The use of cervical screening history data to interpret cervical cancer incidence trends

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ABSTRACT

Background Regional Cervical Screening Quality Assurance Reference Centres maintain and improve the quality of their local cervical screening programmes by monitoring standards based on a range of outcome measures. The classification of invasive cervical cancer screening histories can aid the interpretation of cervical cancer incidence trends in cervical screening services.

Methods Cervical cancer incidence rates were calculated for cytology laboratory catchment areas, which reflected where local general practitioners sent cervical samples. After reviewing changes in invasive cervical cancer incidence rates in the West Midlands during the period 1988–2004 to identify unusual trends, a detailed retrospective screening history analysis was carried out for one local screening service.

Results An upward trend in invasive cervical cancer incidence in one laboratory catchment area was caused by an increase in cases occurring in women who had not been routinely screened. Quality assurance data provided supporting evidence for non-attendance at screening during this time.

Conclusions Assigning a screening status to invasive cervical cancers provides valuable information through which to understand the reasons for changes in cancer incidence with time in local screening services. These data can be used to identify areas of potential concern, thereby facilitating quality assurance activities.

Keywords cervical cancer, cervical screening, geographical information systems (GIS), quality assurance, screening history

Introduction

Following the re-organisation of the NHS cervical screening programme (NHSCSP) in 1988, invasive cervical cancer incidence rates in women aged 20–64 years in the West Midlands health region have decreased from a pre-programme peak of 26.6 per 100 000 population in 1985 to just 13.1 per 100 000 population in 2004. This decrease is probably due to improved coverage in cervical screening, which has led to the increased detection and treatment of pre-invasive grade III cervical intraepithelial neoplasia, (CIN III/CGIN or in situ cervical cancer) which in turn has resulted in a decrease in invasive cervical cancer. However, within the West Midlands health region, there is significant variation between the highest and lowest invasive cervical cancer incidence rates in individual Primary Care Trusts (PCTs); the highest invasive cervical cancer incidence rate in more recent years being over two and a half times the lowest rate.

The underlying risk of developing cervical cancer depends on the demographic mix of an area because factors such as socio-economic status and ethnicity are strongly associated with variations in cervical cancer incidence rates. However, in cervical screening, varying practice and policies in screening processes such as screening invitation arrangements, primary care sample taking, cytology laboratory sample reading and colposcopy management may also contribute to differences in incidence rates. As reducing variation has been suggested to be a key feature in improving healthcare, it is important that all of the factors affecting cervical cancer incidence are understood if the highest incidence rates are to be reduced.

The role of regional cervical screening Quality Assurance Reference Centres (QARCs) is to maintain and improve the

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quality of their local CSPs by monitoring standards based on a range of outcome measures (e.g. cervical screening coverage). QARCs are also expected to collect and classify screening history data for invasive cervical cancers to allow a screening status at diagnosis to be assigned.3 The West Midlands QARC (WMQARC) has developed a detailed method for the classification of invasive cervical cancers.4 This method assigns each cancer a screening status at diagnosis and classifies the woman's cytology screening history; allowing more detailed analysis. The method provides information for the QARC to use in the local audit of invasive cervical cancers within its region.

This paper describes how the WMQARC has used screening history data for invasive cervical cancers to investigate an unusual trend in invasive cervical cancer incidence and to establish if this reflects problems within the local screening service. In order to carry out the work, health geographic information systems (GIS) were used to generate invasive cervical cancer incidence rates for the catchment areas of each cervical screening service.

**Methods**

**Screening status classification**

Demographic and tumour details for all invasive cervical cancers recorded in women aged 20–64 on the West Midlands Cancer Intelligence Unit’s cancer registration database with diagnosis dates during the period 1988–2004 were provided to the WMQARC. Demographic information including date of birth, diagnosis forename, surname, postcode and NHS number allowed each patient to be matched on the cervical screening call and recall computer systems using the ‘Open Exeter’ secure look-up facility.5 Screening histories were obtained for 98.9% of women (aged 20–64) diagnosed with invasive cervical cancer between these dates (n = 4471). Forty-nine cases, (1.1%), which could not be completely matched were excluded from subsequent analyses. Each screening history included the test date of each sample, laboratory code, result, recommended recall interval (months) and information on where the sample was taken (in order to identify general practitioner (GP) or hospital samples). All samples taken prior to the diagnosis of cervical cancer were classified as previously described4 in order to assign each case to one of seven screening status at diagnosis categories.

**Cytology laboratory catchment methodology**

In order to link cervical cancer incidence with laboratory catchment areas, the West Midlands Health GIS (WMHGIS) service used the location of each cytology laboratory in the West Midlands as the centre point to which Theissen polygon areas were defined using standard geographic tools. Each polygon represented the area around each laboratory that was closer to this laboratory than any other on the basis of straight-line distance. Each polygon may be referred to as representing a nearest neighbour catchment area. Information obtained by the WMQARC from local screening programmes, was used to ascertain where cervical samples taken in each general practice were sent for testing in 2001. General practice locations were mapped and classified by cytology laboratory to validate the catchment area identified by nearest neighbour analysis. Initial results showed a broadly similar pattern of ‘actual’ and ‘nearest neighbour’ allocations to cytology laboratories. Where major discrepancies were found between the two sets of data, these could be explained by recent changes in cytology laboratory service provision or by the use of laboratories outside the region. To better reflect the actual use of cytology laboratories, the Theissen polygons were re-run using a more geo-centric ‘pseudo laboratory location’ for those cytology laboratory services where provision had recently changed or where the laboratory lay outside the region. These adjustments produced a set of nearest neighbour catchment areas for cytology laboratories, which closely reflect both geographical and service use patterns (Fig. 1). Having established a schematic geographical catchment area for each cytology laboratory, this was

![Fig. 1 Nearest neighbour catchment areas for cytology laboratories which closely reflect both geographical and general practice patterns of laboratory use.](image)
Cervical cancer incidence trends

Invasive cervical cancer incidence rates from 1980–2004 were calculated for women of screening age (20–64 years). Populations were based on 2001 census wards combined to create each cytology laboratory catchment area. Rates were directly age-standardised using the European Standard Population and 95% confidence intervals were applied. Cytology laboratory catchment areas with unusually high invasive cervical cancer incidence in specific years were identified from plots of three-year rolling incidence rates. Screening status classification data for the periods of concern were then reviewed in order to identify possible reasons for the changes in invasive cervical cancer incidence. Chi-squared tests were used to compare screening status data. Other routine information recorded at the WMQARC during the time period of interest was also obtained.

Results

Figs. 3 and 4 show how three year rolling directly age standardised incidence rates for invasive cervical cancer in women aged 20–64 years in the West Midlands changed during the period 1980–2004 in comparison with trends in one service of interest (Laboratory A). In the region as a whole in situ cervical cancer incidence rates levelled off at around 155–178 per 100,000 3–4 years after the introduction of the NHSCSP, whilst the incidence of invasive cervical cancer fell by 51% from 25.8 per 100,000 [95% CI 24.3, 27.4] in 1985–87 to only 12.7 per 100,000 [95% CI 11.7, 13.7] in 2002–04. In the catchment area of Laboratory A, the invasive cervical cancer incidence rate decreased more rapidly than in the region as a whole until 1995–97, after which there was an unexpected upward trend between 1999–2000 and 2000–02. Further investigation highlighted the incidence rates in 2000 and 2001 as being significantly higher in Laboratory A’s catchment area (33.2 per 100,000 [95% CI 22.3, 44.1] and 25.3 per 100,000 [95% CI 15.9, 34.7], respectively) than that in the region as a whole (12.5 per 100,000 [95% CI 10.8, 14.3]).

Table 1 shows the total number of invasive cervical cancers diagnosed in Laboratory A’s catchment area and the West Midlands region in 2000 and 2001 and their screening status classifications. Screen-detected cases accounted for around 30% of cancers in both groups of women (30.2% compared with 29.4%, \( P = 0.899 \)), but non-attenders and defaulters together accounted for a higher proportion of the cancers in Laboratory A’s catchment area (39.7% compared with 24.7%, \( P = 0.012 \)). There was a smaller but not significantly different proportion of lapsed attenders in Laboratory A’s catchment area (22.2% compared with 29.8%, \( P = 0.213 \)).
Cervical cancers diagnosed in non-routinely screened women
The trends in invasive cervical cancers in non-routinely screened women diagnosed in the Laboratory A catchment area and in the West Midlands as a whole are shown in Fig. 5. From 1991 to 1993, the proportion of non-attenders diagnosed with invasive cervical cancer in the Laboratory A catchment area was always slightly higher than in the region as a whole. In the period 1999–2001, the proportion of cancers in non-attenders in Laboratory A’s catchment area reached a peak at 25.6% (95% CI 16.4–34.8%). This was 8.5% higher than in the region as a whole (17.1%, 95% CI

Fig. 3 Three year rolling directly age standardised invasive and in situ cervical cancer incidence rates in the West Midlands in women aged 20–64 years. The dotted lines represent 95% confidence intervals. The solid vertical line indicates when the national NHS Cervical Screening Programme was implemented.

Fig. 4 Three year rolling directly age standardised invasive cervical cancer incidence rates in Laboratory A catchment area and the West Midlands. The dotted lines represent 95% confidence intervals. The solid vertical line indicates when the national NHS Cervical Screening Programme was implemented.
14.2–20.0%). The highest numbers of cancers in non-attenders in Laboratory A’s catchment area (n = 18) since the start of the screening programme were diagnosed in 2000 and 2001. The proportion of cancers diagnosed in defaulters in Laboratory A’s catchment area was between 7.0 and 9.0% higher than in the region as a whole from 1994–96 to 1996–98, but followed the regional trend from 1997–99 onwards.

The proportion of cancers diagnosed in lapsed attenders in Laboratory A’s catchment area gradually increased from 1992–94 when it was significantly lower (3.7%, 95% CI –0.4 to 7.8%) compared to the region as a whole (12.0%, 95% CI 9.8–14.2%) and peaked in 1999–2001 at 23.3% (95% CI 14.3–32.2%). The highest numbers of cancers in lapsed attenders since the start of the screening programme (n = 14) were diagnosed in 2000 and 2001. From 2000 to 2002, the percentage of cancers diagnosed in lapsed attenders in Laboratory A’s catchment area steadily decreased again to 10.2% (95% CI 1.7–18.7%) in 2002–04, which is significantly lower than in the region as a whole (25.6%, 95% CI 22.1–29.1%).

Changes in cytology laboratory catchment area
Because of local service reorganisation, over the time period studied, two laboratories were involved in the routine screening of the women included in the catchment area for Laboratory A. Laboratory A had, however, screened all of the previous samples for 82.2% of the cases diagnosed in 2000 and 2001 and the invasive cervical cancer incidence rates for the catchment area were still significantly higher even if the cases previously screened by the other laboratory were excluded. This indicates that the increased invasive cervical cancer rates were unlikely to be related to service organisation.

Other supporting quality assurance information
As the screening status data highlighted increased rates of non-attendance for screening during the years 1999–2002, additional information collected during the first round of cervical screening QA Team visits in 2000–02 was obtained. This highlighted two issues, which may have affected attendance for screening. Firstly, the health authority (now the PCT) which organised screening call and recall for the majority of women in Laboratory A’s catchment area during this time sent only 50% of cervical screening invitations directly, with the remainder being sent by individual GPs. The QA Team recommended that invitations for screening should be sent routinely by the health authority so that there was no ambiguity as to whether the letters had been sent or not. It was also noted that, although five-year screening coverage of the eligible population was just above the national standard (>80%), three-year coverage was almost 20% lower in 25–64 year olds.

Discussion
Main findings of this study
This retrospective analysis of invasive cervical cancer incidence in one laboratory catchment area highlighted an increase in cancers diagnosed in women who had either defaulted from screening surveillance or who had never attended in 2000 and 2001. The proportion of interval cancers was lower than that in the region as a whole indicating that poor laboratory performance was unlikely to be a factor. Other intelligence available to the QARC from QA Team visits had highlighted issues that could have affected attendance for screening. Screening coverage rates and the proportion of invitations and results sent centrally by the health authority increased after the QA Team visit, and it is possible that taking action on these issues contributed to the subsequent decrease in invasive cervical cancer incidence.

The study demonstrates the value of linking the routine datasets collected by cancer registries and QARCs to investigate the possible reasons for differences in incidence trends between screening services, thereby facilitating the evaluation of the NHS CSP. Routine monitoring of such data, using robust methods as advocated in previous studies, can identify typical or atypical variation within screening services and highlight particular areas for investigation.
What is already known on this topic

Previous studies have used the audit of screening histories of women diagnosed with invasive cervical cancer to assess the efficacy of cervical screening. However, the authors have not identified any studies that have investigated possible reasons for the variation in incidence rates using derived catchment populations served by different screening services.

What this study adds

The study shows that the use of routinely collected screening status data for invasive cervical cancers can offer insight into incidence data trends and help to highlight areas of possible concern in a service. For example, high interval cancer rates may indicate historical problems either in the reading of cervical samples by cytology laboratories or in the treatment of in situ disease by colposcopy services. Non-attendance for screening may be a sign of lack of initiatives to improve uptake in certain groups of women. The current work shows how these data can be used on a practical level to enhance quality assurance activities. The implementation of the national invasive cervical cancer audit will further facilitate the development of this type of work within services, as colposcopy and histology data will also be collected routinely.

The formulation of cytology laboratory catchment areas was a valuable part of this work as this relates cervical

Fig. 5 Variation in the proportion of invasive cervical cancers diagnosed in non-routinely screened women (a) non-attenders (b) lapsed attenders and (c) defaulters in Laboratory A catchment area and the West Midlands in 3 year rolling periods between 1988 and 2004. The dotted lines represent 95% confidence intervals.
cancer incidence rates specifically to cervical screening services. Information regarding GP usage of cytology laboratories collected by the WMQARC allowed the WMHGIS service to create and validate catchment areas in a low cost way without accessing GP patient lists and encountering problems with over inflated list sizes.\(^{10}\) Defining catchment area boundaries using standard geographic tools produced timely results using standard datasets which are neither complex nor costly to collect.

**Limitations of this study**

Due to the complex nature of cervical screening services, calculating cervical cancer incidence by laboratory catchment area still had some interpretation problems. Usually, it is events occurring in the years before the diagnosis of an invasive cervical cancer (which prevent the detection or successful treatment of the pre-invasive disease) that may explain the development of the invasive disease. In the intervening time period, cytology services may have been re-organised, and some cytology samples may have been reported at laboratories that no longer existed. The extent of such complications can, however, be evaluated as the screening history data collected by the WMQARC, contain the laboratory code for individual samples; thus recording all the services involved in each woman’s screening history prior to her diagnosis of invasive cervical cancer.

Other limitations in investigating cervical cancer incidence trends retrospectively are that the availability of timely cervical cancer data and supporting relevant information (e.g. from QA Team visits) may be limited and that the numbers of cervical cancers are small when broken down by individual service, which means conclusions should be treated cautiously. Factors such as the population demographics of each service (e.g. socio-economic status and/or ethnicity), cervical screening outcome data (e.g. laboratory report profiles) and additional tumour information (e.g. tumour stage) are also important to consider, but were not included in the scope of this paper.

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