Public Health England

Protecting and improving the nation's health

Cancer registration ascertainment in Kent, London, Surrey and Sussex

Investigating the increase in cancers registered from 2008 to 2014 in the region covered by the London-based registration team

National Cancer Registration and Analysis Service

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Executive summary

The National Cancer Registration and Analysis Service register data on all cancers diagnosed in England. A key performance indicator identified the London regional registration office as an outlier in the percentage increase in registrations for the most recent year, compared to the average of the previous three years. The indicator in 2013 for the region covered by the London-based registration team was 9% compared to 5% for the rest of England. This corresponded to the migration of the registration process to a national electronic system, English National Cancer Online Registration Environment (ENCORE).

This report estimates that approximately two thirds of the increase in cancers registered in 2013 was due to the impact of the migration to the national electronic system. The impact appears to be greater in the London residential region compared to the South East residential region. The improvements made in cancer registration practice and the use of electronic data sources have improved the case ascertainment nationally, but most noticeably in London and the South East, and there are now more cancers registered than in previous years.

Introduction

The National Cancer Registration and Analysis Service register data on all cancers diagnosed in England. There are eight regional registration teams which cover the whole of England. The London-based NCRAS registration team primarily registers all new cancer cases diagnosed in persons normally resident in London, Kent, Surrey and Sussex (see Appendix for a list of the Local Authorities covered) at the time of diagnosis, and it is these cases that are the focus of this report.

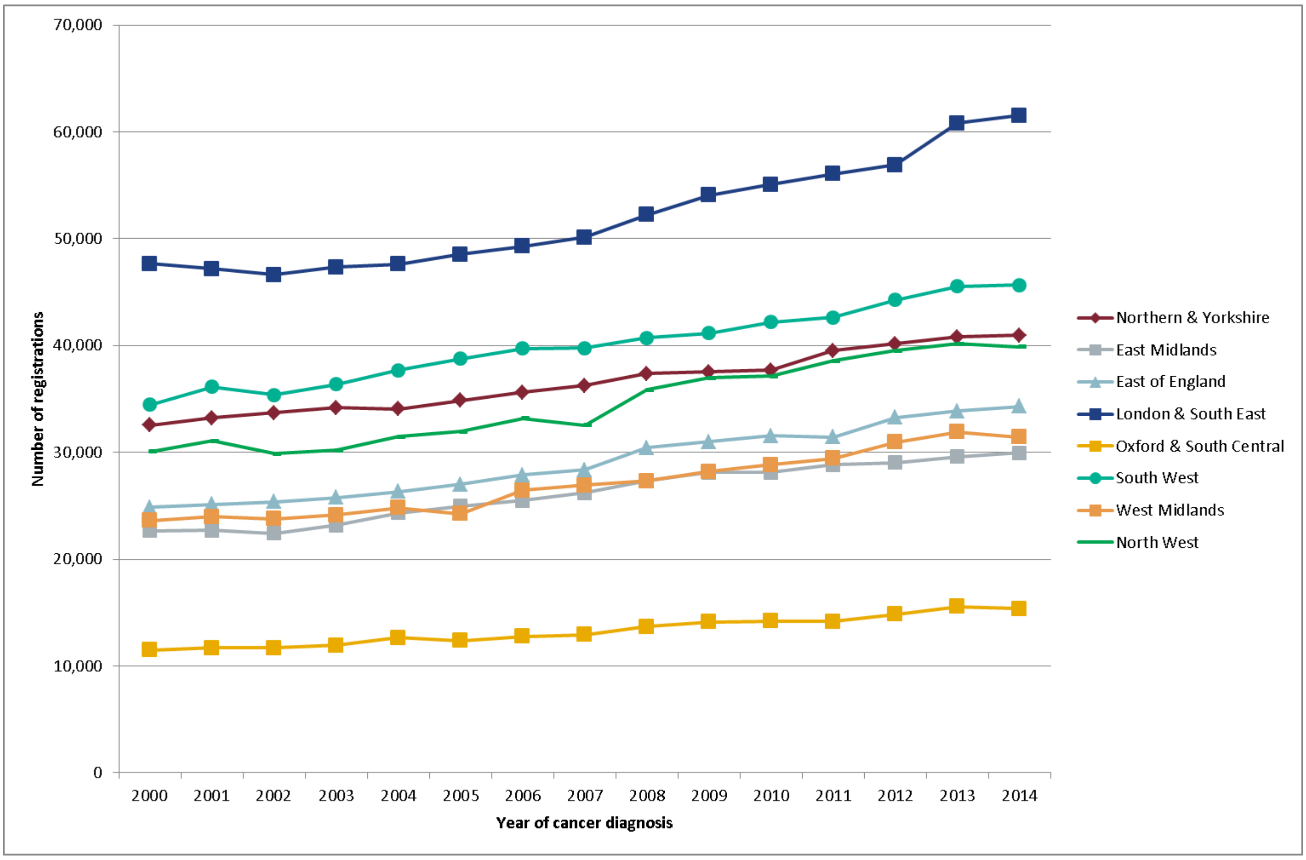
Nationally, the registration teams have a number of key performance indicators (KPIs) for monitoring the registration of cancers across the country. One of these KPIs is the percentage increase in registrations for the most recent year, compared to the average of the previous three years. Three years pooled data is used as a comparator to factor in the impact of annual fluctuations. This KPI was noticed to be particularly high for the London-based team, where the number of finalised cases in 2013 was a 9% increase on the average over the previous three years. The corresponding value for the rest of England was 5%.

There are three possible main reasons for the increase in the number of cancers registered: the underlying population changed; there was a true increase in the number of cancers diagnosed; or improvements in registration practice improved the case ascertainment. These three possibilities will be addressed throughout this report.

Cancer registrations in England 2000 to 2014

Figure 1 shows the annual number of finalised malignant tumour (excluding non-melanoma skin cancers (NMSC)) registrations among England residents by region. As can be seen, the number of finalised records increased throughout the period for every region. Throughout the time period, the London-based registration team (who primarily register cancers diagnosed in persons normally resident in London and the South East, and will from now on be referred to as 'London and the South East') registered the greatest number of cancers which is as expected based on the population size. However, an anomalous step change in the number of cancers registered was seen in 2013 for London and the South East but not the other areas.

Figure 1: Number of finalised cancer registrations of malignant tumours (excluding NMSC) among England residents, by the residential area covered by each regional cancer registration team and year of cancer diagnosis



Cancer registrations in London and the South East 2000 to 2014

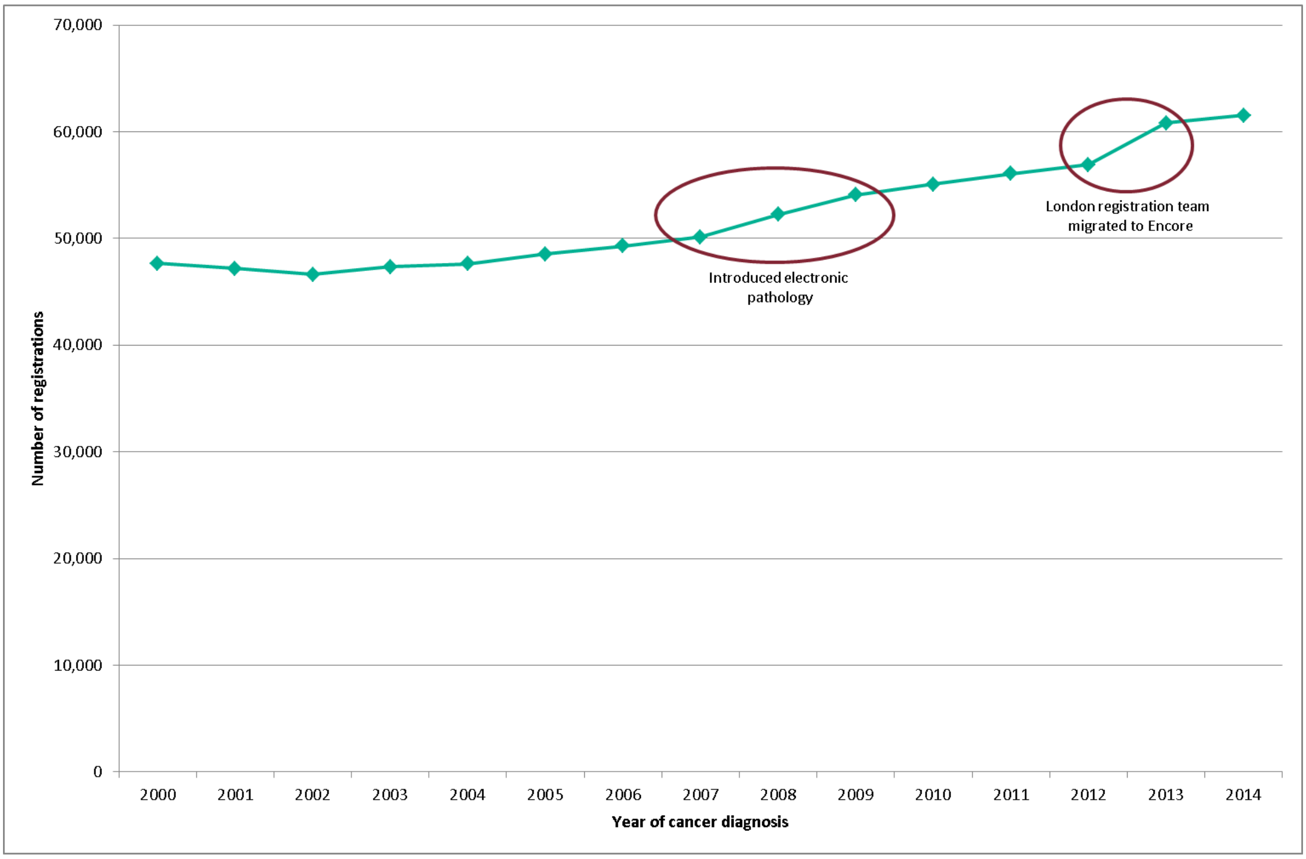
Figure 2 shows the trend from 2000 to 2014 in the number of finalised diagnoses of new malignant tumours (excluding NMSC) registered in London and the South East (a focused version of Figure 1). The number of finalised malignant tumours registered increased throughout the period, with two large increases occurring between 2008 and 2009, and 2012 and 2013.

The numbers of cancer registrations in the English National Cancer Online Registration Environment (ENCORE) continue to change as more cancers are registered over time and details of existing registrations are updated. At the time of reporting, the numbers of cancer registrations for the more recent years such as 2014 may be fewer than expected but would continue to increase in the following months. The data used in this report was extracted in August 2016.

The first noticeable increase in 2008 to 2009 may be the result of the introduction of electronic pathology records. Trusts in London and the South East started to submit some data in an electronic format from around 2005/2006. Prior to this, all pathology information was gathered from paper records. The number of trusts submitting electronic pathology records increased through 2007 and 2008, with the majority of trusts submitting electronic records by 2009. This corresponds to an increase compared to the previous three years of 6% in 2008 and 7% in 2009. This means that a change in registration practice resulted in an increase in case ascertainment.

During the merger of the cancer registries into a single national function, all regions migrated to the same registration system: ENCORE. The larger second increase in Figure 2 corresponds to this migration, with an annual increase in 2013 in the number of finalised malignant records of 7% compared to 2012. The three-yearly increase in 2013 was 9%, compared to the average of 2010 to 2012. For context, the respective values in the rest of England were 2% and 5%. The migration to ENCORE allowed the cancer registry to receive more data feeds, and therefore more information on diagnosed cancers. The hypothesis is that this increased case ascertainment through enabling registration of cancers that were not previously fully captured.

Figure 2: Number of finalised cancer registrations of malignant tumours (excluding NMSC) among residents of London and the South East at the time of diagnosis by year of cancer diagnosis



Trend in number of cancers registered in London and the South East during 2000 to 2014 subdivided by region of residence

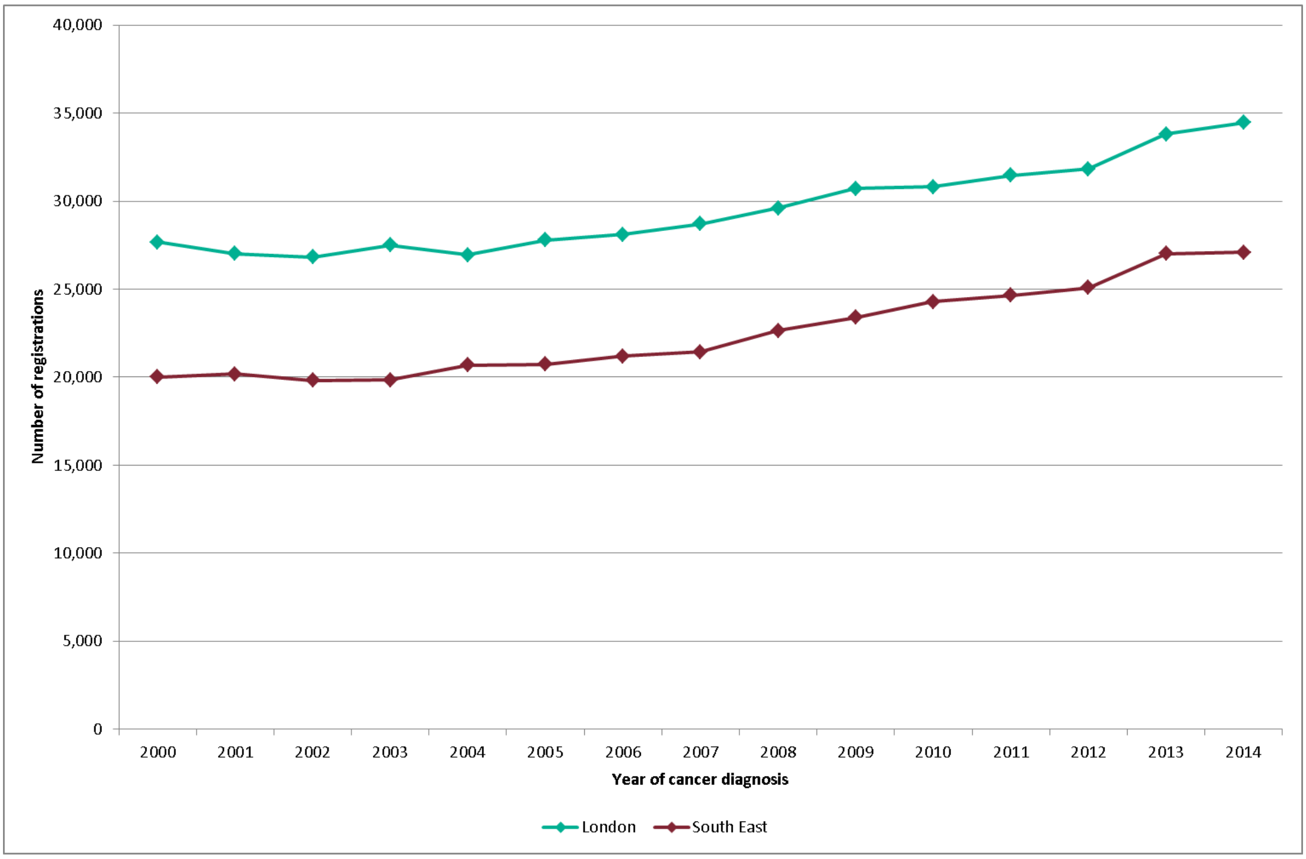
The London-based registration team covers a diverse group of geographies. Broadly speaking, it can be split into London, Kent and Medway, Surrey, and Sussex (all non-London is labelled as South East). This region provides an opportunity to establish if the unique demographics in London explain the findings. The South East is demographically similar to other areas of the country, therefore offering a natural control.

Figure 2 has been replicated to show data for London and the South East separately, and this is shown in Figure 3 below. The trend varied in the two regions, particularly during 2012 to 2013. The increase in 2013 was more pronounced in the South East. Considering the percentage change (compared to the previous three years), the value for 2009 was 7% in London and 8% in the South East. In 2013, the value was 8% in London and 10% in the South East.

As the hypothesis is that the migration to ENCORE increased case ascertainment, there is likely to be one step change from 2012 to 2013 (rather than a gradual increase over a number of years) in the number of cancers registered. The annual percentage increase in 2013 compared to 2012 was 6% in London and 8% in the South East. This was a step change compared to a 1% and 2% increase in the two regions in 2012.

The fact that both London and the South East demonstrated a step change in 2013, while other areas of the country similar to the South East didn't, is evidence against any sudden changes in the national cancer incidence and implies that the registration change was the most significant factor.

Figure 3: Number of finalised cancer registrations of malignant tumours (excluding NMSC) among individuals resident in London and the South East by year of cancer diagnosis and region

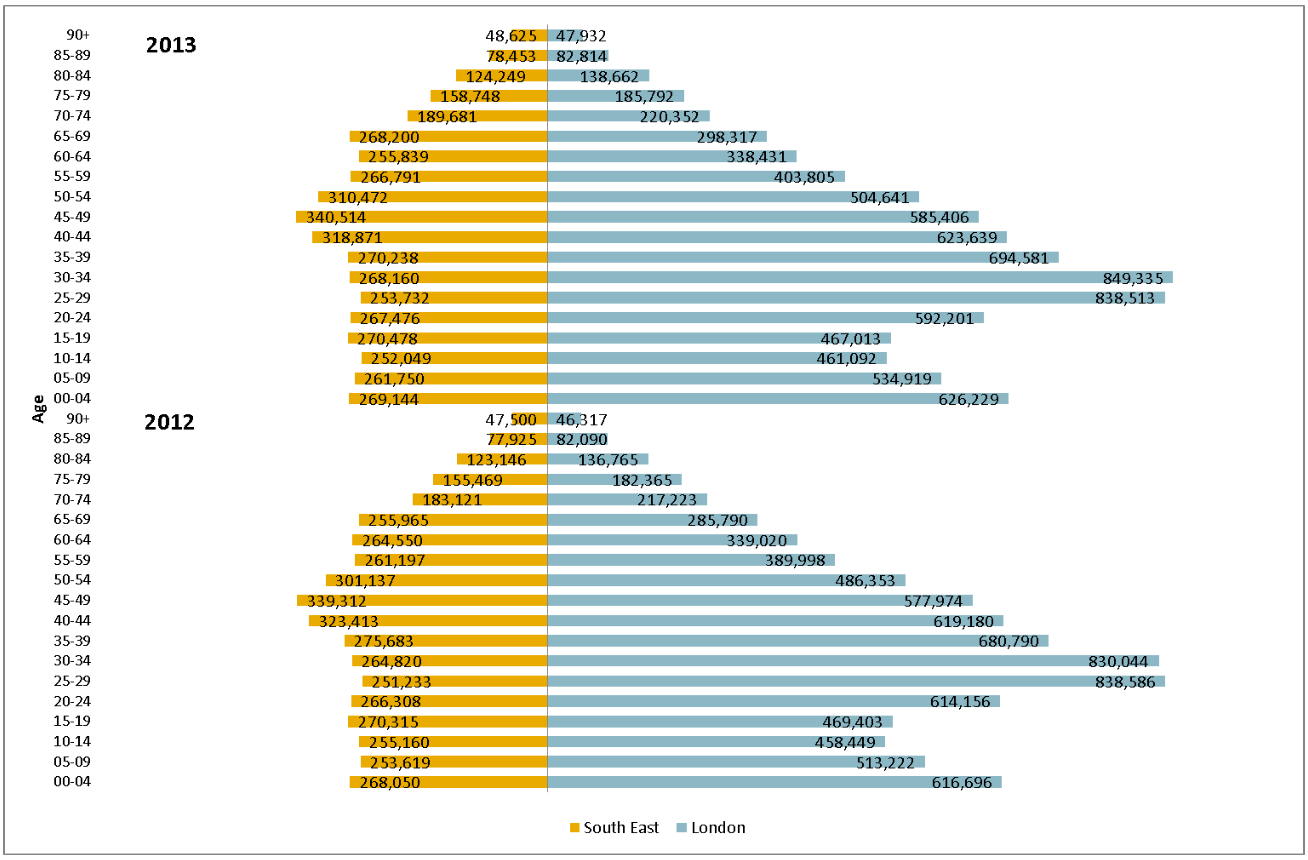


The impact of changes in the underlying population

If the population of any area increases, there will be more individuals at risk of developing cancer. This is the first factor that we will investigate as a potential explanation for the percentage increase in the number of finalised cases registered among individuals who were resident in the London registration area and diagnosed in 2013.

Firstly, it is important to understand the population distribution in the regions of interest. Figure 4 shows the population size of the two regions in 2012 compared to 2013, when the migration to ENCORE happened. In both years, the London region is more skewed to the younger age groups, with 25 to 29 and 30 to 34 being the most common age groups (10% each of population), compared to 45 to 49 in South East (8% of population). If 70 is taken as the age cut-off for the older population (due to end of screening eligibility), in both 2012 and 2013, 8%, 13% and 12% of the population were aged 70+ in London, South East and the rest of England, respectively (data for the rest of England not shown).

Figure 4: Population size of London and the South East in 2012 and 2013 by 5-year age groups, persons and region (source: Office for National Statistics)



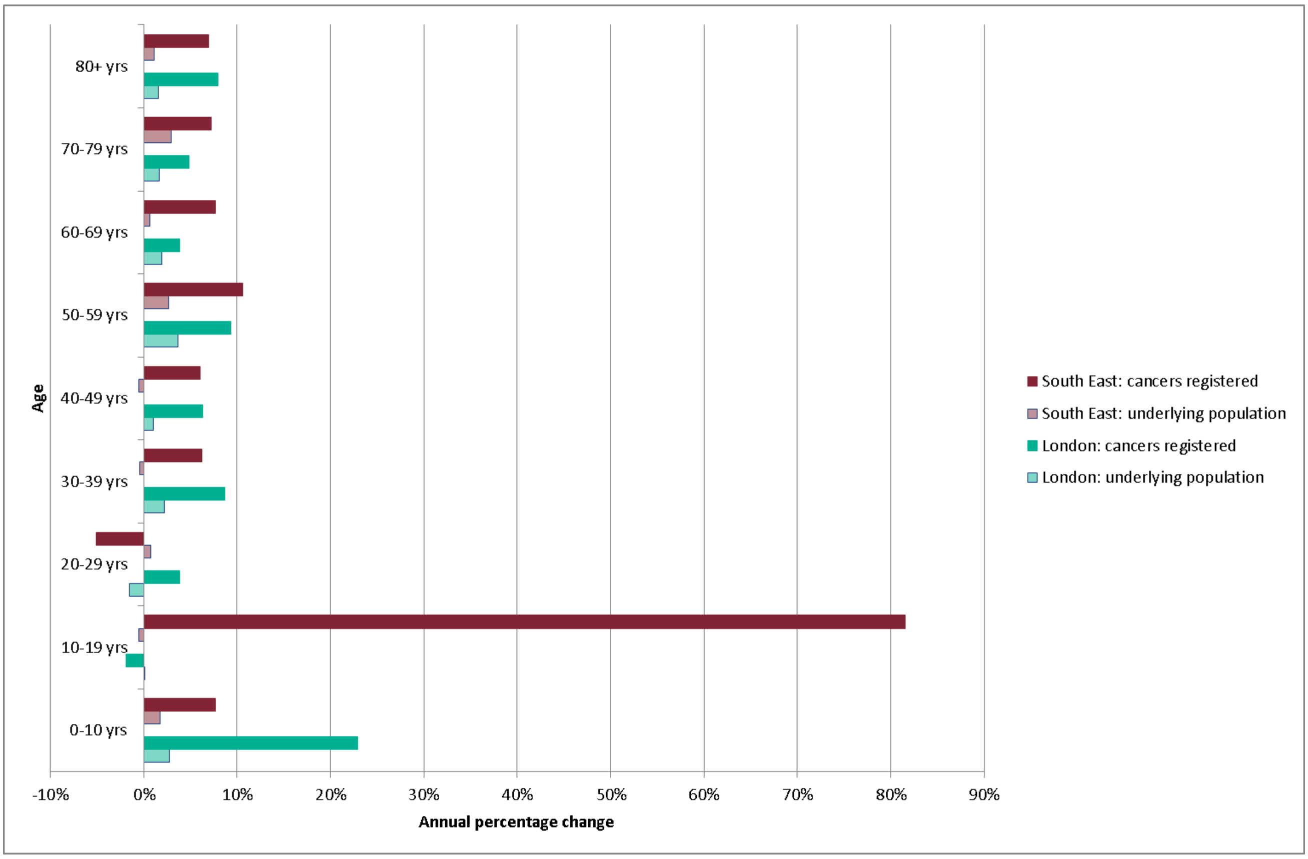
The key performance indicator established that there was a step change from 2012 to 2013 in the number of cancers registered. One hypothesis is that this is due to a large population shift in London and the South East from 2012 to 2013. The percentage increase in the population size in 2013 was 1% in both London and the South East, as it was in 2012 (see Table 1). This does not explain the 6% and 8%, respectively, annual increase in the registrations of cancer.

The risk of developing cancer increases with age. Therefore, a discrepancy between the increase of the underlying population and the increase in cancer incidence would have a greater influence overall if it occurred among older individuals. If there was a substantial increase in the underlying population at older ages, this would support the hypothesis above.

Figure 5 shows the percentage change from 2012 to 2013 by age, for both the number of cancers registered and the size of the underlying population. For both London and the South East, the increase in the number of cancers registered is greater than the increase in the underlying population for all ages apart from 20 to 29 years old (South East) and 10 to 19 years old (London). However, 2% of the cancers diagnosed in 2012 and 2013 were among individuals aged less than 30 years. So the impact of this is minimal.

Across all ages, the increase in the underlying population does not match the increase in the number of cancers registered. Therefore, this hypothesis does not fully explain the entire step change from 2012 to 2013 in the number of cancers registered.

Figure 5: Percentage difference from 2012 to 2013 of the number of cancers registered and the size of the underlying population for London and the South East



A more detailed assessment can confirm this finding. Table 1 shows the population size for London, the South East, and for the rest of England combined for 2009 (once electronic pathology records were introduced) to 2014. As can be seen, compared to the previous three years, 2013 saw the London population increase by 3% and the South East population by 2%. This is in comparison to 1% in all other regions in England.

Table 1: Population estimates for 2009 to 2014 for England, subdivided by London, the South East and the Rest of England for all ages and persons

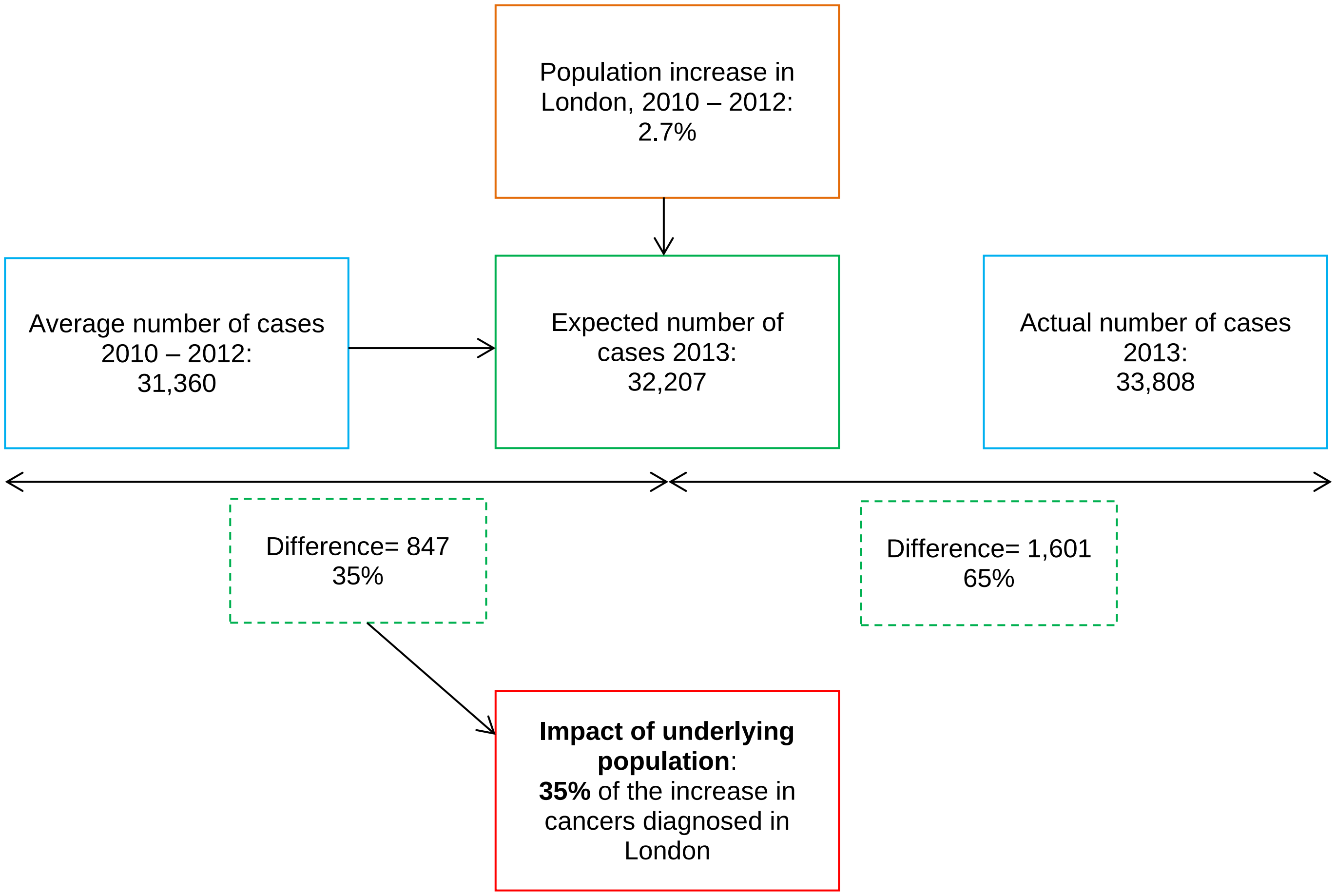
Year	London resident population			South East resident population			Rest of England		
	Count	% difference		Count	% difference		Count	% difference	
		Annual	3-year		Annual	3-year		Annual	3-year
2009	8,015,700			4,318,051			39,862,630		
2010	8,135,773	1.5%		4,362,469	1.0%		40,144,210	0.7%	
2011	8,279,598	1.8%		4,400,607	0.9%		40,426,964	0.7%	
2012	8,384,421	1.3%	3.0%	4,437,923	0.8%	1.8%	40,671,385	0.6%	1.3%
2013	8,493,674	1.3%	2.7%	4,473,470	0.8%	1.7%	40,898,673	0.6%	1.2%
2014	8,617,007	1.5%	2.8%	4,516,547	1.0%	1.8%	41,183,064	0.7%	1.3%

To assess the impact of this change in the underlying population, calculations were performed by region (London and South East). The calculations for London are as follows. If the number of cancers diagnosed in 2013 was proportional to the increase in the population size of London, the cancers registered in 2013 would hypothetically have increased by 2.7% compared to the previous three years (see Table 1).

This would mean that in 2013, 1,601 excess cancers were diagnosed than expected if the increase in cancer registrations was in line with the population increase. This means that 65% of the actual increase was not explained by the underlying population increase. This example is visualised in Figure 6 below. In the South East, it was estimated that 2,050 excess cancers were diagnosed than expected from the population increase.

This was 87% of the actual increase. Therefore, only 35% of the increase in cancer cases in London and 13% of the increase in cancer cases in the South East are accounted for by changes in the underlying population. This calculation was repeated for individuals aged under and above 70 separately, and the conclusions hold (data not shown). Therefore, the changes in the underlying population do not fully account for the increase in the cancers registered in 2013.

Figure 6: Visualisation of the calculations used to assess the impact of the underlying population on the cancers registered in London in 2013



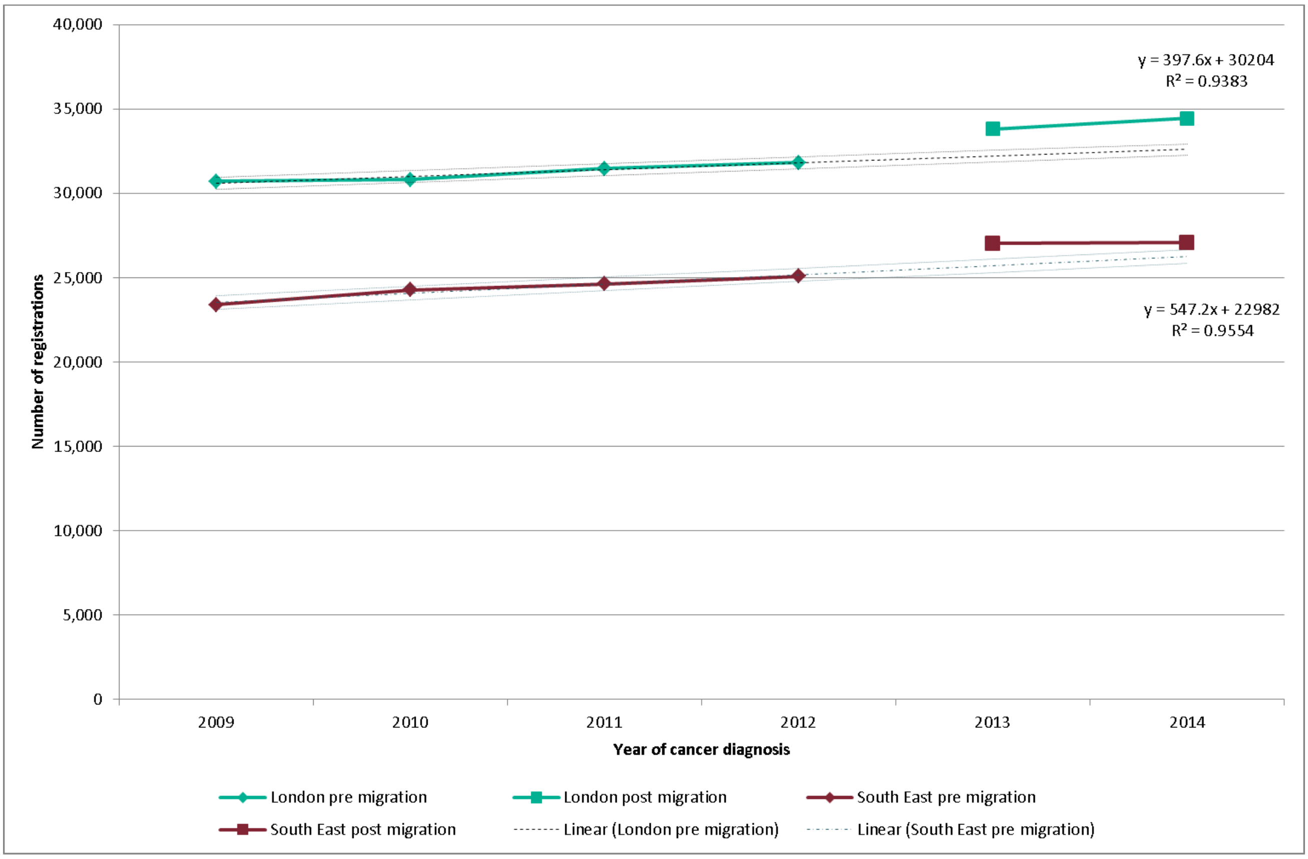
An empirical assessment of the trend

The previous section demonstrated that there was an increase in the underlying population, which would result in an increase in the number of cancers diagnosed. However, this does not account for the impact of the migration to ENCORE. Therefore, an empirical approach was adopted to estimate the number of cancers expected in 2013, assuming the trend from 2009 to 2012 continued.

A linear trend was applied to the number of finalised cancers registered in London and the South East during 2009 to 2012. This can be seen in Figure 7. The linear trend was projected to 2014, to give an estimate of the number of cancers predicted to be registered if all other factors, including the registration system, remained constant. In London, there were 33,808 cancers recorded in 2013. However, there were 32,192 cancers predicted based on the linear trend. Therefore, there were 1,616 excess cancers registered in 2013 in London. This equated to 81% (CI: 64% - 99%) of the increase from 2012 to 2013 being above the expected value, and could be attributed to the migration to ENCORE. In the South East, there were 1,299 extra cancers registered in 2013 compared to the expected value from the linear trend. This equated to an estimate of 67% (CI: 47% - 88%) of the increase in the South East which could be attributed to the migration to ENCORE.

Considering the South East in Figure 7, the number of cancers registered was almost the same as predicted by the linear regression model by 2014 (cancers registered: 27,086 compared to 26,265 (95% CI: 25,863 - 26,667)). This implies that the impact of the migration to ENCORE was temporary for the South East. This was not the case for London, where there have continued to be more cancers registered than predicted by the linear regression model. However, these values are as of August 2016 and the number of cancers registered does increase over time as late registrations are processed.

Figure 7: Number of finalised cancer registrations of malignant tumours (excluding NMSC) among individuals resident in London and the South East, by year of cancer diagnosis and region with a linear trend applied on the data for years 2009 to 2012



Two methodologies have been applied to estimate the impact of the migration to ENCORE. Table 2 summarises these findings, and an approximate estimate is that two thirds of the increase in the number of cancers registered in 2013 by the London-based registration team was due to the migration to ENCORE. The empirical approach combines trends in population growth, changes in population distribution (eg ageing) and any ongoing changes in cancer incidence.

Table 2: Proportion of the increase in number of cancer registrations in 2013 explained by the two methodologies

	London resident population	South East resident population
Impact of underlying population	35%	13%
Empirical approach (linear trend)	19% (CI: 1% - 36%)	33% (CI: 12% - 53%)

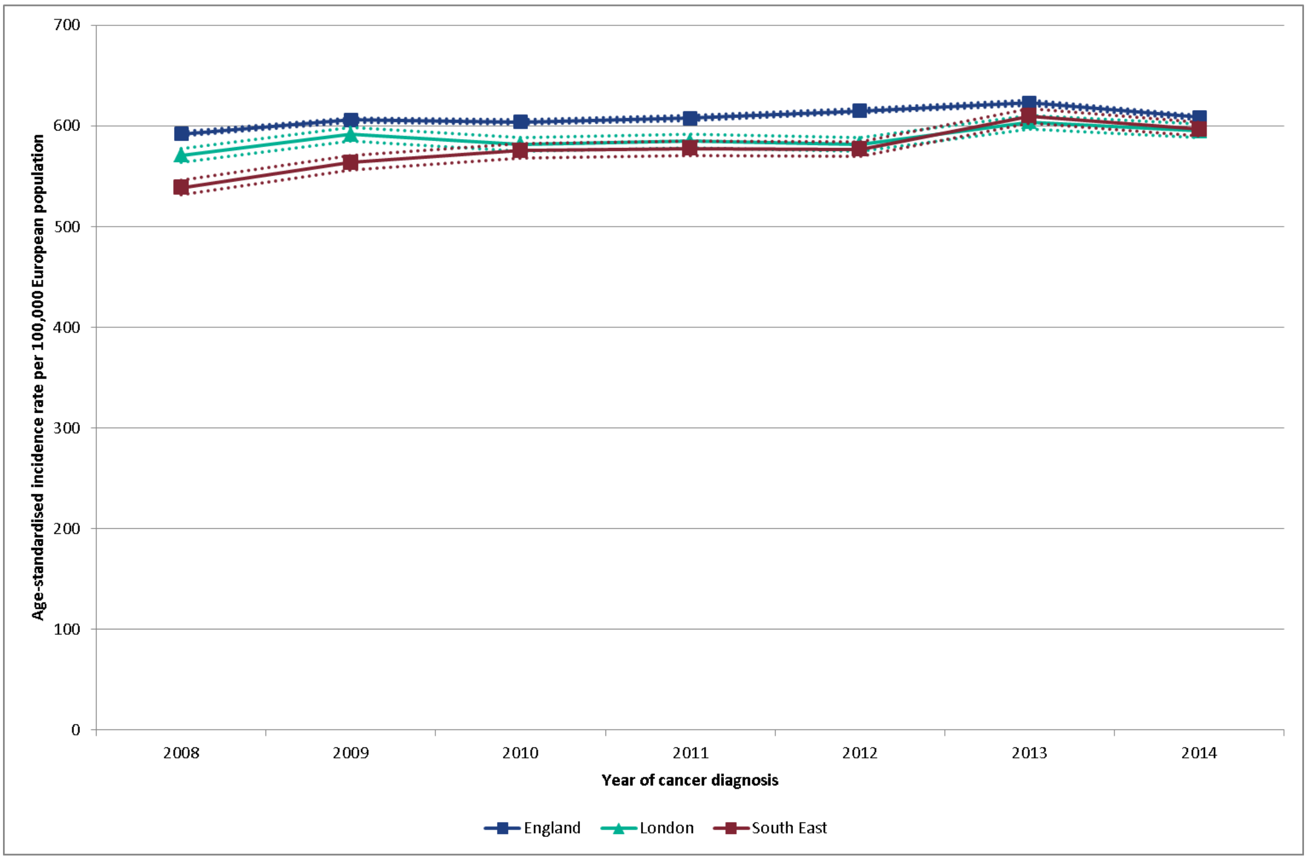
Age-standardised incidence rates for London and the South East 2008 to 2014

The impact of the migration to ENCORE will now be investigated using age-standardised incidence rates per 100,000 as it is the measure most commonly used to analyse trends and to compare populations.

Age-standardisation takes into account the age distribution of the underlying population, and allows incidence to be compared across time and geography. Figure 8 shows the age-standardised incidence rates per 100,000 European population for all malignant cancers for England and for all cancers registered in London and the South East (excl. NMSC).

The trend in the incidence rate for London and the South East was very similar to the national trend. The annual fluctuation in trend in Figure 8 was similar in London, the South East and England. The step change seen in the number of cases from 2012 to 2013 can also been seen in the age-standardised rates, particularly in the South East. The percentage increase in 2013 compared to the previous three years was 2% in England, 4% in London and 6% in the South East.

Figure 8: Age-standardised incidence rates per 100,000 European Standard Population for all malignant cancers (excluding non-melanoma skin cancer) by year of cancer diagnosis (dashed lines represent confidence limits)



It has been demonstrated that the underlying population had an impact on the number of cancers registered. Therefore, the empirical approach was then applied to the age-standardised rates from 2009 (to remove the time period when electronic pathology records were introduced), to assess if the impact of the migration to ENCORE was apparent whilst taking account of the underlying population. Figure 9 shows the age-standardised incidence rates per 100,000 for London and the South East with linear trend lines.

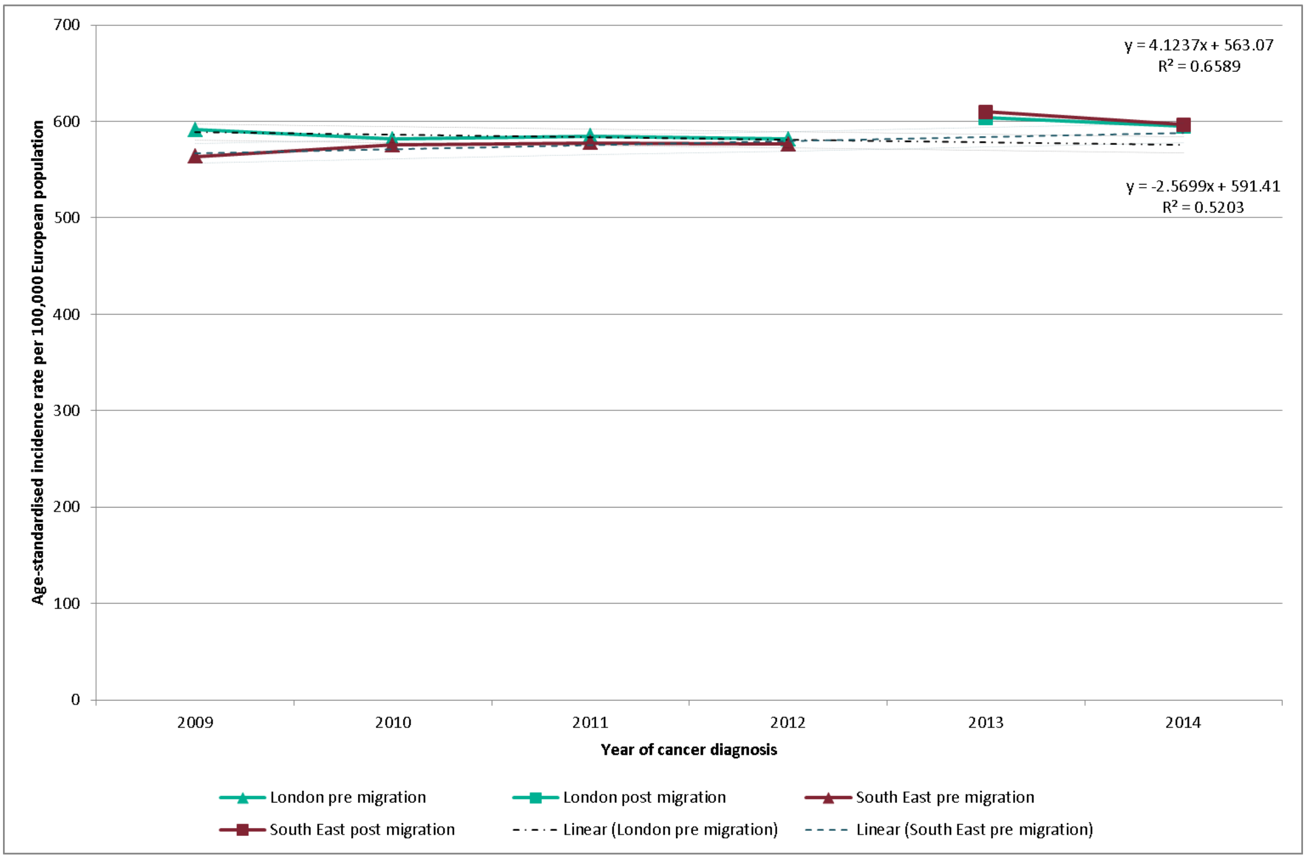
The linear trend was applied to the rates for 2009 to 2012 and projected to predict the expected values in 2012 to 2014. The age-standardised rates per 100,000 for 2013 were greater than the upper confidence limit of the predicted value from the linear trend, for both London (604 compared to 579 (CI: 570 – 587) per 100,000) and the South East (610 compared to 584 (CI: 574 – 594) per 100,000).

Based on the rates for 2009 to 2012, the projected trend decreased in 2013 and 2014 for London, but increased for the South East. Comparison of the actual and projected age-standardised rates equated to an estimate of 115%

(CI: 77% - 153%) of the increase from 2012 to 2013 being above the expected values in London, and 79% (CI: 49% to 109%) in the South East.

Therefore, the impact of the migration to ENCORE was that the age-standardised incidence rates for 2013 were higher than expected if all other factors, including the registration system, remained unchanged. This was particularly true for London.

Figure 9: Age-standardised incidence rates per 100,000 European Standard Population for all malignant cancers (excluding NMSC) by year of cancer diagnosis with a linear trend applied on the data for years 2009 to 2012 (dashed lines represent confidence limits)



Discussion

Overall findings

Improvements in cancer registration which have occurred with the increasing use of electronic records, and the move to a single national registration system, have increased the case ascertainment of cancers nationally. The registration service is confident that over 95% of all cancers are registered. This conclusion is based on the proportion of tumours diagnosed from details on their death certificate only (which was 3% in 2013).

The migration to ENCORE had a noticeable impact on the number of cancers registered. The London-based registration team was an outlier compared to other regions in England with a 9% increase in all cases registered in 2013 among the resident population, compared to the average of the previous three years. This corresponded to 8% and 10% in London and the South East, respectively. After investigation of both the counts of cancers registered and the age-standardised rates, it was estimated that approximately two thirds of the increase in cancers registered in 2013 were due to the impact of the migration to ENCORE. There appeared to be a greater impact of the migration to ENCORE in London compared to the South East. ENCORE registers more cancer cases than in previous years, and our counts of registered cancers are better since 2013.

To summarise, there was a step change in the number of cancers registered during 2012 to 2013 with an annual increase of 7%, which could be due to either changes in the underlying population, incidence shift or a change of registration practice. An examination of the underlying population found a 1% increase during 2012 to 2013 which doesn’t explain the step change. An empirical approach was then adopted to assess the combined impact of a change in incidence and registration practice as it is difficult to estimate incidence shift directly. This found that approximately one third of the step change could be accounted for. Therefore, it was estimated that two thirds of the step change were due to changes in registration practice, specifically the migration to ENCORE.

Methodological discussion

This type of analysis is not straightforward as there are a large number of factors that may be driving the variation. This report has attempted to address the main potential factors. Sophisticated statistical modelling could have been employed, which would take account of known confounding factors. However, there may be unmeasured confounders which cannot be accounted for. There are also a large number of factors which are potentially associated with the number of cancers registered, and the size of the underlying population would limit the statistical power.

An empirical approach was chosen as it is often very difficult to fully account for all the factors that influence the number of registrations. Therefore, it was decided that the best approach would be to base our estimates on the previous trends. These trends exist both because of and despite the contextual information. For example, changing demographic structures.

Factors associated with increasing cancer incidence

As demonstrated by this analysis, there is a true increase in the incidence of cancer. There are a number of reasons why the incidence of cancer is increasing, both nationally (1) and internationally (2-3), many of which are related. The World Health Organization estimates that over 30% of cancer deaths could be prevented if modifiable risk factors were reduced (4). The increase in cancer incidence is partly due to an ageing population (3). However, as age-standardised rates are also increasing this is not the sole factor.

As demonstrated by global studies, there are a number of factors which are associated with increasing rates of cancer (5), including smoking (6-7), exercise and lifestyle (8), UV exposure (8), environmental hazards (8), dietary, hormonal and reproductive factors (9). These factors are relevant to the UK. For example, increasing obesity could contribute to an overall increase in cancer incidence in England.

There are a number of public health initiatives which have improved the early diagnosis of cancer. Cancer screening is offered for breast, cervical and bowel cancer and aims to diagnose cancer at an early stage and improve survival. Screening uptake, however, is particularly poor in London (10-12). There are a number of reasons for the low uptake in London. For example, lower uptake in some ethnic groups (13), those from areas of higher deprivation (14) and practical reasons (15).

Initiatives have attempted to reduce the deprivation gap. However, the geographical variation persists (16). Be Clear on Cancer awareness campaigns were introduced in January 2011, and aim to promote awareness and early diagnosis of specific cancers. The campaigns aim to raise awareness of the signs, and encourage people to see their GP without delay. The campaigns have been demonstrated to have varying levels of impact on the number of referrals and diagnoses (17-18). However, the interim results for skin cancer demonstrated an increase in public awareness of symptoms of skin cancer (18).

Limitations

This report aimed to investigate the net increase of all cancers registered. Variations in trends across cancer groups were not addressed. Neither were variations across deprivation or gender. These variations were not addressed as an empirical approach was adopted. There were many potential confounders, and it was decided to simply base our estimates on the current data. Variation in smaller geographies was also not considered, as numbers would be too low to meaningfully analyse trends.

Summary

The improvements made in cancer registration practice and the increase use of electronic data sources have improved the case ascertainment. There are now more cancers registered than in previous years in London and the South East. Two thirds of the total increase in the cancers registered in 2013 was due to the registration change, which was imposed on otherwise smooth trends due to population growth, ageing and secular trends in cancer incidence.

However, the conclusions that can be drawn from the trends in age-standardised rates (ie the increase in age-standardised incidence rates from 2008 to 2014 in both London and the South East) are valid, with consideration of increased rates in 2013.

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Appendix

List of local authorities covered

A cancer registered by the London-based registry team must be for an individual with a postcode located in one of the following local authorities.

Kent and Medway:
- Ashford
- Canterbury
- Dartford
- Dover
- Gravesham
- Maidstone
- Medway
- Sevenoaks
- Shepway
- Swale
- Thanet
- Tonbridge and Malling
- Tunbridge Wells

Surrey and Sussex:
- Adur
- Arun
- Brighton and Hove
- Chichester
- Crawley
- Eastbourne
- Elmbridge
- Epsom and Ewell
- Guildford
- Hastings
- Horsham
- Lewes
- Mid Sussex
- Mole Valley
- Reigate and Banstead
- Rother
- Runnymede
- Spelthorne

- Surrey Heath
- Tandridge
- Waverley
- Wealden
- Woking
- Worthing

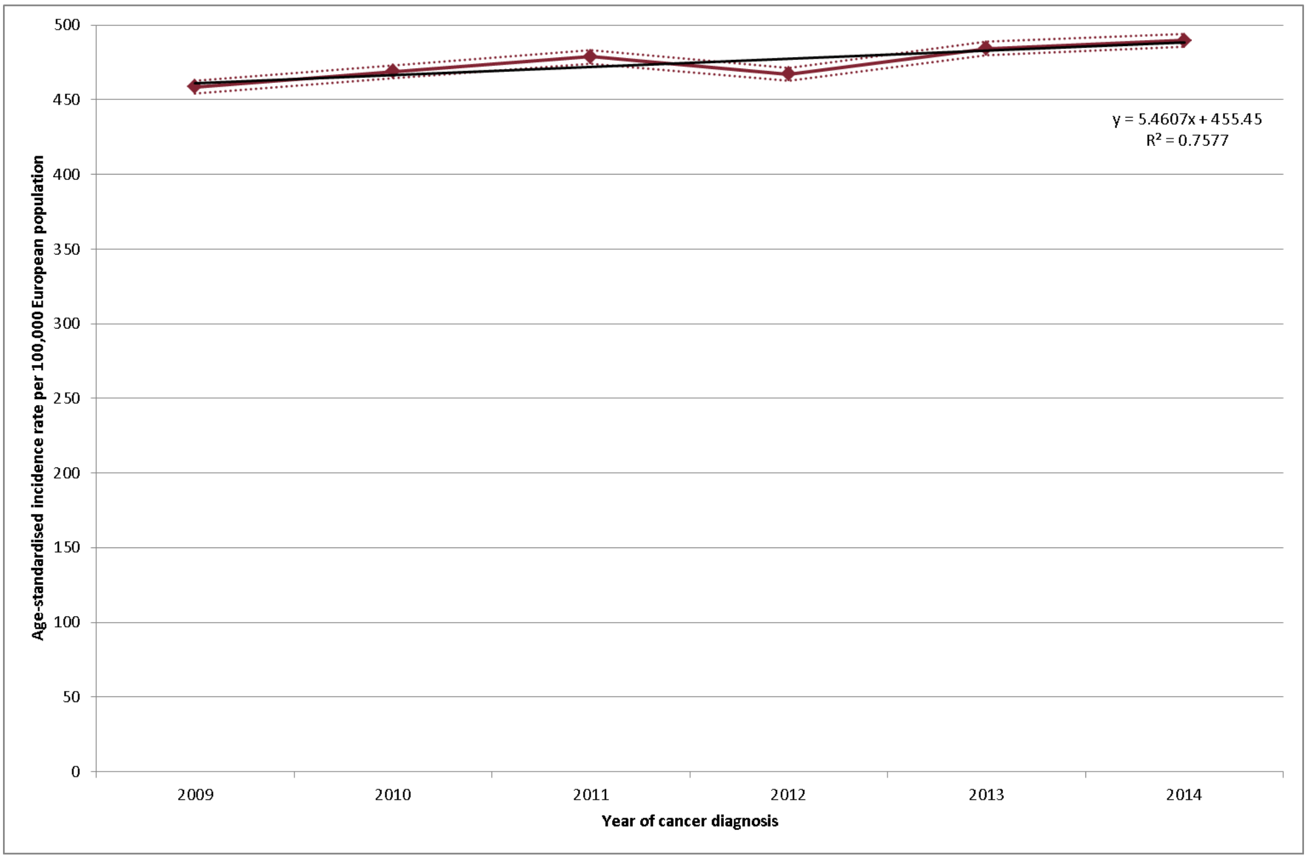
London:

- Barking and Dagenham
- Barnet
- Bexley
- Brent
- Bromley
- Camden
- City of London
- Croydon
- Ealing
- Enfield
- Greenwich
- Hackney
- Hammersmith and Fulham
- Haringey
- Harrow
- Havering
- Hillingdon
- Hounslow
- Islington
- Kensington and Chelsea
- Kingston upon Thames
- Lambeth
- Lewisham
- Merton
- Newham
- Redbridge
- Richmond upon Thames
- Southwark
- Sutton
- Tower Hamlets
- Waltham Forest
- Wandsworth
- Westminster

Additional Information on the Basis of Diagnosis of Cancers

Every registered tumour is assigned a basis of diagnosis from eight categories using the International Agency for Research on Cancer (IARC) classifications: death certificate, clinical, clinical investigation, specific tumour markers, cytology, histology of metastasis, histology of primary, and unknown. For the remainder of this report, histology of metastasis and histology of primary will be combined and referred to as ‘pathological basis’. Clinical and clinical investigation will be combined and referred to as ‘clinical basis’.

Additional Figure 1: Age-standardised incidence rates per 100,000 European Standard Population for all malignant cancers (excluding NMSC) registered using a pathological basis for London and the South East during 2009 to 2014



The national registration team believe that since the introduction of electronic pathology in 2007, the vast majority of pathologically diagnosed cases have been registered. Improving data quality since migration is more likely to have found clinically diagnosed cases which would previously have been missed.

Since the introduction of electronic processing in 2007, the process has remained consistent, even throughout the migration to ENCORE. Additional Figure 1 displays the age-standardised incidence rate for pathological cases in London and the South East. There is a reduction in the rate from 2011 to 2012, due to changes in registration in preparation for the introduction of ENCORE. However, when a linear trend is applied (the black line), the overall increase is as expected. This provides further evidence to the conclusions made in the report.