

# CERVICAL CANCERS IN THE SOUTHERN HEALTH AND SOCIAL CARE TRUST AREA

### **A Summary Report**

Prepared by the Public Health Agency on behalf of the Cervical Cytology Review Steering Group

11th December 2024

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#### **Executive Summary**

In October 2023 the Southern Health and Social Care Trust (SHSCT) announced that it was undertaking a precautionary Cervical Cytology Review (CCR) in response to an independent report commissioned by the trust which found that there had been ongoing performance issues within its cervical cytology laboratory. The independent report had concluded that while the majority of results issued by the laboratory were correct, a significant number of women were likely to have received negative screening results on tests that would have been identified as abnormal in other laboratories.

The aim of the CCR was to undertake a precautionary review to ensure women had been given the correct result and to minimise the risk of developing cervical cancer for anyone who may have been given an incorrect result.

The CCR was overseen by the SHSCT and the Public Health Agency (PHA) and sought to:

- i. check if women had been given the correct result for their last **smear** test carried out within the review period 2008-2021;
- ii. identify any women who may have been given an incorrect result;
- iii. provide an up-to-date risk assessment (with a new **smear** test) for those women who had a change to their original result or for those women who did not have a slide available to review;
- iv. ensure that appropriate follow-up care and treatment was provided if and as required.

As the focus of the CCR was to identify women who had been given an incorrect **smear** result and minimise their risk of progressing to cervical cancer by providing a new assessment, the CCR did not include women who already had a diagnosis of cervical cancer.

A separate CCR Activity and Outcomes Report has been produced by the SHSCT and the PHA<sup>1</sup>. This current report on cervical cancers is a companion report to the CCR Activities and Outcomes Report and is being published at the same time. The two reports should be read together.

This current report describes the cervical cancers reported within the SHSCT between 2009-2023. This timeframe aligns to the timeframe also addressed within the CCR Report. This report on cervical cancers has drawn on data reported by two sources - the Northern Ireland Cancer Registry (NICR) and from the Audit of Invasive Cervical Cancers (AoICC) which is a routine and ongoing activity within the Northern Ireland Cervical Screening Programme. The report also compares data relating to cervical cancer in the SHSCT with other trusts in Northern Ireland and with England.

<sup>&</sup>lt;sup>1</sup> Southern Health and Social Care Trust Cervical Cytology Review. Activity and Outcomes Report. Public Health Agency and Southern Health and Social Care Trust, 11 December 2024

#### Key findings:

- 207 cases of cervical cancer were diagnosed by the SHSCT between 2009-2023.
- There is no statistically significant difference in the number of cervical cancers diagnosed in the SHSCT between 1997-2021<sup>2</sup> compared with the Northern Ireland average.
- There is no statistically significant difference in the stage at diagnosis of women living in the SHSCT who were diagnosed with invasive cervical cancer when compared with the Northern Ireland average between 1997-2021.
- There is no statistically significant difference in the mortality rate (deaths) from cervical cancer between 2002-2021 in women living in the SHSCT area compared with the Northern Ireland average. Prior to 2002, the mortality rate in the SHSCT was lower than elsewhere.
- In the period 1997-2011, there was a significantly higher rate of precancerous cervical changes diagnosed in those living in the Southern HSCT area compared with the Northern Ireland average. Between 2012-2021, there has been no statistically significant difference.
- SHSCT audit data shows that of the 207 women diagnosed by the trust with cervical cancer between 2009-2023, 12 (5.8%) would have met the criteria for inclusion in the CCR had they not been diagnosed with cervical cancer. This is because their last smear before diagnosis was reported as cytology negative or inadequate by one of the screeners identified as underperforming in the independent report.
- All 12 cases were subject to detailed assessment as part of the Audit of Invasive Cervical Cancer.
   This has identified concerns about the accuracy of the original screening result in 8 of the 12 cases. Five of these 8 are subject to further investigation in line with the regional serious adverse incident (SAI) process.
- An additional number of women (<5) who were diagnosed with cervical cancer in other trust
  areas, would have met the criteria for inclusion in the CCR had they not been diagnosed with
  cancer. This is because their last smear before diagnosis was reported in SHSCT laboratory as
  cytology negative or inadequate by one of the screeners identified as underperforming in the
  RCPath report. These cases are currently being further assessed in detail in partnership with the
  Trust where they were diagnosed.</li>

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<sup>&</sup>lt;sup>2</sup> 1997-2021 is the most up to date data published by the Northern Ireland Cancer Registry.

#### 1. Introduction

In May 2023 a report commissioned by the Southern Health and Social Care Trust (SHSCT)<sup>3</sup> concluded that underperformance within the SHSCT cervical cytology laboratory between 2008-2021, may have led to women being given an incorrect **smear test** result. The report concluded that while the majority of results issued by the laboratory were correct, a significant number of women were likely to have received negative screening results on tests that would have been identified as abnormal in other laboratories.

In October 2023, the trust announced that it was undertaking a Cervical Cytology Review (CCR) which would look at the slides of women whose most recent cervical screening programme **smear** had been screened by staff whose performance may have been below the required standard during 2008-2021. The findings of the CCR are documented in *Southern Health and Social Care Trust Cervical Cytology Review. Activity and Outcomes Report (PHA & SHSCT, 11 December 2024).* 

The aim of the CCR was to undertake a precautionary review to ensure women had been given the correct result and to minimise the risk of developing cervical cancer for anyone who may have been given an incorrect result.

The CCR was overseen by the SHSCT and the Public Health Agency (PHA) and sought to:

- i. check if women had been given the correct result for their last **smear** test carried out within the review period 2008-2021;
- ii. identify any women who may have been given an incorrect result;
- iii. provide an up-to-date risk assessment (with a new smear test) for those women who
  had a change to their original result or for those women who did not have a slide
  available to review;
- iv. ensure that appropriate follow-up care and treatment was provided if and as required.

As the focus of the CCR was to reduce the risk of developing cervical cancer for women given an incorrect result, the CCR did not include women who already had a diagnosis of cervical cancer. Women diagnosed with cervical cancer would not benefit from a call forward within the CCR and their previous screening slides are assessed as part of the invasive cervical cancer audit. This report, which is a companion report to the main CCR Activity and Outcomes Report, describes the cervical cancers diagnosed by the SHSCT between 2009-2023. This timeframe aligns to the period addressed by the CCR (2008-2021). The report also compares data relating to cervical cancers in the SHSCT with other trusts in Northern Ireland and with England.

Please note, all words that appear in bold are defined in the glossary.

<sup>&</sup>lt;sup>3</sup> RCPath Consulting Report, For the Southern Heath & Social Care Trust, May 2023. Redacted version available at <u>Cervical Screening Review | Southern Health & Social Care Trust</u>

#### 2. Cervical cancer

The cervix is found at the opening between the vagina and the womb (uterus) and forms part of the female reproductive system. It is sometimes called the neck of the womb. A cervical cancer is a cancer that is found anywhere in the cervix.

There are two main types of cervical cancer. The most common type is **squamous cell carcinoma** which develops from the cells that line the cervix at the top of the vagina. The other type is **adenocarcinoma**. This develops from a glandular type of cell that is found in the cervical canal. There are also a number of rarer types of cervical cancer which are much less common.

Anyone with a cervix can get cervical cancer and nearly all cases are caused by a persistent infection with high risk types of **human papillomavirus (HPV)**. Cancer usually develops very slowly, over a period of years, from abnormal changes in the cells that line the cervix. Cell changes do not cause symptoms and are not cancer. In many cases, cell changes will go back to normal by themselves. However, in a small number of cases these abnormal cell changes will persist and go on to develop into cancer. Individuals can reduce their risk of developing cervical cancer by participating in cervical screening which aims to identify cell changes early so that they can be monitored and treated if necessary.

#### 2.1. Incidence of cervical cancer

The Northern Ireland Cancer Registry (NICR) was established in 1994 and is based in Queen's University Belfast. The registry collects detailed and accurate data on all cancers diagnosed in Northern Ireland and the services those patients who are diagnosed with cancer receive. The NICR uses this data to produce annual Official Statistics on cancer **incidence**, **prevalence** and **survival** in Northern Ireland and to provide evidence to help inform decision making about cancer services. Further information on the work of the NICR and the most recent publications can be found on the NICR website<sup>4</sup>. A patient information leaflet about cancer registration is available at <a href="www.pha.site/aboutcancerregistration">www.pha.site/aboutcancerregistration</a> or by scanning the QR code below.



NICR data on cervical cancer is available for the period 1993-2021. The NICR reports that for the five year period 2017-2021, there was an average of 81 cases of cervical cancer diagnosed in Northern Ireland each year, with an average of 14 cases per year identified among people who live in the SHSCT

<sup>4</sup>https://www.qub.ac.uk/research-centres/nicr/AboutUs/Registry/

area. The trend in the number of cases of cervical cancer in the SHSCT area from 1993 is shown in **Figure**1. The data for all trusts in Northern Ireland are provided at **Appendix 1**.

The data published by the NICR are based on where women live. The figures presented in this report in relation to the audit of invasive cancer are based on women who were diagnosed by SHSCT. The numbers are not exactly the same as a small number of women who are diagnosed in SHSCT may live in another trust area and similarly, some women who live in the SHSCT may be diagnosed in another trust.

Cases diagnosed

Cases

Figure 1: Number of cases of cervical cancer per year, for women living in SHSCT, 1993-2021. (Source: NICR)

As the size and age profile of the population living in each trust area is different (for example some areas will have more young people), a standard method is used to adjust the figures to show what would be happening if each trust had the same population structure. This is called the European age-standardised population, and it allows a more accurate comparison of information between trusts.

When this method is used, the NICR reports that there is no statistically significant difference in the **incidence rate** of cervical cancer between the SHSCT and the Northern Ireland average. This means that the number of cancers diagnosed each year in SHSCT was no higher or lower than any other trust area. **Table 1** shows this comparative data and fuller information is provided at **Appendix 2**.

Table 1: European age-standardised incidence rate of cervical cancer per 100,000 person years, by HSCT and period of diagnosis. (Source: NICR)

	Belfast	Northern	South Eastern	Southern	Western	Northern
	HSCT	HSCT	HSCT	HSCT	HSCT	Ireland
1997-2001	10.7	11.7	10.0	9.8	9.4	10.5
2002-2006	13.6	9.6	10.3	8.0	8.2	10.0
2007-2011	14.3	11.4	12.8	10.1	10.4	11.8
2012-2016	13.3	7.3	9.9	9.7	9.4	9.7
2017-2021	10.2	7.9	8.4	7.4	11.0	8.8

Information from the Northern Ireland Cancer Registry shows that there is no statistically significant difference in the number of cervical cancers diagnosed in women living in the SHSCT area between 1997-2021 compared with the Northern Ireland average, when adjusted for the population.

Comparative data across the UK<sup>5</sup> for the period 2017-2019, show that the European age standardized incidence rate of cervical cancer in Northern Ireland is similar to the UK average (Northern Ireland = 9.1 new cases per year per 100,000 females, UK average =9.9).

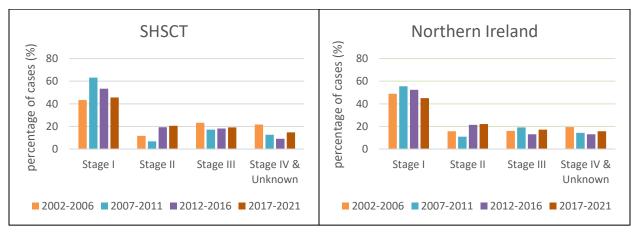
#### 2.2. Stage at diagnosis

The stage of any cancer generally refers to its size and whether it has spread beyond the area of the body where it first started. Cervical cancer is divided into four main stages<sup>6</sup>.

Stage 1 The cancer cells are only within the cervix
 Stage 2 The cancer has spread into the upper part of the vagina or the tissues next to the cervix
 Stage 3 The cancer has spread to the lower part of the vagina, or to the tissues at the sides of the pelvic area (called the pelvic wall), or to nearby lymph nodes
 Stage 4 The cancer has spread to the bladder or bowel or beyond the pelvic area.

As with all cancers, identifying cervical cancer at an earlier stage gives a better chance of successful treatment. **Figure 2** shows the stage of all cervical cancers at diagnosis between 2002 and 2021 in the SHSCT area, and compares this with information for Northern Ireland. Full comparative information for all trusts is included at **Appendix 3**.

Figure 2: Stage at diagnosis of cervical cancer by time period, SHSCT and Northern Ireland (Source: NICR)



<sup>&</sup>lt;sup>5</sup> https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence#heading-Zero

<sup>&</sup>lt;sup>6</sup> https://www.macmillan.org.uk/cancer-information-and-support/cervical-cancer/stages

Analysis of this data by the NICR shows no statistically significant difference in the stage at diagnosis of cervical cancer between people living in the SHSCT area and the Northern Ireland average. This means that women diagnosed with cervical cancer in the SHSCT were generally diagnosed at the same stage as women diagnosed in other trusts.

Information from the Northern Ireland Cancer Registry shows that there is no statistically significant difference in the stage at diagnosis of women living in the SHSCT who were diagnosed with invasive cervical cancer when compared with the Northern Ireland average between 1997-2021

#### 2.3. Deaths from cervical cancer (mortality)

The NICR reports that, for the five year period 2017-2021, there was an average of 20 deaths from cervical cancer in Northern Ireland each year, with an average of two deaths per year in people who live in the SHSCT area.

When the data are adjusted to a standard population profile, there is no statistically significant difference in the mortality rate from cervical cancer between the SHSCT and the Northern Ireland average (see **Table 2**). Fuller information is provided at **Appendix 4**.

Table 2: European age-standardised mortality rate from cervical cancer per 100,000 person years, by HSCT and period of death. (Source: NICR)

	Belfast HSCT	Northern	South	Southern	Western	Northern
		HSCT	<b>Eastern HSCT</b>	HSCT	HSCT	Ireland
1997-2001	5.0	4.8	3.1	2.2	5.7	4.2
2002-2006	4.4	2.8	3.3	3.2	5.9	3.8
2007-2011	3.0	2.4	2.7	2.4	3.7	2.8
2012-2016	3.7	2.6	1.3	2.5	2.5	2.5
2017-2021	3.2	2.0	1.8	1.3	3.0	2.2

Information from the Northern Ireland Cancer Registry shows that between 2002-2021, there is no statistically significant difference in the mortality rate from cervical cancer in women living in the SHSCT area compared with the Northern Ireland average, when adjusted for the population. Prior to 2002 the mortality rate in the SHSCT was lower than elsewhere.

#### 2.4. Incidence of pre-cancerous changes of the cervix

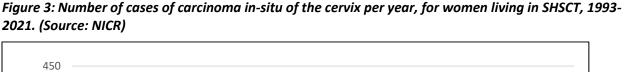
Abnormal changes of the cells that line the cervix are called cervical intraepithelial neoplasia (CIN). CIN does not cause symptoms and for some people the changes go back to normal by themselves. A **smear** test does not show if someone has CIN. CIN is diagnosed by taking a biopsy of the abnormal area during a **colposcopy examination**.

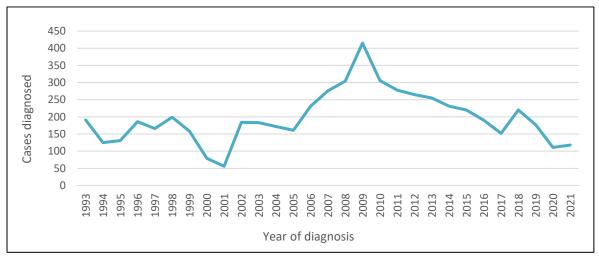
#### There are three levels of CIN:

- **CIN 1** where one third of the thickness of the surface layer of the cervix is affected by abnormal cells. These will often return to normal with no treatment.
- CIN 2 where two thirds of the thickness of the surface layer of the cervix is affected by abnormal cells. There is a higher risk that this will develop into cancer. In these cases, treatment may be offered or women may be invited for another colposcopy to keep the abnormal cells under observation.
- CIN 3 where the full thickness of the surface layer of the cervix is affected by abnormal cells. This is not cervical cancer but treatment is offered to those with CIN3 to prevent cancer from developing. CIN 3 is considered pre-cancerous and is also often called carcinoma-in-situ. Cancer occurs when abnormal cells affect the deeper layers of the cervix.

The NICR collects and publishes information on CIN 3, which is referred to from here on as carcinoma insitu. For the five year period 2017-2021 there was an average of 795 cases of carcinoma insitu of the cervix in Northern Ireland each year, with an average of 156 cases per year in people who live in the SHSCT area. The trend in the number of cases of carcinoma insitu of the cervix in the SHSCT area is shown in **Figure 3**. The numbers for all trusts in Northern Ireland are provided at **Appendix 5**.

A peak in **incidence** of carcinoma in-situ of the cervix was seen across Northern Ireland around 2008/09. This pattern was experienced across the UK and coincided with an increase in participation in screening in response to the diagnosis and subsequent death from cervical cancer of the reality TV star Jade Goody<sup>7</sup>.





<sup>&</sup>lt;sup>7</sup> Lancucki L, Sasieni P, Patnick J, Day TJ, Vessey MP. The impact of Jade Goody's diagnosis and death on the NHS Cervical Screening Programme. J Med Screen 2012;19:89-93.

When the data are adjusted to a standard population profile, for the periods up to 2011 there were significantly higher incidence rates for in-situ carcinomas in the SHSCT compared with the Northern Ireland average. The reasons for this higher rate at that time are unclear. However, there has been no difference in more recent periods from 2012 onwards. **Table 3** shows this comparative data and fuller information is provided at **Appendix 6**.

Table 3: European age-standardised incidence rate of carcinoma in-situ of the cervix per 100,000 person years, by HSCT and period of diagnosis. (Source: NICR)

	Belfast HSCT	Northern HSCT	South Eastern HSCT	Southern HSCT	Western HSCT	Northern Ireland
1997-2001	54.7	64.7	64.3	79.0	71.2	66.3
2002-2006	87.5	85.6	90.3	107.4	87.0	90.9
2007-2011	133.2	114.0	137.8	160.9	148.0	137.0
2012-2016	121.0	93.0	123.9	117.0	122.6	113.9
2017-2021	86.9	70.3	82.6	78.9	103.6	83.0

In the period 1997-2011, there was a significantly higher rate of precancerous cervical changes diagnosed in those living in the Southern HSCT area compared with the Northern Ireland average, when adjusted for the population.

Between 2012-2021, there was no statistically significant difference.

#### 2.5. HPV vaccination programme

Vaccination of girls aged 12 to 13 against **HPV** was introduced in Northern Ireland in 2008 with the aim of reducing the future risk of cervical cancer. Girls aged up to 18 were given the opportunity to access the vaccine at that time. Vaccination was later extended to include boys from 2019 to further reduce the spread of **HPV**. It is also known that **HPV** infection has a role in some other types of cancer as well.

For the year 2022/23, the PHA reported that 71.2% of Year 10 girls (aged 13-14) and 65.2% of Year 10 boys in Northern Ireland had completed their two-dose course of vaccination against **HPV**.

As reported elsewhere in the UK, the success of the vaccination programme is contributing to a reduction in the number of cases of carcinoma in-situ of the cervix and the number of cervical cancers diagnosed from 2015 onwards<sup>8,9</sup>.

<sup>&</sup>lt;sup>8</sup> Falcaro M, Soldan K, Ndlela B, Sasieni P. Effect of the HPV vaccination programme on incidence of cervical cancer and grade 3 cervical intraepithelial neoplasia by socioeconomic deprivation in England: population based observational study. BMJ 2024;385:e077341 Available at <a href="https://www.bmj.com/content/385/bmj-2023-077341">https://www.bmj.com/content/385/bmj-2023-077341</a>
<sup>9</sup> Palmer TJ, Kavanagh K, Cushieri K, Cameron R, Graham C, Wilson A, Roy K. Invasive cervical cancer incidence

<sup>&</sup>lt;sup>9</sup> Palmer TJ, Kavanagh K, Cushieri K, Cameron R, Graham C, Wilson A, Roy K. Invasive cervical cancer incidence following bivalent human papillomavirus vaccination: a population-based observational study of age at immunization, dose, and deprivation. Journal of the National Cancer Institute, 2024:116(6);857-865

#### 3. Screening and cervical cancer

#### 3.1. Role of screening

An organised cervical screening programme has been operating in Northern Ireland since 1988. It aims to find and treat changes to cervical cells before they turn into cancer, reducing ill health and deaths from this disease. The test (smear test) looks for early (pre-cancerous) changes in the cells of a woman's cervix. It is designed to pick up any changes to the cells in the cervix so that they can be monitored or treated. In many cases cervical cell changes return to normal by themselves but in some cases they do not and preventative monitoring and/or treatment is required.

The purpose of screening is to identify apparently healthy people who may have an increased chance of developing a disease or condition. Cervical screening aims to reduce the chance of developing cervical cancer by identifying pre-cancerous changes and supporting early treatment.

The **UK National Screening Committee** states that is important to have realistic expectations of what a screening programme does. Screening does not guarantee protection from the disease being screened for and receiving a result which indicates the person has a low chance of developing the disease does not prevent the person from developing the condition at a later date<sup>10</sup>.

Similar to every other screening programme, cervical screening will not identify all cases of disease. It is well recognised that a cytology-based screening programme (which was in place in Northern Ireland until December 2023) can expect to pick up approximately 75% of cases with abnormal cells (meaning 25% of cases with abnormal cells will not be picked up at screening). Screening programmes are designed with a trade-off between detecting the maximum number of potential cases of a disease while not subjecting women to unnecessary diagnostic tests and treatment (benefit versus harm).

The introduction of the cervical screening programme in England in 1988 reduced the **incidence** of cervical cancer by one third<sup>11</sup> and has reduced deaths from cervical cancer by more than half. Regular attendance for cervical screening reduces the risk of developing cervical cancer at all by almost 70% and reduces risk of developing advanced cervical cancer or dying from cervical cancer<sup>12</sup>.

Screening is currently offered to all eligible individuals aged 25-49 every three years, and to those aged 50-64 every five years.

Screening is intended for those who do not have symptoms. Women of any age who present to their General Practitioner with symptoms suggestive of a cervical abnormality (such as bleeding or pain) should be examined and referred for onward investigation as clinically appropriate through **diagnostic** 

<sup>&</sup>lt;sup>10</sup> https://www.gov.uk/guidance/population-screening-explained

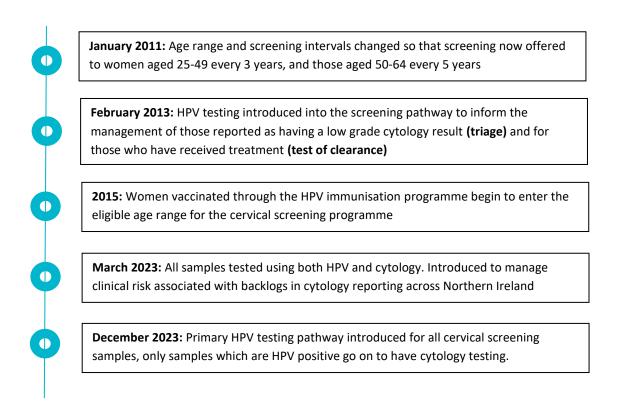
<sup>&</sup>lt;sup>11</sup> F Pesola, P Sasieni. Impact of screening on cervical cancer incidence in England a time trend analysis. BMJ 24 January 2019. Available at https://bmjopen.bmj.com/content/bmjopen/9/1/e026292.full.pdf

<sup>&</sup>lt;sup>12</sup> R Landy et al. Impact of cervical screening on cancer mortality: estimation using stage-specific results from a nested case-control study. British Journal of Cancer 15 September 2016.

services. A **screening test** is not a **diagnostic test** and could give false reassurance that symptoms are not significant or don't need further investigation.

#### 3.2. Changes to screening policy over time

Prior to 2011, cervical screening was offered to eligible individuals aged 20-64 every five years. The **screening test** involved preparing a slide from a sample obtained through a **smear** test and a trained individual examining the cells on the slide using a microscope (a cytology test). A number of significant changes have been made to the cervical screening programme during the timeframe covered by this report. These are outlined below.



It should also be noted that invitations to participate in cervical screening were paused across Northern Ireland during the first wave of the COVID-19 pandemic, from March 2020. Routine invitations resumed from August 2020.

#### 4. Cases of cervical cancer diagnosed and audited by the SHSCT

#### 4.1. Purpose of the Audit of Invasive Cervical Cancers

Each individual case of invasive cervical cancer diagnosed in NI is assessed through an audit process, known as the Audit of Invasive Cervical Cancers (AoICC). Audits of cases of cervical cancer have been in place across the UK for many years. This audit process and its underpinning approaches were established for purposes of learning and improvement.

#### The aim of the AoICC is:

- to monitor the effectiveness of the cervical screening programme;
- to identify areas of good practice and where improvements might be made; and
- to support the continuous learning and development of health professionals involved in the screening programme.

The AoICC involves a review of all parts of the screening pathway in those who are diagnosed with invasive cervical cancer<sup>13</sup>. This includes the review of the invitation process, any results of **screening tests** over the previous ten years and any prior treatment within the **colposcopy** service where this applies.

New regional guidance<sup>14</sup> was published by the PHA in February 2019 with the purpose of standardising approaches to the AoICC in Northern Ireland. This guidance covered:

- reporting and reviewing all stages of the screening pathway;
- categorisation of audit outcomes; and
- informing women about the audit activities and telling them about any audit findings.

From 2019 onwards the AoICC process includes a multidisciplinary meeting to discuss the findings arising through the audit. There are three possible categories to capture the audit outcome for each case reviewed: i) satisfactory; ii) satisfactory with learning points within the limitations of a screening programme; or iii) unsatisfactory. Following completion of the AoICC process and categorisation of individual audit findings there should be an offer of disclosure of the findings of her audit to each woman. Where the audit outcome is considered to be unsatisfactory (category iii), a detailed further review of that case is undertaken in line with the regional Serious Adverse Incident (SAI) procedure<sup>15</sup>.

<sup>&</sup>lt;sup>13</sup> NI Cervical Screening Programme. Protocol for the Audit of Invasive Cervical Cancers. Public Health Agency December 2014. Available at <a href="https://cancerscreening.hscni.net/download/27/cervical-resources-for-professionals/849/ni-protocol">https://cancerscreening.hscni.net/download/27/cervical-resources-for-professionals/849/ni-protocol</a> audit-of-invasive-cervical-cancers december-2014.pdf

<sup>&</sup>lt;sup>14</sup> Framework for the Audit of Invasive Cervical Cancers and Disclosure of Findings. Public Health Agency, February 2019. Available at <a href="https://cancerscreening.hscni.net/download/27/cervical-resources-for-professionals/847/framework-aic-and-disclosure-v1-0-080219.pdf">https://cancerscreening.hscni.net/download/27/cervical-resources-for-professionals/847/framework-aic-and-disclosure-v1-0-080219.pdf</a>

<sup>&</sup>lt;sup>15</sup> Reporting and Follow-up of Serious Adverse Incidents (SAIs) in Northern Ireland. Health and Social Care Board November 2016. Available at <a href="https://online.hscni.net/wpfd\_file/procedure-for-the-reporting-and-follow-up-of-sais-2016/">https://online.hscni.net/wpfd\_file/procedure-for-the-reporting-and-follow-up-of-sais-2016/</a>

In support of the newly updated regional guidance, a patient information leaflet about the audit was developed. This leaflet should be given to every woman diagnosed with cervical cancer from 2019 onwards. A copy of this leaflet is available at <a href="www.pha.site/cervical-review-FAQs">www.pha.site/cervical-review-FAQs</a> or by scanning this QR code.



As outlined above, the AoICC process is undertaken by other screening programmes across the UK. NHS England has published information relating to the AoICC for patients diagnosed with invasive cervical cancer in England. The most recent publication relating to the AoICC in England was in November 2023, addressing the period from April 2016 to March 2019<sup>16</sup>. There are around 2,500 cases of invasive cervical cancer diagnosed each year in England. Case numbers in Northern Ireland are much smaller, with around 81 cases of invasive cervical cancer diagnosed each year. The small numbers of cases in Northern Ireland and even smaller numbers in individual HSC Trust areas make benchmarking (or any comparison) difficult. However, to help give some comparative information for the purposes of this report, data from the AoICC reports relating to England are presented alongside information relating to the findings from the AoICC in the SHSCT in Tables 4 and 6 below.

## **4.2.** Cases of cervical cancer diagnosed by the Southern HSCT and reported in the AoICC

The data reported through the AoICC process are different to that reported by the NICR. The AoICC collects further information on cases of cervical cancer. Audit data are available for 2009-2023 and are based on the trust which makes the diagnosis, whereas NICR data is based on which trust area the woman lives in.

The number of cases of cervical cancer diagnosed by the SHSCT each year is shown in **Figure 4**. A total of 207 cases of cervical cancer were reported through the audit process as being diagnosed by the SHSCT between 1 January 2009 and 31 December 2023.

<sup>&</sup>lt;sup>16</sup> NHS Cervical Screening Programme Audit of invasive cervical cancer: national report. 1 April 2016 to 31 March 2019. Published 30 November 2023. Available at <a href="https://www.gov.uk/government/publications/cervical-screening-invasive-cervical-cancer-audit-2016-to-2019/nhs-cervical-screening-programme-audit-of-invasive-cervical-cancer-national-report-1-april-2016-to-31-march-2019</a>

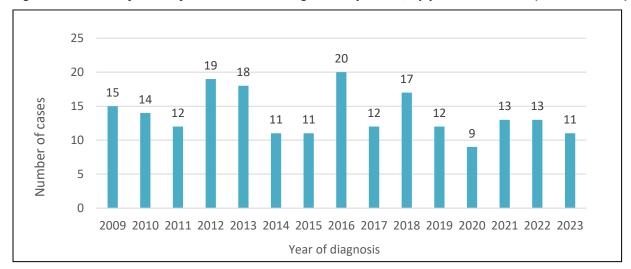


Figure 4: Number of cases of cervical cancer diagnosed by SHSCT, by year, 2009-2023. (Source: SHSCT)

#### 4.3. Age at diagnosis of cases reported in the AoICC

The age profile of those diagnosed with cervical cancer by the SHSCT between 2009-2023 is shown in **Figure 5**. The peak number of cases is observed to be in the 35-39 year age group (17.4%) with 44.9% of all cases diagnosed before the age of 40.

During this period, 88.9% of cases diagnosed were within the current age group eligible for cervical screening (25-64 years).

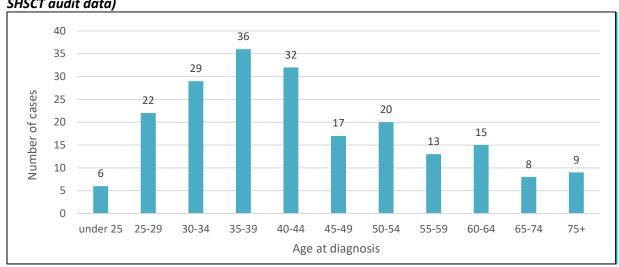


Figure 5: Age profile of cases of invasive cervical cancer diagnosed by the SHSCT, 2009-2023 (Source: SHSCT audit data)

#### 4.4. Cancer type reported in the AoICC

There are two main types of cervical cancer. The most common type is **squamous cell carcinoma** which develops from the cells that line the cervix at the top of the vagina. The other type is **adenocarcinoma**. This develops from a glandular type of cell that is found in the cervical canal. There are also a number of rarer types of cervical cancer which are much less common.

The types of cervical cancer diagnosed in the SHSCT aligns with the profile of cancers reported through the AoICC of cases diagnosed in England, with over two thirds of cases being **squamous cell carcinomas** (69% in SHSCT; 65% in England) and less than one in five being adeno-carcinomas (18% in SHSCT; 18% in England), **Table 4**.

Table 4: Type of cervical cancers diagnosed, SHSCT, 2009-2023 (Source: SHCST audit data)

	England audit	SHSCT	audit
	Cervical cancers 2016-2019 <sup>17</sup>	Cervical cancers 2009-2023	
	%	Number	%
Squamous cell carcinomas	65.4	143	69.1
Adenocarcinomas	18.4	38	18.4
Adenosquamous	2.0	6	2.9
Unknown/other	14.2	20	9.7
Totals	100	207	100

#### 4.5. Screening history of cases reported in the AoICC

Attendance at screening is an important way for women to reduce their risk of developing cervical cancer. However, as noted above, cervical screening cannot prevent all cancers. It is also important to note that not all women who are diagnosed with an invasive cervical cancer will have undergone screening. While attending for screening reduces a woman's risk of developing cervical cancer, screening will not prevent all cases. Some women who have attended for screening will still develop cervical cancer.

Among the 207 cases of invasive cancer diagnosed between 2009 and 2023 in SHSCT, 184 women were in the screening age range (25-64 years) at the time of diagnosis; 54.9% of these (101 of 184) had had at least one **screening test** in the 10 years prior to their diagnosis (other than the test that led to their diagnosis) and 37% (68 of 184) were up to date with screening. Up to date with screening is defined as having an adequate screening result recorded within 3.5 years of the cancer diagnosis for those aged 25-49, and within 5.5 years for those aged 50-64.

<sup>&</sup>lt;sup>17</sup> NHS Cervical Screening Programme Audit of invasive cervical cancer: national report. 1 April 2016 to 31 March 2019. Published 30 November 2023. Available at <a href="https://www.gov.uk/government/publications/cervical-screening-invasive-cervical-cancer-audit-2016-to-2019/nhs-cervical-screening-programme-audit-of-invasive-cervical-cancer-national-report-1-april-2016-to-31-march-2019</a>

Table 5: Screening history of women aged 25-64, diagnosed with cervical cancer by SHSCT, 2009-2023 (Source: SHSCT audit data)

		result recorded in ior to diagnosis	Previous smear results indicating woman is up to date with screening		
	Number %		Number	%	
Yes	101	54.9	68	37.0	
No	83	45.1	116	63.0	
Total	184	100	184	100	

Of those aged 25-49 who were diagnosed with cancer, 18.4% (n=25 of 136) were up to date with screening and had a negative screening result recorded within 3.5 years of the cancer diagnosis.

Of those aged 50-64 who were diagnosed with cancer, 25% (n= 12 of 48) were up to date with screening and had a negative screening result recorded within 5.5 years of the cancer diagnosis.

This information along with comparative data from England is presented in **Table 6** below.

Table 6: Percentage of women diagnosed with cancer who were up to date with screening, England and SHSCT

Age	Screening Result Recorded	England audit 2013-2016 <sup>18</sup>	SHSCT audit 2009-2023	
			Number	%
25-49 yrs	Negative cytology within	20.3%	25 <i>18.4%</i>	
	3.5 yrs of diagnosis		(out of 136)	
50-64 yrs	Negative cytology within	27.2%	12	25.0%
	5.5 yrs of diagnosis		(out of 48)	

#### 4.6. Cervical cancers and the SHSCT cervical cytology review (CCR)

The aim of the Cervical Cytology Review (CCR) in the SHSCT was to ensure women had been given the correct result and to minimise the risk of developing cervical cancer for anyone who may have been given an incorrect result. The CCR did not include women who already had a diagnosis of cervical cancer, as women diagnosed with cervical cancer would not have benefitted from a call forward within the CCR and their previous screening slides are assessed as part of the AoICC.

To understand if women diagnosed with cervical cancer by the SHSCT would have been included in the CCR if they had not been diagnosed with cancer, the screening history of the 207 cases of cancer

<sup>&</sup>lt;sup>18</sup> Cervical screening. Invasive cervical cancer audit, 2013-2016 Audit report. Public Health England, October 2019. Available at <a href="https://www.gov.uk/government/publications/cervical-screening-invasive-cervical-cancer-audit-2013-to-2016/audit-report">https://www.gov.uk/government/publications/cervical-screening-invasive-cervical-cancer-audit-2013-to-2016/audit-report</a>

diagnosed between 1 January 2009 and 31 December 2023 have been reviewed. Each case has been assessed to determine if they would have met the criteria for inclusion in the CCR<sup>Error! Bookmark not defined.</sup>

SHSCT audit data shows that 12 (5.8%) of the 207 women diagnosed by the Trust with cervical cancer between 2009-2023, would have met the criteria for inclusion in the CCR, if they had not been diagnosed with cervical cancer.

An additional number of women (<5) who were diagnosed with cervical cancer in other trusts between 2009-2023 would have met the criteria for inclusion in the CCR, if they had not been diagnosed with cervical cancer.

Inclusion in the CCR does not mean that their previous smear test result would have been upgraded or that their cancer could have been detected earlier or prevented.

#### 4.6.1. Women diagnosed with cervical cancer in SHSCT

The 12 cases of invasive cervical cancer diagnosed by SHSCT who would have met the criteria for inclusion in the CCR were diagnosed across an 11 year period. The first of these was diagnosed in 2011 and the most recent in 2021. As referenced above, guidance on how the AoICC should be carried out was updated during this time period. The SHSCT has provided AoICC documentation for all 12 cases. The audits were carried out in line with the guidance in place at the time. In eight of the 12 cases the assessment identified abnormalities on a smear test which had previously been reported as negative at the time of screening.

As noted above a cytology-based screening programme, as was in place during the timeframe the CCR considered, is expected to correctly identify around three in four smears where abnormalities are present. It will not detect all smears with abnormalities. It is therefore expected that in some cases of cervical cancer, an assessment of previous screening slides will find some abnormalities that were not detected at the time of screening. However, it is important to note that the person undertaking the audit knows that the woman now has cancer, so reporting a slide during an audit is very different to reporting it during routine screening.

Every time some abnormalities are found at audit that were not detected at the time of screening, it is important to consider if what has happened is within the limitations of the screening programme, or if the original result was unsatisfactory. From 2019 onwards the AoICC process includes a multidisciplinary meeting to discuss the findings arising through the audit. There are three possible categories to capture the audit outcome for each case reviewed; i) satisfactory, ii) satisfactory with learning points within the limitations of a screening programme or iii) unsatisfactory. Following completion of the AoICC process and categorisation of individual audit findings there should be an offer of disclosure of the findings relating to her audit to each woman. Where the audit outcome is considered to be unsatisfactory

(category iii), a detailed further review of that case is undertaken in line with the regional Serious Adverse Incident (SAI) procedure.

In five of the 12 cases, the AoICC were carried out following publication of the 2019 framework. All five had unsatisfactory outcomes and further review of each case is currently either being taken forward, or has been undertaken, in line with the regional SAI process. For some of these, the unsatisfactory outcome and related findings of the AoICC contributed to concerns about laboratory performance which led to the Royal College of Pathologists (Consulting) being commissioned to undertake a formal independent risk assessment and provide a report on the cervical cytology laboratory service in SHSCT. The recommendations in this RCPath (Consulting) report led to the CCR being undertaken.

In the other seven cases the AoICC were completed before the 2019 framework was issued. The assessments carried out as part of the audit found abnormalities on screening slides in three cases that were not detected at the time of screening. Because these audits were carried out before 2019, the categorisation process was not in place so could not be applied. The slides relating to these cases are all more than 10 years old, so retrospectively applying the 2019 Framework is not straightforward and may not be reliable.

However, further assessment has taken place and is ongoing. Any learning arising from the further assessment of these cases will be used to further improve the screening programme. Clinical teams will consider individual circumstances as part of the assessment. As part of this they will consider the need to offer women disclosure of any findings from the assessment.

#### 4.6.2. Women diagnosed with cervical cancer in other Trusts

An additional small number of women (<5) who were diagnosed with cervical cancer in other trusts but who had a previous **screening test** reported by SHSCT, would have met the criteria for inclusion in the CCR if they had not been diagnosed with cervical cancer. This information has been shared with the trusts where they were diagnosed. Further assessment and disclosure in relation to this and any findings of their AoICC is ongoing to these women, in collaboration with clinical staff in the trust where they were diagnosed.

Any learning from the AoICC or any SAI processes associated with these cases will be shared across the cervical screening programme to improve systems, as well as patient care and treatment, going forward.

#### 5. Conclusions

Each year approximately 81 women are diagnosed with cervical cancer in Northern Ireland. The Northern Ireland Cancer Registry has been collecting data on all cases of cervical cancer diagnosed since 1993. When adjusted for the population, data from the registry show that there is no statistical difference between trusts in the number of cases of cervical cancer, the stage at which they have been diagnosed, deaths from cervical cancer or the number of cases of pre-cancerous changes of the cervix. The incidence of cervical cancer in Northern Ireland has also been reported as being similar to the UK average.

The cervical screening programme aims to find and treat changes to cervical cells before they turn into cancer, reducing ill health and deaths from this disease. The test (**smear** test) looks for early (precancerous) changes in the cells of a woman's cervix. It is designed to pick up any changes to the cells in the cervix so that they can be monitored or treated. In many cases cervical cell changes return to normal by themselves but in some cases they do not and preventative monitoring and/or treatment is required. Screening is currently offered to all eligible individuals aged 25-49 every three years, and to those aged 50-64 every five years. Studies have shown that regular attendance for screening reduces the risk of developing cervical cancer by almost 70%.

However, similar to every other screening programme, cervical screening will not identify all cases of disease. It is well recognised that a cytology-based screening programme (which was in place in Northern Ireland until December 2023) can expect to pick up approximately 75% of cases with abnormal cells (meaning 25% of cases with abnormal cells will not be picked up at screening). From December 2023 the primary HPV pathway for cervical screening was introduced in Northern Ireland. Testing all samples for HPV infection has been shown to be a more accurate method of identifying those women with abnormalities which are most likely to go on to develop into cancer.

The introduction of the HPV vaccination programme in 2008 which is offered to both girls and boys at age 12-13, is now contributing to a reduction in the number of cases of cervical cancer and precancerous cervical changes in women.

For the purpose of learning and improvement, each individual case of invasive cervical cancer diagnosed in Northern Ireland is assessed through an audit process, known as the Audit of Invasive Cervical Cancers (AoICC). The audit involves a review of all parts of the screening pathway, including the invitation process, any results of **screening tests** over the previous ten years and any prior treatment within the colposcopy service where this applies. New regional guidance was published by the PHA in 2019 to standardize approaches to the audit, and in particular how outcomes were categorized and women informed about the findings.

All screening programmes have limitations. In the SHSCT, 207 women have been diagnosed by the trust with cervical cancer between 2009-2023. As expected, a proportion of these women were up to date with screening and received a negative screening test result at their last smear. The data for the SHSCT are similar to that reported from the audit in England.

Twelve of the 207 women with cervical cancer would have been included in the CCR if they had not been diagnosed with cancer, along with a small number of women diagnosed in other trusts (<5). Each of these cases have been reviewed as part of the AoICC and a number have progressed on to a further detailed Serious Adverse Incident review, where audit findings have been considered unsatisfactory. Any learning from the AoICC or any SAI processes associated with these cases will be shared across the cervical screening programme to improve systems, as well as patient care and treatment, going forward.

The World Health Organisation has adopted a Global Strategy for cervical cancer elimination focused on the three key pillars of: i) HPV vaccination; ii) cervical screening; and iii) treatment of pre-cancer and invasive cancer. To achieve the elimination of this cancer, it is important that women continue to make informed decisions to come forward for screening when invited.

**Appendix 1: Number of cases of cervical cancer by HSCT and year of diagnosis (Source: NICR)** 

	Number of cases									
Year of diagnosis	Northern Ireland	Belfast HSCT	Northern HSCT	South Eastern HSCT	Southern HSCT	Western HSCT				
1993	83	25	15	22	11	10				
1994	75	23	14	17	12	9				
1995	86	21	19	14	19	12				
1996	93	19	24	18	13	19				
1997	85	22	26	10	11	15				
1998	80	13	22	16	15	12				
1999	76	18	19	20	9	9				
2000	95	24	28	15	20	8				
2001	71	14	21	17	10	9				
2002	82	19	25	13	14	11				
2003	73	19	18	14	9	13				
2004	72	27	13	17	10	5				
2005	88	24	26	12	10	16				
2006	103	27	21	30	17	8				
2007	88	15	29	19	17	7				
2008	127	29	38	30	16	14				
2009	118	29	28	24	18	19				
2010	89	19	16	18	18	17				
2011	106	34	20	19	18	15				
2012	94	30	13	22	20	9				
2013	104	20	20	18	24	22				
2014	80	25	18	15	11	11				
2015	82	23	19	16	13	11				
2016	83	19	13	16	20	15				
2017	67	15	20	8	12	12				
2018	96	19	22	21	20	14				
2019	88	19	24	19	11	15				
2020	74	20	16	15	11	12				
2021	82	16	12	13	14	27				

Note: Northern Ireland total includes cases with an unknown HSCT of residence

Appendix 2: Incidence of cervical cancer by HSCT and period of diagnosis (Source: NICR)

Health and Social Care Trust	Period of diagnosis	Total number of cases	Average cases per year	Incidence rate per 100,000 persons	European age- standardised incidence rate per 100,000 person years	Confidence interval of European age- standardised incidence rate
Northern	1997-2001	407	81	9.5	10.5	(9.5 - 11.6)
Ireland	2002-2006	418	84	9.5	10.0	(9.0 - 11.0)
	2007-2011	528	106	11.6	11.8	(10.8 - 12.8)
	2012-2016	443	89	9.4	9.7	(8.8 - 10.7)
	2017-2021	407	81	8.5	8.8	(7.9 - 9.6)
Belfast HSCT	1997-2001	91	18	9.8	10.7	(8.4 - 12.9)
	2002-2006	116	23	12.9	13.6	(11.1 - 16.1)
	2007-2011	126	25	14.0	14.3	(11.8 - 16.8)
	2012-2016	117	23	12.9	13.3	(10.9 - 15.8)
	2017-2021	89	18	9.7	10.2	(8.1 - 12.3)
Northern	1997-2001	116	23	10.7	11.7	(9.5 - 13.8)
HSCT	2002-2006	103	21	9.2	9.6	(7.7 - 11.5)
	2007-2011	131	26	11.2	11.4	(9.4 - 13.3)
	2012-2016	83	17	6.9	7.3	(5.7 - 8.9)
	2017-2021	94	19	7.7	7.9	(6.3 - 9.5)
South Eastern	1997-2001	78	16	9.5	10.0	(7.7 - 12.2)
HSCT	2002-2006	86	17	10.2	10.3	(8.1 - 12.5)
	2007-2011	110	22	12.5	12.8	(10.4 - 15.3)
	2012-2016	87	17	9.6	9.9	(7.8 - 11.9)
	2017-2021	76	15	8.2	8.4	(6.5 - 10.3)
Southern	1997-2001	65	13	8.4	9.8	(7.3 - 12.2)
HSCT	2002-2006	60	12	7.4	8.0	(5.9 - 10.0)
	2007-2011	87	17	9.8	10.1	(7.9 - 12.2)
	2012-2016	88	18	9.5	9.7	(7.6 - 11.7)
	2017-2021	68	14	7.0	7.4	(5.6 - 9.2)
Western HSCT	1997-2001	53	11	7.5	9.4	(6.8 - 12.0)
	2002-2006	53	11	7.4	8.2	(6.0 - 10.5)
	2007-2011	72	14	9.7	10.4	(8.0 - 12.9)
	2012-2016	68	14	9.1	9.4	(7.1 - 11.6)
	2017-2021	80	16	10.5	11.0	(8.6 - 13.4)

 ${\it Note: Northern\ Ireland\ total\ includes\ cases\ with\ an\ unknown\ HSCT\ of\ residence}$ 

**Appendix 3: Incidence of cervical cancer by HSCT, stage and period of diagnosis (Source: NICR)** 

Health and		TNM stage at diagnosis						
Social Care Trust	Period of diagnosis	All stages	Stage I	Stage II	Stage III	Stage IV & Unknown		
Northern	2002-2006	418	204 (48.8%)	66 (15.8%)	67 (16.0%)	81 (19.4%)		
Ireland	2007-2011	528	293 (55.5%)	58 (11.0%)	101 (19.1%)	76 (14.4%)		
	2012-2016	443	232 (52.4%)	95 (21.4%)	58 (13.1%)	58 (13.1%)		
	2017-2021	407	183 (45.0%)	90 (22.1%)	70 (17.2%)	64 (15.7%)		
Belfast HSCT	2002-2006	116	56 (48.3%)	22 (19.0%)	17 (14.7%)	21 (18.1%)		
	2007-2011	126	71 (56.3%)	14 (11.1%)	20 (15.9%)	21 (16.7%)		
	2012-2016	117	54 (46.2%)	33 (28.2%)	12 (10.3%)	18 (15.4%)		
	2017-2021	89	36 (40.4%)	21 (23.6%)	17 (19.1%)	15 (16.9%)		
Northern	2002-2006	103	58 (56.3%)	18 (17.5%)	10 (9.7%)	17 (16.5%)		
HSCT	2007-2011	131	74 (56.5%)	17 (13.0%)	21 (16.0%)	19 (14.5%)		
	2012-2016	83	47 (56.6%)	14 (16.9%)	8 (9.6%)	14 (16.9%)		
	2017-2021	94	43 (45.7%)	19 (20.2%)	17 (18.1%)	15 (16.0%)		
South	2002-2006	86	44 (51.2%)	11 (12.8%)	17 (19.8%)	14 (16.3%)		
Eastern	2007-2011	110	62 (56.4%)	15 (13.6%)	20 (18.2%)	13 (11.8%)		
HSCT	2012-2016	87	54 (62.1%)	12 (13.8%)	10 (11.5%)	11 (12.6%)		
	2017-2021	76	34 (44.7%)	21 (27.6%)	10 (13.2%)	11 (14.5%)		
Southern	2002-2006	60	26 (43.3%)	7 (11.7%)	14 (23.3%)	13 (21.7%)		
HSCT	2007-2011	87	55 (63.2%)	6 (6.9%)	15 (17.2%)	11 (12.6%)		
	2012-2016	88	47 (53.4%)	17 (19.3%)	16 (18.2%)	8 (9.1%)		
	2017-2021	68	31 (45.6%)	14 (20.6%)	13 (19.1%)	10 (14.7%)		
			( ::	- /	- 4			
Western	2002-2006	53	20 (37.7%)	8 (15.1%)	9 (17.0%)	16 (30.2%)		
HSCT	2007-2011	72	31 (43.1%)	6 (8.3%)	25 (34.7%)	10 (13.9%)		
	2012-2016	68	30 (44.1%)	19 (27.9%)	12 (17.6%)	7 (10.3%)		
	2017-2021	80	39 (48.8%)	15 (18.8%)	13 (16.3%)	13 (16.3%)		

Note: Northern Ireland total includes cases with an unknown HSCT of residence Note: Caution should be exercised in interpreting trends by stage due to changes in the TNM version used.

Appendix 4: Deaths from cervical cancer by HSCT and period of death (Source: NICR)

Health and Social Care Trust	Period of death	Total number of deaths	Average deaths per year	Mortality rate per 100,000 persons	European age- standardised mortality rate per 100,000 person years	Confidence interval of European age- standardised mortality rate
Northern Ireland	1997-2001	150	30	3.5	4.2	(3.5 - 4.9)
	2002-2006	140	28	3.2	3.8	(3.1 - 4.4)
	2007-2011	113	23	2.5	2.8	(2.2 - 3.3)
	2012-2016	110	22	2.3	2.5	(2.0 - 3.0)
	2017-2021	101	20	2.1	2.2	(1.8 - 2.6)
Belfast HSCT	1997-2001	40	8	4.3	5.0	(3.4 - 6.6)
	2002-2006	36	7	4.0	4.4	(3.0 - 5.9)
	2007-2011	26	5	2.9	3.0	(1.8 - 4.2)
	2012-2016	31	6	3.4	3.7	(2.4 - 5.0)
	2017-2021	27	5	2.9	3.2	(2.0 - 4.4)
Northern HSCT	1997-2001	43	9	4.0	4.8	(3.4 - 6.2)
	2002-2006	26	5	2.3	2.8	(1.7 - 3.8)
	2007-2011	25	5	2.1	2.4	(1.5 - 3.4)
	2012-2016	29	6	2.4	2.6	(1.6 - 3.5)
	2017-2021	24	5	2.0	2.0	(1.2 - 2.8)
South Eastern HSCT	1997-2001	22	4	2.7	3.1	(1.8 - 4.4)
	2002-2006	25	5	3.0	3.3	(2.0 - 4.7)
	2007-2011	22	4	2.5	2.7	(1.6 - 3.9)
	2012-2016	12	2	1.3	1.3	(0.6 - 2.1)
	2017-2021	17	3	1.8	1.8	(1.0 - 2.7)
Southern HSCT	1997-2001	13	3	1.7	2.2	(1.0 - 3.4)
	2002-2006	21	4	2.6	3.2	(1.8 - 4.6)
	2007-2011	17	3	1.9	2.4	(1.2 - 3.5)
	2012-2016	21	4	2.3	2.5	(1.4 - 3.5)
	2017-2021	12	2	1.2	1.3	(0.6 - 2.1)
Western HSCT	1997-2001	30	6	4.3	5.7	(3.7 - 7.8)
	2002-2006	32	6	4.5	5.9	(3.8 - 7.9)
	2007-2011	23	5	3.1	3.7	(2.2 - 5.2)
	2012-2016	17	3	2.3	2.5	(1.3 - 3.7)
	2017-2021	21	4	2.8	3.0	(1.7 - 4.3)

Note: Northern Ireland total includes deaths with an unknown HSCT of residence

Appendix 5: Number of cases of carcinoma in situ of the cervix by HSCT and year of diagnosis (Source: NICR)

	Number of cases								
Year of diagnosis	Northern Ireland	Belfast HSCT	Northern HSCT	South Eastern HSCT	Southern HSCT	Western HSCT			
1993	693	136	154	96	191	104			
1994	674	126	167	94	125	157			
1995	757	121	241	119	131	138			
1996	845	143	235	154	186	120			
1997	536	52	157	80	166	75			
1998	600	65	123	96	199	113			
1999	622	89	163	108	158	98			
2000	693	174	156	142	79	136			
2001	649	171	165	131	56	125			
2002	795	166	185	130	184	126			
2003	807	166	205	124	183	125			
2004	801	145	187	156	172	133			
2005	858	186	219	173	161	115			
2006	1,003	194	212	185	231	178			
2007	1,040	181	234	178	276	169			
2008	1,290	284	292	247	304	159			
2009	1,734	368	321	309	415	317			
2010	1,444	305	308	249	306	272			
2011	1,253	246	231	233	278	265			
2012	1,135	228	252	197	265	192			
2013	1,144	243	225	219	255	201			
2014	1,173	255	210	256	231	221			
2015	1,168	285	236	220	220	206			
2016	937	228	182	202	190	135			
2017	837	206	167	162	152	149			
2018	1,013	214	203	191	220	185			
2019	924	191	182	185	177	187			
2020	595	139	115	103	111	127			
2021	606	119	153	89	118	127			

Note: Northern Ireland total includes cases with an unknown HSCT of residence

Appendix 6: Incidence of carcinoma in situ of the cervix by HSCT and period of diagnosis (Source: NICR)

Health and Social Care Trust	Period of diagnosis	Total number of cases	Average cases per year	Incidence rate per 100,000 persons	European age- standardised incidence rate per 100,000 person years	Confidence interval of European age- standardised incidence rate
Northern	1997-2001	3,100	620	72.1	66.3	(64.0 - 68.7)
Ireland	2002-2006	4,264	853	97.2	90.9	(88.2 - 93.7)
	2007-2011	6,761	1,352	148.0	137.0	(133.7 - 140.2)
	2012-2016	5,557	1,111	118.5	113.9	(110.9 - 116.9)
	2017-2021	3,975	795	82.9	83.0	(80.4 - 85.6)
Belfast HSCT	1997-2001	551	110	59.6	54.7	(50.1 - 59.3)
	2002-2006	857	171	95.5	87.5	(81.6 - 93.4)
	2007-2011	1,384	277	154.0	133.2	(126.1 - 140.3)
	2012-2016	1,239	248	136.4	121.0	(114.2 - 127.8)
	2017-2021	869	174	94.4	86.9	(81.1 - 92.7)
Northern	1997-2001	764	153	70.8	64.7	(60.1 - 69.3)
HSCT	2002-2006	1,008	202	90.3	85.6	(80.3 - 90.9)
	2007-2011	1,386	277	118.8	114.0	(108.0 - 120.0)
	2012-2016	1,105	221	92.5	93.0	(87.5 - 98.4)
	2017-2021	820	164	67.4	70.3	(65.4 - 75.1)
South Eastern	1997-2001	557	111	68.0	64.3	(58.9 - 69.6)
HSCT	2002-2006	768	154	91.3	90.3	(83.9 - 96.6)
	2007-2011	1,216	243	138.3	137.8	(130.0 - 145.5)
	2012-2016	1,094	219	120.9	123.9	(116.6 - 131.3)
	2017-2021	730	146	78.6	82.6	(76.6 - 88.6)
		650	400	24.0	70.0	(70.0.05.4)
Southern	1997-2001	658	132	84.9	79.0	(72.9 - 85.1)
HSCT	2002-2006	931	186	114.3	107.4	(100.5 - 114.3)
	2007-2011	1,579	316	178.6	160.9	(153.0 - 168.9)
	2012-2016	1,161	232	124.9	117.0	(110.3 - 123.8)
	2017-2021	778	156	80.4	78.9	(73.3 - 84.4)
Western HSCT	1997-2001	547	109	77.7	71.2	(65.1 - 77.2)
Westelli H3Cl	2002-2006	677	135	94.2	87.0	(80.5 - 93.6)
	2002-2006	1,182	236	160.0	148.0	(139.5 - 156.4)
	2012-2016	955	191	127.2	122.6	(114.8 - 130.3)
	2012-2016	775	155	101.7	103.6	(96.3 - 110.9)
	2011-2021	113	133	101.7	103.0	(30.3 - 110.3)

Note: Northern Ireland total includes cases with an unknown HSCT of residence

#### **Glossary of Terms**

Adenocarcinoma – a cancer that develops from a glandular type of cell that is found in the cervical canal

**Colposcopy examination** – an examination of the cervix using a colposcope. This is a type of magnifying glass which allows a doctor or nurse to look more closely at any changes in the cervix and determine if treatment is required.

**Diagnostic test** – a test that is undertaken when an individual has symptoms to detect disease or a health condition

**Human papillomavirus (HPV)** – HPV is a common sexually transmitted infection (STI) that most people contract at some point in life. The body will usually get rid of the virus by itself, typically within a couple of years. There are different types of HPV, and if you have a high-risk type and it remains in your body for a long time, abnormal cells can begin to develop. These cells can then turn into cancer if left undetected and untreated. According to the World Health Organization Trusted Source, 95% of all cervical cancers are caused by a long lasting HPV infection. The high-risk types that tend to be responsible for cervical cancer are HPV 16 and HPV 18.

**Incidence** – the occurrence of new cases of a disease

**Incidence rate** – a measure of the frequency of new cases of a disease. It is the number of new cases of the disease occurring in a given time period in relation to the total population.

**Prevalence data** – the proportion of individuals in a population who have a disease or condition at a point in time

**Screening test** – a test that detects potential health disorders or diseases in people who do not have any symptoms

Smear – A Smear test checks for abnormal cells in the lining of the cervix (neck of the womb)

**Squamous cell carcinoma** – a cancer that develops from the cells that line the cervix at the top of the vagina

**Survival data** – data relating to people who remain alive following a diagnosis with a specific disease or condition

**Test of clearance** – where HPV testing is done on smears taken after a woman has undergone treatment for abnormal cells, to determine if HPV infection is still present.

**Triage** – where HPV testing is done on smear samples which have mild or borderline abnormal cell changes, to determine if the woman needs further investigation.

**UK National Screening Committee** – this is an independent committee that advises the NHS and UK Ministers on population screening. It makes evidenced-based recommendations about whether to introduce, continue, change or withdraw screening programmes for a variety of conditions