charges when she visited the hospital for check-ups.

Source: Demos interview, name changed

Conclusion

It is clear that women diagnosed with cervical cancer face a personal health crisis, and the emotional impact on them and their families cannot be overstated. It is hardly surprising, then, that the financial impact is not at the forefront of people's minds. Yet the negative effects of this impact can last long after a woman's recovery and, in some cases, exacerbate the emotional and physical strain associated with cancer, making recovery harder.

Our survey shows that the financial impact is threefold for women diagnosed with cervical cancer:

- a range of additional costs associated with illness and treatment – such as medicines, equipment, parking and travel costs
- a range of everyday costs which are higher – such as energy bills or childcare
- the combination of these additional costs with a loss of income, as most women diagnosed with cancer are of working age

Further analysis suggests that these costs are higher, and more frequently experienced, when women are diagnosed with later stages of cancer. Similarly, larger reductions in income resulting from reduced hours or time off work are also associated with more advanced cancers, reflecting the fact that women diagnosed in later stages may well experience more prolonged periods of ill health, and/or more invasive treatments, requiring longer recovery time away from work and with more support.

In this chapter we have focused solely on costs incurred during treatment and recovery. Yet the financial impact of cancer does not end when cancer ends. Many women – particularly those who are treated for more advanced cervical cancers –

How much does cervical cancer cost patients?

experience ongoing medical issues as a result of their treatment, which requires further hospital trips, with all the ensuing costs of travel, car parking and potentially childcare. Women who have been diagnosed with cervical cancer also face significantly higher premiums on insurance products – particularly travel insurance. Some of the financial impacts of cervical cancer therefore are long-lasting.

4 What happens to costs if screening rates change?

As we have seen in chapters 2 and 3, the costs to the individual, NHS and state more widely of cervical cancer very much depends on the stage at which it is diagnosed. Understandably – and like most other types of cancer – the earlier it is identified, the less extensive and intrusive the medical treatment required. This, in turn, is often less disruptive to patients’ lives – requiring less time off work, and so on. Our research thus far confirms this hypothesis – women in our survey reported higher living costs and needing more time off work, while our analysis of the available data concluded that 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. We can conclude, therefore, that the best possible outcome for the health and finances of individual patients and the cheapest possible outcome for the NHS is if as many cervical cancers as possible can be diagnosed at the pre-cancer stage, or while they are still at stage 1a. At these pre-cancerous or early cancerous stages, cervical cancer is largely symptomless – making screening vital as a method of detection. However, as we have seen in chapter 1, screening rates are starting to decline. Investment is undoubtedly required to reverse this trend.

In this chapter we consider the cost savings of such investment, by considering the savings to the NHS and the state more broadly if screening rates were to increase.

Nationally, 78.3 per cent of women aged between 25–64 are screened regularly.⁴⁵ According to the data that Queen Mary University of London provided to Demos for this report, this screening rate detected 2,288 cervical cancers in women aged 25–79 in England in 2011, and around a third of these were detected at stage 1a, a third at stage 1b and a third at stage 2 or

above. As we explain in chapter 2, this costs the NHS around £21 million each year in direct treatment costs, and more than half again in costs to the state as a result of women giving up work or dying (around 590 women annually).

To demonstrate how the number of cancers, mortality and related treatment costs can be affected by the national screening rate, Demos undertook modelling of four different scenarios:

- if national screening rates fell to 70 per cent
- if national screening rates increased to 80 per cent
- if national screening rates increased to 85 per cent
- if national screening rates increased to 100 per cent (all women over 24 were screened regularly)

We calculated the impact each screening rate scenario would have on:

- the prevalence of cancers diagnosed at each stage, in each age range
- the subsequent five-year mortality risk
- the demand on NHS treatments reflecting the different prevalence of cancers diagnosed at different stages in different age bands

Further details on the assumptions we made when undertaking this modelling can be found in the methodological appendix in chapter 1. It is important to bear in mind that the data we use do not include the numbers of pre-cancers detected, or the treatment costs. As explained in chapter 1, the pre-cancer treatment costs are included in the overall cost of the NHS Cervical Screening Programme. It is reasonable to assume that if cervical cancer screening increases, more pre-cancers will be detected, and treatment costs of pre-cancers would increase. As we do not have costs or prevalence for pre-cancer treatment, we have not taken this potential increased cost into account when modelling the savings to the NHS of treating cancers earlier. However, it is clear that treatment of pre-cancer (often either laser cauterisation or a loop excision) is substantially less costly

to the NHS than treatment needed for cancer, whether in early or more advanced forms. In this chapter we demonstrate the next stage of this spectrum – how in increasing the number of earlier stage cancers to be treated, screening saves costs to the NHS by reducing the need for more intensive treatments.

Results of our modelling - improving the national screening rate

Our modelling clearly shows how increasing the screening rate has a significant impact on the number of cancers detected and – importantly – the stage at which these are detected (table 11). As current screening rates, mortality risks and the types of treatment the NHS offers varies by age group, so the potential impact also varies – we have broken our findings down by age group below where relevant.

Table 11 **Number of instances of cervical cancer diagnosed in England in one year (aged 25–79) if national screening coverage were increased to 80%, 85% and 100%, by stage**

| | Screening rate | | | |
|---------------|-----------------|-------|-------|-------|
| | 78.3% (current) | 80% | 85% | 100% |
| Stage 1a | 799 | 771 | 715 | 603 |
| Stage 1b | 780 | 739 | 680 | 533 |
| Stage 2+ | 709 | 651 | 575 | 362 |
| Total cancers | 2,288 | 2,162 | 1,970 | 1,498 |

The figures in table 11 show that the numbers of cancers detected fall as screening rates increase because the number of *pre-cancers* detected increase – the very earliest signs of cervical cancer, taking the form of abnormal cells on the surface of the cervix, before it reaches stage 1a. With laser or cauterisation or loop excision, these abnormal cells can be tackled, stopping cancer before it starts. Therefore, if everyone was regularly

screened as they should be, our analysis suggests that there would be a 35 per cent reduction in the number of cervical cancers diagnosed.

The 1,498 cases of cervical cancer that would be diagnosed with 100 per cent screening coverage assumes that women being screened would have the same mix of screening histories as in the current population. In reality, the reduction in number of cervical cancers over time would not be quite as linear as these numbers imply. If coverage of cervical screening suddenly increased to 100 per cent, the immediate consequence would be that – as was the case after Jade Goody’s death in 2009, when many more women attended screening – there would be a short-term *increase* in the number of cervical cancers diagnosed, as many that were previously ‘hidden’ would be discovered in the new women coming into the screening programme, many of whom would be lapsed screeners or previously unscreened. In the long term, there would be a dramatic fall in the number of cervical cancers.

In addition to the overall reduction in cancers, increased screening rates also leads to the cancers that *are* detected being detected at an earlier stage – so, for example, while 35 per cent of cancers currently detected are at stage 1a, 40 per cent would be detected at stage 1a if screening rates were 100 per cent.

Broken down by age

Our analysis also shows how the benefits of increasing screening rates to 80 per cent, 85 per cent or 100 per cent are distributed by age (table 12).

Using the figures given in table 12, figure 6 shows that the prevalence of cervical cancer detected through screening decreases with age, and that the greatest numerical gains made in reducing cancers (detecting pre-cancer) occurs in the 30–44 age range (where the distances between lines are the greatest in the figure). However, table 12 also shows the potential reductions in cancers as a percentage of the total – and here we can see that women aged between 60 and 70 have the most to gain: as a

Table 12 **Number of instances of cervical cancer diagnosed in England in one year if national screening coverage is 80%, 85% and 100%, by age**

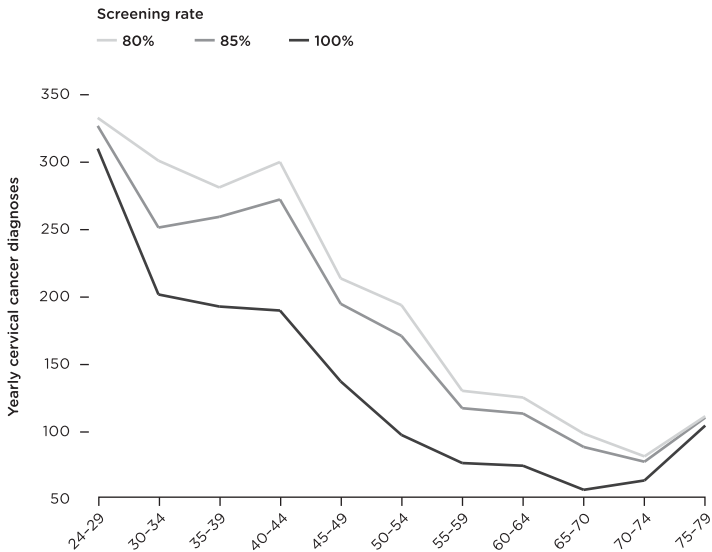
| Age range | Screening rate | | | | Reduction in cancers achieved by 100% screening (%) |
|-----------|----------------|-----|-----|------|---|
| | Current | 80% | 85% | 100% | |
| 25-29 | 353 | 333 | 327 | 311 | 11 |
| 30-34 | 299 | 301 | 251 | 201 | 33 |
| 35-39 | 310 | 281 | 259 | 192 | 38 |
| 40-44 | 323 | 300 | 272 | 189 | 41 |
| 45-49 | 228 | 213 | 194 | 136 | 40 |
| 50-54 | 182 | 193 | 170 | 99 | 46 |
| 55-59 | 141 | 129 | 116 | 75 | 47 |
| 60-64 | 143 | 124 | 112 | 73 | 49 |
| 65-69 | 112 | 97 | 87 | 56 | 51 |
| 70-74 | 87 | 80 | 76 | 62 | 29 |
| 75-79 | 113 | 110 | 109 | 104 | 9 |

group, they would halve their chances of having cervical cancer if they all attended screening aged 60–64.

It is particularly unfortunate that screening rates have also fallen in recent years for those in these later ages (where the most significant decreases in cancer can be achieved). As noted in chapter 1, lower numbers of 25–29-year-olds and 50–64-year-olds are attending screening regularly than in the past.

At the moment, in England, 353 cancers per year are detected in the younger of these groups, and 466 per year are identified in the 50–64-year-olds. More importantly, older women are much more likely to have more advanced stages of cancer – half of cancers detected in the 50–64-year-old groups are at stage 2 or above, compared with about 9 per cent of the 25–29-year-olds. It is unsurprising then that the number of deaths per 100,000 women over five years for these two groups is so different – less than 10 in 100,000 for the 25–29-year-olds compared with 42 in 100,000 of their older peers. Boosting

Figure 6 **Number of instances of cervical cancer diagnosed in England in one year if national screening coverage is 80%, 85% and 100%, by age**

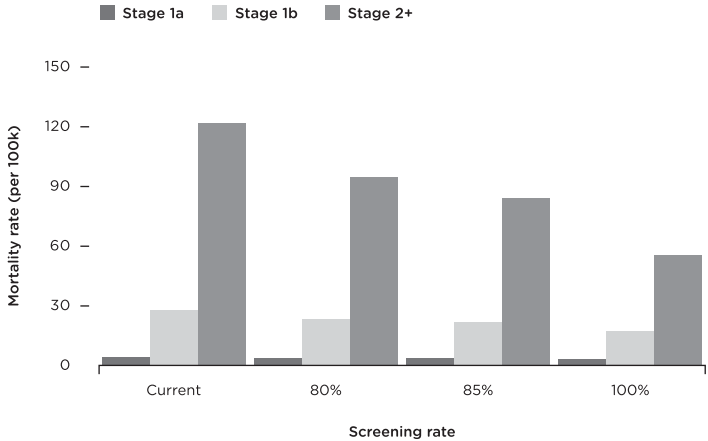


screening rates in this older group – reversing the trend of decline – is therefore crucial. Even a modest increase to 80 per cent would result in a 5 per cent average drop in cancers in this age group, but a 8 per cent drop among cancers diagnosed at stage 2 and above.

What are the implications of these changes?

Reducing the prevalence of cancer through increased screening rates has a number of benefits. The first and most fundamental is reduced mortality. Women whose cervical cancer is detected at the pre-cancerous or earliest cancerous stage have a significantly reduced risk of mortality – it stands to reason, therefore, that with improved screening rates comes improved survival rates of

Figure 7 Deaths over five years from cervical cancer per 100,000 women aged 25–79, by diagnosis stage and screening rate



cervical cancer. Second, the costs to the NHS associated with treating cancer will also reduce. With fewer cancers overall to treat, and more to treat at the earlier stages (where less invasive and less expensive treatments are required), the costs to the NHS reduce with improved screening.

Mortality

Figure 7 and table 13 show the number of deaths by cervical cancer over a five-year period, showing the rates by the stage that cancer is diagnosed – diagnosis at stage 2 or above carries a significantly higher risk of death than if the cancer is diagnosed earlier. It also compares the rates in the three scenarios we modelled – screening rates at 80 per cent, 85 per cent, and 100 per cent – with the current situation where screening rates nationally are 78.3 per cent. Clearly the numbers of deaths (at all stages of diagnosis) fall as screening rates increase. If we achieved a 100 per cent screening rate – if everyone were screened regularly – deaths of cervical cancer would halve over a

Table 13 **Deaths over five years per 100,000 women aged 25–79, by diagnosis stage and screening rate**

| Screening rate | All stages | Stage 1a | Stage 1b | Stage 2+ |
|-----------------|------------|----------|----------|----------|
| (current) 78.3% | 197.6 | 4.2 | 27.8 | 121.5 |
| 80% | 156.8 | 3.7 | 23.3 | 94.3 |
| 85% | 141.0 | 3.4 | 21.5 | 84.2 |
| 100% | 96.8 | 2.9 | 17.0 | 55.4 |

five-year period, resulting in 1,176 lives being saved. Even a modest increase, from the screening current level to 80 per cent nationally, would achieve an 18 per cent reduction in deaths by cervical cancer over a five-year period. An 85 per cent screening rate would achieve a 27 per cent reduction over five years.

Costs to the NHS

As we have seen in chapter 2, the NHS currently spends about £21 million per year on the direct interventions and operations needed to treat cervical cancer – not including follow up or nursing care, palliative care and so on. We calculated this by using data provided by Queen Mary University of London on the types of treatment given to women with cervical cancer, broken down by the stage of their diagnosis and the age at which they were diagnosed. Understandably, the types of treatments more commonly used when cancers are diagnosed at later stages are more costly – such as hysterectomies, often combined with radiotherapy or chemotherapy. As the treatment breakdown per age range was not as granular as our treatment rate data (the former were collated in four age ranges – 25–40, 40–54, 55–64 and 65+, while our data regarding prevalence and mortality were broken down into 11 five-year age bands between 24 and 79) we are unable to provide the same age-cohort breakdown of NHS costs as for our other analysis. Nonetheless, below we provide overall costs to the NHS in the four scenarios, as well as an age breakdown in the four age cohorts for which we had data.

Table 14 **Annual cost of cervical cancer to the NHS in England currently and if the screening coverage was increased to 80%, 85% or 100%**

| Screening coverage | Direct cost to the NHS |
|--------------------|------------------------|
| (current) 78.3% | £21,126,025.13 |
| 80% | £19,676,163.56 |
| 85% | £17,661,640.14 |
| 100% | £12,111,586.03 |

If screening rates improve the numbers of cancers needing treatment and the need for more expensive treatments (such as hysterectomy) due to earlier diagnosis are reduced. Table 14 shows current NHS treatment costs borne and those under the three scenarios we modelled.

This shows that the savings to the NHS – just in direct costs – would be £1.44 million per year with just a modest 1.7 percentage point increase in the national screening rate. If everyone was screened regularly as they should be, the NHS would save £9 million every year, just in direct treatment costs.

When breaking this down by age range, we see that the greatest savings would be in the 55–64 age group, where cancers are both more numerous and detected at later stages, so treatment costs are higher (table 15). Moving from the current screening rate to a 100 per cent screening coverage would lead to costs in the oldest and youngest groups falling by around one-third, while for 40–54-year-olds the costs would halve, and among 55–64-year-olds costs would fall by 54 per cent. More modest increases in the screening coverage – say to 80 per cent – would reduce the differences in the amounts saved by age group. There would be a reduction of around 15 per cent in NHS treatment costs for 25–40-year-olds and 40–54-year-olds, and of 22 per cent for 55–64-year-olds. It is particularly concerning, therefore, that this latter age group (55–64-year-olds) – where NHS savings are potentially the highest through improved screening – is the one for which screening rates have been declining in recent years.

Table 15 **Annual cost to the NHS in England of treating cervical cancer currently and if screening was increased by 80%, 85% or 100%, by age**

| Age range | Screening rate | | | |
|-----------|----------------|---------------|---------------|---------------|
| | Current | 80% | 85% | 100% |
| 25–39 | £5,377,398.94 | £4,518,325.44 | £4,518,325.44 | £3,537,894.49 |
| 40–54 | £6,963,938.05 | £5,923,967.91 | £5,923,967.91 | £3,447,330.07 |
| 55–64 | £3,912,665.24 | £3,034,528.40 | £3,034,528.40 | £1,787,365.59 |
| 65+ | £4,872,022.90 | £4,184,818.39 | £4,184,818.39 | £3,338,499.67 |

We have included the costs of treating women over 65 in table 15. In England, women over 65 are not invited for regular screening through the NHS Cervical Screening Programme in England, and so screening coverage could not be increased in the same way as it could be among women who fall within the target population (ages 25–64).

Nevertheless, interventions aimed at boosting the numbers of women attending screening between the ages of 50 and 65 in particular would have an effect on the numbers of cancers being diagnosed and treated – and the costs of doing so – in the 65+ age group. Screening among older women has been shown to provide greater protection against cervical cancer than in younger women (83 per cent reduction in cancers in women aged 55–69 being screened once every five years, compared to only 61 per cent in women aged 20–39, who are screened more frequently at three-yearly intervals⁴⁶). Regular screening up to the age of 65 (when routine screening ends in England) would therefore offer some protection to women over this age.

The costs of dying

As we have seen in chapter 2, when women die of cervical cancer – apart from the devastating blow to their families – they can be considered a financial loss to the state. Many women diagnosed with cervical cancer are in work, and many have children – so their death also leaves a legacy of partners and families having to

raise children without a mother. It is for this reason we have 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. In our survey, 84 per cent of the women who had had cervical cancer had been in work at the time of diagnosis – higher than the average labour force participation rate of 67.2 per cent. It is possible that those who are diagnosed with cervical cancer are more likely to be in work, but we can use these two figures as the lower and upper bounds of the likely costs of the death of these women.

Our analysis shows that in England currently 2,137 women aged 25–64 (roughly the working age population) die over a five-year period of cervical cancer. We can estimate that between 1,436 (67.2 per cent) and 1,795 (84 per cent) of these were in work when they were diagnosed, so approximately between 287 and 359 working women currently die of cervical cancer each year.

Our survey also shows that 57 per cent of those diagnosed with cervical cancer have children, so we can cost their deaths, in purely tax terms, as:

- working mothers = 164–205 deaths per year @ 150% tax take of median income
= £1.4–1.74 million per year
- working non-mothers = 123–154 deaths per year @ 100% tax take of median income
= £695,000–870,000 per year

Thus the total current cost to the Treasury of cervical-cancer-related mortality ranges is around £2.1–2.6 million per year.

As improved screening rates reduce the risk of dying from cervical cancer, the costs of cervical-cancer-related mortality also falls:

- cost of cervical-cancer-related mortality with 80 per cent screening rate = (with 143–179 deaths among working mothers

What happens to costs if screening rates change?

and 108–135 among non-working mothers) = £1.8–2.3 million per year

- cost of cervical-cancer-related mortality with 85 per cent screening rate = (with 126–157 deaths among working mothers and 95–119 among non-working mothers) = £1.6–2 million per year
- cost of cervical-cancer-related mortality with 100 per cent screening rate = (with 79–99 deaths among working mothers and 60–74 among non-working mothers) = £1–1.2 million per year

Therefore if everyone was screened as they should be, the costs to the Treasury of cervical-cancer-related deaths would more than halve.

What if screening coverage keeps falling?

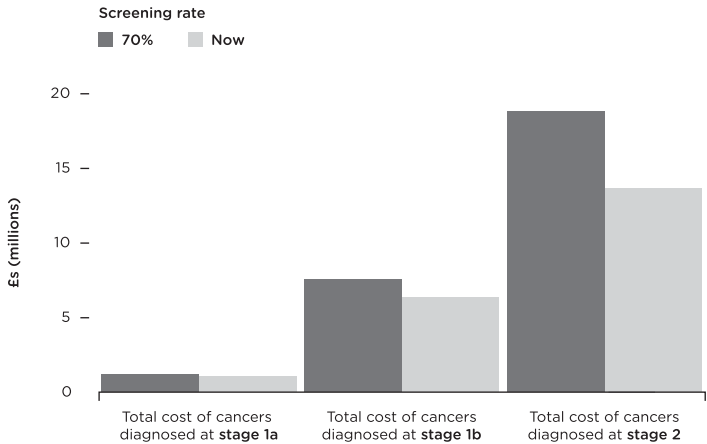
In addition to the three positive scenarios – where screening rates increased nationally – we also modelled what would happen if screening rates fell to 70 per cent. Some age groups are perilously close, or even below this screening rate already – for example the 25–29 and early 30s age groups. What if the entire female population were to mimic the screening habits of these younger women?

Our analysis demonstrates, predictably, that fewer pre-cancers would be detected – in other words, more women would be diagnosed with cancer, at later (harder to treat) stages, and mortality would rise. As a result, the cost to the NHS would increase to £27,585,702.22 per year – an additional £6.5 million per year compared with current costs. The greatest increase in costs would be in the treatment of later stage cancers (figure 8).

The view from Scotland, Wales and Northern Ireland

Unfortunately, the risk of developing cervical cancer based on screening history, or the incidence of cervical cancer broken down by stage of diagnosis, were not available for any of these three countries. This means we cannot link cervical screening

Figure 8 **Cost per year to the NHS of treating cervical cancer, current and if screening rate fell to 70%**



with cervical cancer outcomes – and thus costs – in the same way that we have for England.

However, there are data on the numbers of cancers diagnosed per age group, and the mortality rates. We have used three-yearly averages to estimate cancer incidence in Scotland, Wales and Northern Ireland. This enables us to compare the rates of cervical cancer in these three nations, and we see that the lower the screening rate, the higher the instances of cervical cancer and related deaths (table 16).

With this information, we are able to project the possible impact of improved screening rates of these populations.

If we assume the screening programme in Scotland and Northern Ireland achieves the same level of success at detecting cancers and pre-cancers as in England, then increasing screening rates in these two nations will have a commensurate impact on the prevalence of cancers and mortality rates as it does in England. Overall, the gains made in the modelled scenarios will be greater than in England, because the improvement to 80 per

Table 16 **Cervical screening rates and cervical cancer incidence and deaths in England, Scotland, Wales and Northern Ireland, 2010/11⁴⁷**

| | Cervical cancer screening rate (of eligible female population) ⁴⁸ | Cervical cancer rate aged 25-79 per 100k of population | Deaths from cervical cancer diagnosed aged 25-79 per 100k of population |
|---------------------------------------|--|--|---|
| England (screened age 25-64) | 78.3% | 13.12 | 3.3 |
| Wales (screened age 25-64) | 79.5% | 13.52 | 4.4 |
| Scotland (screened age 20-60) | 78.1% | 16.39 | 5.1 |
| Northern Ireland (screened age 25-64) | 77.3% | 16.81 | 3.2 |

cent screening rates will be larger from the lower Scottish and Northern Irish baselines.

Tables 17, 18 and 19 show the one-year prevalence of cancers in Scotland, Wales and Northern Ireland, now and under different screening rates, assuming the impact of improved rates would be the same as in England. Note the age ranges in Wales are over ten years not five years, as there are fewer instances of cervical cancer in Wales as it has a smaller population than Scotland.

We know that between 2009 and 2011, on average, 298 women in Scotland and 136 in Wales were diagnosed with cervical cancer aged 25-79 each year, and 95 were diagnosed on average in Northern Ireland each year between 2007 and 2010. We also know that on average 89, 48 and 17 died of cervical cancer each year in these three nations respectively. In England, the equivalent (looking over a five year average) is that on average 2,288 cancers were diagnosed, and on average there were

Table 17 **One year prevalence of cervical cancer in Scotland for different screening rates, by age group**

| Age range | Screening rate | | | |
|-----------|----------------|-----|-----|------|
| | Current | 80% | 85% | 100% |
| 24-29 | 28 | 24 | 24 | 23 |
| 30-34 | 40 | 37 | 31 | 25 |
| 35-39 | 36 | 30 | 27 | 20 |
| 40-44 | 41 | 35 | 32 | 22 |
| 45-49 | 36 | 31 | 28 | 20 |
| 50-54 | 24 | 23 | 20 | 12 |
| 55-59 | 26 | 22 | 19 | 13 |
| 60-64 | 19 | 15 | 14 | 9 |
| 65-69 | 15 | 12 | 11 | 7 |
| 70-74 | 16 | 13 | 13 | 10 |
| 75-79 | 17 | 15 | 15 | 14 |

Table 18 **One year prevalence of cervical cancer in Wales for different screening rates, by age group**

| Age range | Screening rate | | | |
|-----------|----------------|-----|-----|------|
| | Current | 80% | 85% | 100% |
| 24-29 | 15 | 13 | 13 | 12 |
| 30-39 | 33 | 29 | 25 | 19 |
| 40-49 | 33 | 28 | 25 | 18 |
| 50-59 | 19 | 17 | 15 | 9 |
| 60-69 | 17 | 13 | 12 | 8 |
| 70-79 | 19 | 16 | 16 | 14 |

587 deaths per year. As we can see from table 16, these figures suggest that mortality rates in Scotland are higher than those in England, Northern Ireland and Wales.

If the increases in screening rates we modelled in England reduced mortality levels in Scotland, Wales and Northern Ireland to the same extent as they would do in England, we would find that an 80 per cent screening rate would achieve an 18 per cent drop in mortality rates on average over three years, to 73, 39 and 15 deaths on average per year in Scotland and Wales

Table 19 **One year prevalence of cervical cancer in Northern Ireland for different screening rates, by age group**

| Age range | Screening rate | | | |
|-----------|----------------|-----|-----|------|
| | Current | 80% | 85% | 100% |
| 24-29 | 16 | 14 | 14 | 13 |
| 30-34 | 16 | 15 | 12 | 10 |
| 35-39 | 17 | 14 | 13 | 10 |
| 40-44 | 11 | 9 | 8 | 6 |
| 45-49 | 11 | 9 | 9 | 6 |
| 50-54 | 5 | 5 | 4 | 2 |
| 55-59 | 6 | 5 | 4 | 3 |
| 60-64 | 4 | 3 | 3 | 2 |
| 65-69 | 2 | 2 | 1 | 1 |
| 70-74 | 3 | 3 | 2 | 2 |
| 75-79 | 5 | 4 | 4 | 4 |

respectively. A screening rate of 85 per cent would achieve a 27 per cent drop (65, 35 and 13 deaths) and a 100 per cent screening rate would achieve a 44 per cent drop (50, 27 and 9 deaths).

The health systems in these three nations are very different from the one in England, and we do not have Wales or Scotland-specific data on the distribution of screening rates by age cohort, nor the typical allocation of different treatments according to age and stage of diagnosis in these three nations. We are therefore unable to cost the impact to the NHS of the four scenarios – though can clearly predict reduced treatment costs associated with earlier diagnosis and fewer cancers (there would be more pre-cancers).

5 Reducing the costs of cervical cancer: conclusions and recommendations

Cervical cancer can be a very expensive business – for women who are diagnosed with the illness, for the NHS and for society in general. On average, each woman diagnosed with cervical cancer costs the NHS and the state a combined total of around £13,600 a year, and faces a personal cost of around £5,800 over the course of a year, through lost income and additional spending. This is an average cost only, and the costs are considerably higher for some women, often those whose cancer is diagnosed at a comparatively late stage. For each successive stage, the financial impact of cervical cancer on women – and the cost to the NHS of treating it – increases markedly. The most effective way of reducing such costs to the state and the individual is by preventing cervical cancer, or catching it at the earliest possible stage.

Improving screening rates

I just can't understand why so many women don't bother going for regular smear tests. The consequences of a cervical cancer diagnosis is profound. It turns lives upside down and inside out. Women and men should do everything possible to avoid HPV developing into cancer. For women, a simple smear test will detect the virus before it wreaks havoc. If they knew the consequences of having cervical cancer, the women who don't get tested would be queuing up in droves to get it done!

Woman diagnosed with stage 2 cervical cancer, now in remission⁴⁹

The dramatic results that could be achieved if cervical screening coverage was increased – lives saved, number of

cervical cancers avoided, financial impact on women and their families mitigated, and costs saved to the NHS – add weight to the importance of boosting screening rates. But the question is – what is the best way to achieve this?

The consensus among our interviewees was that boosting uptake of screening invitations remains a tough nut to crack – particularly as the trend towards a plateau and subsequent dip in the number of women regularly screened is a worldwide trend – what Julietta Patnick, Director of the NHS Cancer Screening Programmes, describes as ‘a zeitgeist, as much as anything’. This makes it very difficult to isolate the precise factors that underlie this trend, and develop strategies for beginning to reverse it.

However, some interventions in the UK and internationally have had a demonstrable impact on cervical screening uptake, and these, along with the insight of the experts whom we spoke to in the course of this research, allow us to identify a number of ways forward for England – and the UK more widely.

Public role models and the ‘Jade Goody effect’

Immediately following the diagnosis of TV celebrity Jade Goody with advanced cervical cancer and her death at the age of 27, there was a sharp upturn in both the number of women attending screening, and the incidence of cervical cancer. Between 2008 and 2009, screening coverage among women aged 25–29 jumped by 12 per cent, following a steady year-on-year decline since 2002.

This increase in incidence occurred because many of these women were being screened for the first time, and so a lot of ‘hidden’ cancers were picked up all at once, rather than over a period of years.

The experts whom we interviewed for this research suggested several reasons why Jade’s death was so powerful in encouraging more young women to attend screening. First, her celebrity status and the high-profile nature of her diagnosis and death made cervical cancer front page news, and highlighted the importance of screening to a wide audience. Second, her story also resonated with precisely the audience that the Cervical

Screening Programme struggles most to reach. The women who were most interested in reading about Jade, and identified most with her, were younger and often from disadvantaged backgrounds – exactly the groups who are least likely to attend screening regularly, as we discussed in chapter 1. They are also more likely to be at risk of cervical cancer, because of their low screening rates and as they tend to have started having sex earlier and are more likely to smoke – both risk factors for the disease.

It is incredibly sad that one woman had to lose her life to cervical cancer for so many others to have theirs saved, but one of the key lessons from Jade's death is that women in the younger 'at-risk', underscreened population respond far better to a call for screening from somebody who talked to them on the same level – with whom they identified and who was part of their daily lives through TV and magazines – than to appeals from healthcare professionals. There is scope here then perhaps for cervical cancer 'celebrity ambassadors' to promote the idea of cervical screening.

Dr Tracie Miles observed that as a preventable cancer, cervical cancer has the advantage that women do not have to wait until they have the disease to do something about it – and not all lives need to end as Jade's did:

Actually having somebody popping up and saying 'look, I go for my smears', somebody who people that age can relate to... I think a media campaign, or somebody famous and recognisable and credible to the population that we're not getting hold of.

Tracie suggested that soap storylines could be a good hook for awareness-raising campaigns – citing a plot in *Eastenders* several years ago, where a character was diagnosed with cervical cancer. At the time, Jo's Cervical Cancer Trust had a lot of input into the portrayal of cervical cancer, to ensure that it was as accurate and educational as possible. Tracie suggested that to reach an older audience, a programme like *The Archers* could feature a cervical cancer storyline.

Developing a 'screening habit'

Andy Nordin spoke about the importance of inculcating a 'screening habit' in women as early as possible, so that going for screening becomes part of a woman's routine. Once a woman has delayed her first appointment by a year or more, she might just decide to wait until her next invitation comes around before making an appointment, and then the same thing can happen all over again. The 'Put it on Your List' information leaflets produced by NHS Scotland include 'go for cervical screening test' alongside things like 'renew travel card' and 'book haircut', in an attempt to encourage women to see screening as a matter of routine.⁵⁰

Getting screening onto women's radars could begin even before women receive their first screening invitation, during sex education lessons in schools, for example:

People have suggested... that we are not getting the women when they are young. Cervical screening ceases to become a routine and a habit when they're perhaps learning about women's other health issues and contraception issues and all those sorts of things. If you don't include screening at that point in time, then it's a certain concept that needs to be introduced [later on].

Given the introduction of routine HPV vaccination of 12–13-year-old girls in schools in England, schools – and the NHS – now have a perfect opportunity to reach young women pre-screening age, by delivering strong messages about HPV, cervical cancer and the importance of screening, alongside vaccination. This is especially important, given the risk – noted above – that vaccination will itself reduce screening rates, by lulling women into a false sense of security about their cervical cancer risk.

GPs as gatekeepers

Women are invited to attend screening through their GP, and it is often a GP – or a GP practice nurse – who carries out the procedure. As the 'frontline' of the Cervical Screening Programme, GPs clearly have an invaluable role to play in

encouraging more women to be screened. Although all GP surgeries are set a target of achieving 80 per cent coverage of cervical screening among the target age range of women, there are no incentives for them to meet this target, and our expert interviewees considered that some surgeries are trying harder than others. When the national programme was first set up in 1988, GPs had a financial incentive to have at least 80 per cent of women regularly attend screening, as they were paid a higher rate by the NHS if they met this target. In the context of the potential cost savings outlined in the previous chapter, as well as the reduced incidence and mortality from cervical cancer that result from improved screening coverage, it would seem returning to a preferential payment system would provide good value for money.

At the level of individual contact between GPs and women of screening age, GPs need to understand the reluctance or indifference that many women feel about screening, and rather than expecting women to come to them, do everything possible to bring screening to women. If GPs are the gatekeepers, then they need to be throwing the gates open and rolling out the metaphorical red carpet.

There are several ways that they can do this. If a woman attends an appointment with her GP at around the time her next screening is due, or if the GP's system shows that her patient's screening is overdue, the GP must flag this up in the course of the appointment, and be willing to discuss it and answer any questions from the woman. Better yet – if the appointment is a routine one, a GP could offer to do the test right there and then. One woman responding to the Shropshire PCT and Telford and Wrekin NHS survey mentioned in chapter 1 said that being able to be screened 'then and there' while at the GP for another appointment, just to 'get it out of the way', would help overcome some of the nervousness and reluctance.⁵¹ This is the ideal situation – and gets around a lot of the practical barriers to screening as well. If a woman is already at her GP's surgery, and can be offered screening on the spot, she does not have to worry about calling up and making an appointment, fitting it in around work, or finding someone to look after the children. The

test itself is very quick – lasts only 5 minutes – and would not add significantly to GPs' workload – nonetheless, a financial incentive to boost local screening rates could help offset this and recognise the additional testing.

To be able to offer screening to any woman whose test was overdue who happened to be in the surgery, all GP surgeries would need to have somebody on hand who had been properly trained to take a cervical swab. One of the reasons given by many women for putting off screening is the idea of a male GP or nurse performing the screening – this was identified as a factor in the literature reviewed by Shropshire PCT and Telford and Wrekin NHS. If all GP surgeries and community health clinics were able to guarantee that women could ask to have their screening test performed by a woman, this would undoubtedly help set many women's minds at rest.

Stating the risks

Several of the people we interviewed drew comparisons between cervical cancer and other proactive, preventive behaviours, where the risk that you are preventing appears to be a long way in the future. For example, Professor Kitchener compared it to smoking:

Cervical screening is a precaution that has got huge benefits, but not at the time – there are no symptoms associated with an abnormal smear. So it is more about taking responsibility. It is a bit like smoking – so when you are young, your lungs are fine and you feel well and it is not a big deal. It is only when you reach older age that the effects kick in, or the benefits of having avoided that in the past are felt. So I think that it is more along the lines of taking responsibility for your health in a positive sense.

Peter Sasieni used the analogy of taking out insurance – another form of preventive behaviour:

Most people take out insurance on their homes, and economically that is a bad decision because the premiums have got to be more than the payout or the insurance companies would go bankrupt... If you take out insurance,

most of the time you run at a loss, so why can't we think about it in a similar way for screening? You're not running at a loss, but you might be thinking, 'Oh I will spend 15 minutes going for a screening and it might be a bit uncomfortable and I'm probably not going to benefit like some people do, but I can spare 15 minutes and... if I can avoid cancer then that's definitely worth doing. I can afford the insurance premium, so I'll do it.'

Framing cervical cancer in these sorts of terms of the relative risks to individual women – rather than women as whole – may help women to better weigh up the costs and benefits of screening, and make a better judgement about its importance to their lives. This could take the form of a statement such as ‘x in 100 women of your age who regularly attend screening are diagnosed with cervical cancer each year, compared with y in 100 who have not been screened’. The expert testimony heard by Demos throughout this research suggests that this approach might prove effective – but as with all public health messages designed to encourage behaviour change, further message-testing with the public will be required to identify the types of messages that resonate most with key groups, and are most likely to encourage increased uptake.

Alternative methods of testing

One thing that there is currently no way of getting around is the procedure itself – which many women find uncomfortable and embarrassing. Being able to offer women other ways of being tested, which are sensitive and reliable enough to be analysed in a laboratory, could do a lot to help boost the popularity of screening.

HPV testing – which is currently being piloted as the primary method of screening in the UK – creates some opportunities. Researchers in the Netherlands have looked at the possibility of using urine samples to test for HPV, and evidence so far suggests that urine may be useful as a screening tool, although it is more sensitive in high-risk populations than low-risk ones.⁵²

Elsewhere, self-testing for HPV has been piloted in Mexico⁵³ and trialled in the Netherlands,⁵⁴ after studies

comparing the sensitivity and accuracy of samples collected by women themselves with samples collected by healthcare professionals found self-sampling to be no less effective at detecting pre-cancerous changes to the cervix.⁵⁵ Women who were lapsed screeners were also more likely to accept an invitation to be screened if they were offered self-sampling.⁵⁶

Depending on the results of the HPV primary screening pilots currently under way, the screening programme may in future use HPV testing as the primary form of screening – and only look for cervical cell abnormalities if an HPV test shows a positive result. This would open the door for methods like urine sampling and self-sampling, to be looked at in more detail, to see whether they are suitable for use in the national screening programme.

Conclusions and recommendations

Helping women mitigate the financial impact of cancer

Cervical cancer – and its impact on women and their families – can never be entirely prevented. Our analysis shows that even with 100 per cent screening take-up in the current population, 1,493 cancers per year would be diagnosed after one year – over 200 of these at stage 2 or above. However, where cancer, and its costs, cannot be prevented, they can be mitigated.

Our research suggests that childcare was a particular burden for women who were diagnosed who had young children to look after, costing on average £263 a month. Travel to and from hospital appointments, which affected almost all women, was also a substantial cost. Two-thirds had incurred extra costs on driving to and from hospital, costing on average £94 a month, with a similar number paying hospital car parking charges, at a cost of £64 a month. Almost half had spent money on specialist food and dietary supplements, and half again had spent money on non-prescription medicines and medical products, such as painkillers and bandages.

Moreover, the bills and more general costs of daily living of a high proportion of women with cervical cancer increased while they were ill, while women whose cancer was diagnosed at a

more advanced stage – who were more likely to take time off work or stop work altogether – had a substantial loss of income, totalling thousands of pounds a year.

There is a range of measures that could ensure that women diagnosed with cervical cancer are spared some of these costs, and that lost income is kept to a minimum. Drawing on previous Demos research on the costs of cancer, and reflecting on the expert interviews and reports from women diagnosed with cervical cancer themselves, we make the following recommendations:

- 1 Free patient transport run by the NHS should be extended to a wider group of people. Currently, this service is restricted to people on low-incomes, or with visual or mobility difficulties that make other forms of transport impossible to use. We believe that treatment for cancer – which can last months and require several visits a week for radiotherapy or chemotherapy – ought to be supported with free transport.
- 2 The Government's new childcare subsidy scheme should be extended to parents who are undergoing treatment for cancer. The scheme, set to be rolled out in September 2015, will currently be available to 'anyone working part time and earning more than £50 a week, parents on maternity, paternity and adoption leave and those starting their own business'.⁵⁷ Extending this to parents receiving treatment for long-term illnesses such as cancer could help significantly reduce the cost of private childcare while they attend hospital appointments.
- 3 People being treated for cancer and their partners should have a legal right to request flexible working arrangements from their employer, including the opportunity to work from home, or work reduced or flexible hours, in order to accommodate treatment schedules, the side-effects of treatment, and the recovery process.

Preventing cancer and its financial impact by boosting screening rates

There are clearly ways in which cervical cancer – and other cancers – can be made less expensive for people who are diagnosed with them. However, we believe the Government, the NHS and cancer charities can be more ambitious in mitigating the impact of cervical cancer and preventing many cervical cancers from occurring to begin with.

As we have demonstrated, improving cervical screening uptake holds the key to achieving this – as well as keeping costs to a minimum by detecting cancers at the earliest possible stage, when they are less costly to women, the NHS and society as a whole. Therefore, measures that help to boost screening uptake will not only prevent cancers and save lives but also reduce costs.

In order to tackle the range of emotional, practical and knowledge barriers that may hold women back from attending screening, and recognising that certain demographic groups need specific interventions targeted at them, we make the following recommendations:

- 1 Awareness programmes to encourage screening take-up are vital. We note that cervical cancer was not one of the cancers included in the Be Clear on Cancer campaign in 2013, which covered bowel, kidney, bladder, breast and ovarian cancer.⁵⁸ We recommend that Public Health England includes cervical cancer in further campaigns to promote public awareness of the symptoms and risks of cancers. Our evidence suggests that such campaigns should be designed to do two things: first, to state clearly the prevalence and risks associated with cervical cancer and the effectiveness of screening in cancer prevention; second, to normalise screening as healthy, preventive behaviour. Given the somewhat unique status of cervical cancer being highly preventable through regular screening, there are lessons to be learnt here from smoking cessation programmes – but more work needs to be carried out to test which messages resonate most with different groups of women. The NHS and Public Health England could provide small amounts of funding for targeted local screening campaigns, the lessons from which could be shared nationally.

- 2 Mothers and daughters should be targeted for screening through a campaign that encourages them to remind and encourage each other to attend screening appointments. Currently, the two age groups least likely to get screened – and where numbers of women screened are falling most rapidly – are a mother and daughter generation (late 20s and over 50s). As people are often more likely to worry about the health risks to a loved one than the risks to themselves, such a campaign – ensuring mothers encourage their daughters out of concern for their wellbeing, and vice versa – could well be more effective than targeting these women directly.
- 3 Cancer charities and health providers should engage young, female celebrities with wide appeal to act as ‘cervical cancer’ ambassadors, in an attempt to recreate some of the effect that Jade Goody’s death had on the number of younger women from disadvantaged backgrounds getting screened. This would be important in order to raise awareness of the importance of screening as a normal part of life for women without symptoms: a preventive, sensible, *smart* thing to do. A high-profile figure being open about their screening habits could do much to dispel screening as a source of embarrassment.
- 4 We recommend GPs should offer ‘on the spot’ screening to women who are due (or overdue) for a screen when visiting their GP for another reason. Where this is not convenient for the patient, the GP should make an appointment for their patient there and then. ‘On the spot’ screening could help women who struggle to make appointments at a convenient time, by combining screening with another appointment, as well as overcoming the tendency of women to put off their screening by giving them an immediate opportunity to be screened – one they would find harder to evade. This would require GPs themselves – and not just practice nurses – to have the skills to carry out cervical screening.
- 5 All GP surgeries should give women the option to have their screening carried out by a woman, whether a female GP or

practice nurse, with no disruption to their scheduled appointment.

- 6 Both of the previous recommendations have potential financial implications for GP surgeries. We recommend that this should be recognised and offset by financial incentives given to surgeries for increasing their local screening rates. Evidence from a ten-year study suggests that the end of financial incentives for cervical screening in the UK caused screening rates to fall (rates picked up again during two years when financial incentives were temporarily reinstated).⁵⁹ This suggests that financial incentives, coupled with the other changes to GPs' working practices, would be effective at boosting take-up of cervical screening by rewarding GPs for their efforts.
- 7 In addition, we also recommend that the Government extends the GP Access Fund to cover a larger number of GP surgeries, to help them extend their opening hours. Those surgeries already covered by the fund should be required to offer an out-of-hours cervical screening drop-in session at least once a month, during the evening or at the weekend, during which women could receive screening without the need to make an appointment in advance. Evidence from Jo's Cervical Cancer Trust, cited earlier, showed that 35 per cent of women were put off screening by the inflexibility of appointment times.
- 8 The NHS should follow the example of other countries and look at whether there are alternative ways in which the screening test can be administered, once HPV testing as the primary screening method (rather than smear testing, as is currently the case) has been fully piloted. We recommend that the NHS should pilot self-screening to establish whether this is any less effective than clinician-led screening; if proven effective, it should be offered at first to low-risk groups.

We believe that the costs of these three activities – creating more targeted outreach messaging to encourage screening, compensating GP surgeries for 'on the spot' screening

capabilities and woman-clinician readiness, and piloting HPV urine and self-screening – are more than offset by the clear financial gains of improved screening rates quantified in this report. The reduced prevalence of cancer and mortality, and the subsequent cost savings associated with this, provide a compelling economic case – to accompany the moral case – for attempting to boost screening in the UK population. This is clearly an area to which clinical commissioning groups should give a high priority.

The overarching conclusion we draw from this research is that cervical cancer, like all other cancers, has a life-changing financial and social impact, which can last long after the medical crisis has been overcome. Yet, unlike most other cancers, cervical cancer is highly preventable – regular screening can very effectively identify and treat pre-cancerous cells in a way which is almost unique. With this in mind, there is clearly an opportunity to substantially reduce the prevalence of this very common cancer using a relatively simple and low-cost method – screening. We believe that cervical screening needs to be treated by public health authorities not just as a diagnostic tool, but as a highly effective early intervention measure, where more intelligence and resources need to be brought to bear.

Methodological appendix

Individual costs

In order to model the costs of cervical cancer to individuals and the state, Demos distributed a survey to Jo's Cervical Cancer Trust clients. These were all women who had previously been diagnosed with cervical cancer, most of whom were now cancer-free; we received responses from 182 women. The survey asked women questions about the stage at which their cancer had been diagnosed, how it had originally been detected, and how this had affected them financially, including about the impact on their ability to work and the additional costs linked to their diagnosis (eg travel to appointments, medicines, equipment and dietary supplements). We also asked which daily living costs (eg energy bills) had increased as a result of their diagnosis, and by how much. This allowed us to compare the costs of women by the stage at which cancer had been diagnosed and by their age group.

NHS costs

To estimate the cost to the NHS and the impact that different screening rates would have on the prevalence of cervical cancer and mortality rates, we worked with the team at the Centre for Cancer Prevention at the Wolfson Institute of Preventive Medicine, Queen Mary University of London. They provided Demos with national data on the rate of cervical cancer diagnosis in England in 2011, broken down by age range (in five-year age bands between 24 and 79) and by stage of cancer at diagnosis, as well as modelling the risks of cervical cancer by screening history. The team also modelled the associated mortality rates of these women over a five-year period, and gave a breakdown of the types of treatment given to women according to their age and

stage of cancer – ranging from cone biopsy, to chemotherapy, radical hysterectomy and a combination of these. Note that not all possible treatments were included in this list – notably, there were no separate figures for the number of women who had received brachytherapy (internal radiotherapy).

Demos used these data to model four different scenarios – if screening rates:

- fell to 70 per cent
- increased to 80 per cent
- increased to 85 per cent
- increased to 100 per cent

We calculated the impact each screening rate would have on:

- the prevalence of cancers diagnosed at each stage, in each age range
- the subsequent number of deaths from cervical cancer over a five-year period
- the demand on NHS treatments reflecting the different prevalence of cancers diagnosed at different stages in different age bands

We had more limited data for Scotland, Wales and Northern Ireland, showing us the overall screening rates in these three countries, average incidence of cervical cancer over a three-year period, and the average estimated number of deaths in the same period. With these figures we were unable to carry out a detailed analysis of NHS or individual costs with any accuracy, but could estimate the impact on the rates of cancer detected and subsequent mortality if screening rates increased.

Assumptions

For the English data analysis, we assumed the success of the screening to be static – in other words, a 70 per cent screening rate would be 10 percentage points less effective at diagnosing

cancer than an 80 per cent screening rate. However, each five-year age band has different screening rates (for example, 82.4 per cent of 50–54-year-olds are regularly screened, compared with 70.6 of 30–34-year-olds), so any increase in screening rates will be more or less radical by age. Moreover, screening achieves different levels of success by age (in diagnosing cancer at earlier stages), and each age experiences different mortality risks. Therefore an increase or decrease in screening rates had significantly different effects in each age group. We therefore calculated the impact of each of the four scenarios on prevalence and mortality by individual age band before summing them, rather than applying the modelling to the entire population. It is also for this reason that the cancers diagnosed, mortality risk and NHS costs do not increase or decrease in a linear fashion (eg an 80 per cent screening rate did not achieve a 10 percentage point decrease in mortality compared with a 70 per cent screening rate).

Each age range (apart from the 25–29-year-olds) had in fact three possible screening outcomes – screened regularly, lapsed screening and never screened. When modelling an 85 per cent screening rate, therefore, we assumed this would represent 85 per cent of women being regularly screened. The remaining 15 per cent – a combination of those whose screening had lapsed and those who had never been screened – were allocated between these two groups according to the existing ratio for that age range. For example, 13.8 per cent of 30–34-year-olds have never been screened, 70.6 per cent are regularly screened, while 15.5 per cent have lapsed in their screening. Increasing this to an 80 per cent regular screening rate involved allocating the remaining 20 per cent as 9.4 per cent never screened and 10.6 per cent with lapsed screening (reflecting the 13.8:15.5 ratio).

Costings

Using *NHS Reference Costs 2012–13* we were able to monetise the cost to the NHS of these varying prevalences providing an overall cost to the NHS in the four screening scenarios outlined above.

Obviously, the precise treatment given to a woman with cervical cancer varies from individual to individual. While the data we were able to access guided us on the percentage of women undergoing different treatments in each age group and according to their stage of cancer at diagnosis, we did not have granular data such as the number of individual chemotherapy or radiotherapy treatments given, whether this treatment is carried out on inpatients or outpatients, and whether the groups who had undergone a hysterectomy followed by chemotherapy and/or radiotherapy had had a 'simple' or 'radical' procedure.

This affects overall costs to the NHS. Demos therefore used average costs where necessary, and conservative estimates of the likely scale of treatment, so the resulting costs from our modelling are likely to be an underestimate of the true treatment cost to the NHS. It should also be borne in mind that these estimates do not include costs not directly linked to the procedure itself (such as nursing or follow-up care, and prescription medication needed post-treatment), nor do they include the cost of experimental treatments or of palliative care.

Other state costs

When a woman dies from cervical cancer, or stops working or reduces her hours as a result of cervical cancer, there is a cost to the state in lost income tax and NICs. Demos used the tax and NICs take from full-time and part-time workers earning the median wage (according to the Office for National Statistics' *Annual Survey of Hours and Earnings* in 2013) to model the current costs to the Exchequer associated with women having to stop work or reduce their hours. To do this, we used the proportion of women who reported that cervical cancer had had one of these impacts on their (or their partner's) working life, then scaled this sample up to reflect the number of women diagnosed every year. We took into account mortality rates, and the impact the death would have on the earning potential of a partner, where women leave behind young children. In our calculations, we assumed that women would reduce their hours from full time (35 hours a week) to part time (16 hours a week).

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

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- 31 Average cost across different cytoreduction (CC) scores, indicating the size of residual tumours.
- 32 Average of different costs, depending on whether the surgery is open, laproscopic or endoscopic, and on the specific CC score, as above.
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Cervical cancer is unique among cancers in that it is largely preventable, yet it still affects around 3,000 women each year. Screening can allow for almost all cervical cancers to be detected and treated before they have a chance to develop. 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 leading to an increase in the rates of cervical cancer.

Beyond these human costs, there is also a substantial financial cost to cervical cancer: not just on individuals but also on the NHS and state more widely. For the first time, *Behind the Screen* models the impact of an improved screening rate. It finds 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. Women diagnosed with cervical cancer faced a combined financial loss of £14 million a year – £5,844, on average, for each woman diagnosed.

If screening coverage were to reach 100 per cent, it estimates that costs to the NHS would almost half, 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. More importantly, incidence of cancer would also almost halve. Based on these findings, the report concludes by offering a set of recommendations for a renewed and concerted effort to increase the number of women regularly attending screening by removing some of the practical, psychological and emotional barriers.

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