

# ENCRA 2007 General Meeting

## FINAL PROGRAMME AND ABSTRACTS



**21 September 2007**  
**Cankrjev Dom, Stih Hall**  
**Ljubljana, Slovenia**



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**INTERNATIONAL AGENCY FOR RESEARCH ON CANCER  
CENTRE INTERNATIONAL DE RECHERCHE SUR LE CANCER**



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**INTERNATIONAL ASSOCIATION OF CANCER REGISTRIES  
ASSOCIATION INTERNATIONALE DES REGISTRES DU CANCER**



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# Programme

Venue: Cankrjev Dom, Stih Hall

7.30-8.00	Poster Mounting		
		<b>Use of cancer registration data</b>	<b>Speaker</b>
8:00-8:15	O-01	Cancer Registries: the sky is the limit?	Sabine Siesling
8:15-8:30	O-02	Stomach Cancer	Klemen Rihar
8:30-8:45	O-03	Trends in colorectal cancer incidence and mortality in the Netherlands since 1975 by period and birth cohort	Liza van Steenbergen
8:45-9:00	O-04	Cancer survival analysis as a service for oncological clinics in Hamburg	Alice Nennecke
9:00-9:15	O-05	Breast Cancer incidence in ethnic groups in South East England	Ruth Jack
9:15-9:30	O-06	Trends in the occurrence of second primary cancers in the Thames Cancer Registry (TCR)	Peter Madden
9:30-9:45	O-07	Few differences in treatment, but a worse overall survival for cancer patients with COPD: a large population based analysis	Saskia van de Schans
9:45-10:15	<i>Coffee break and Poster viewing (Authors available for questions)</i>		
		<b>Comparability and quality of cancer registration data</b>	
10:15-10:30	O-08	A method to adjust for ascertainment bias in the evaluation of cancer registry data	Elham Kharazmi
10:30-10:45	O-09	A correction method for under-ascertainment in cancer cases in the very elderly	Mahdi Fallah
10:45-11:00	O-10	A new software for evaluating the quality of cancer registry data	Ivan Rashid
11:00-11:15	O-11	The Cybernetic Patient - the core of the Polish National Health Care System OSOZ	Ryszard Mezyk
11:15-11:30	O-12	Are data on childhood cancer comparable across Europe?	Eva Steliarova-Foucher
11:30-11:45	O-13	Quality control by record linkage of the Icelandic Cancer Registry and the Hospital Discharge Registry	Laufey Tryggvadottir
11:45-12:00	<b>Poster viewing</b>		
12:00-13:00	<i>Lunch break</i>		
<b>ENCR General Meeting: Information for member registries &amp; discussions</b>			
<b>Session OPEN to all registries. Member registries' active participation in the discussions and provision of feedback is very welcome and highly encouraged</b>			
13:00-13:20	ENCR current status		Henrik Moller
13:20-13:40	ENCR gateway - concept and requirements		Freddie Bray Lydia Voti
13:40-13:55	ENCR Aims and Future Directions		Henrik Moller
13:55-14:15	ENCR-IARC		Philippe Autier

# Programme

		<b>Access to data: legal status of the registries, confidentiality and data security issues</b>	
14:20-14:40	O-14	The Austrian National Cancer Registry: Strengths and Limitations of a Cancer Registration Law	Monika Hackl
14:40-15:00	O-15	Confidentiality in cancer registration	Alexander Katalinic
15:00-15:20	O-16	Raising funds for cancer registration: A proposal for and from Greece	Asterios A Terpos
15.45-17:00	<b>Poster viewing</b>		
17.00	<b>End of General Meeting</b>		



**O-02**

**Stomach Cancer: Incidence in Slovenia, Croatia and Tirol (Austria) during the years 1999 - 2003**

Authors: Klemen RIHAR <sup>1)</sup>, Bratko FILIPIČ <sup>2)</sup>, Srečko SLADOLJEV <sup>3)</sup>

Affiliation of Authors: 1) Chengdujska 4, 1000 Ljubljana, Slovenia (e-mail: [klemen\\_r@email.si](mailto:klemen_r@email.si)); 2) Institute of Microbiology and Immunology, Medical Faculty, University of Ljubljana, Zaloška 4, 1105 Ljubljana, Slovenia (e-mail: [A.Stanonik@yahoo.com](mailto:A.Stanonik@yahoo.com)) 3) Institute of Immunology, Rockefellerova 4, 10000 Zagreb, Croatia ([SSladoljev@IMZ.hr](mailto:SSladoljev@IMZ.hr))

**Background:**

Stomach cancer is the fourth most frequent cancer with 876.000 new cases (8,7% of the total) and 647.000 deaths (10,4% of cancer deaths) in 2000. Almost two-thirds of these cases occurred in less developed countries. The age-standardised incidence rate are highest in Japan (69,2/100000 in men and 28,6/100000 in woman. High rates are also present in both sexes in eastern Asia, eastern Europe and central and South America. The rates are low in eastern and northern Africa, North America and southern Asia. The survival for stomach cancer is moderately good only in Japan (52%). The estimated number of incident cases (both sexes) in Europe in 2004 is 171 (5,9%)/2868,8 of all sites, while the estimated numbers of stomach cancer deaths in 2004 is 137,9 (8,1%)/1711,0 of all sites. The difference in incidences of stomach cancer in Slovenia, Croatia and Tirol (Austria) during the years 1999 and 2003 were analysed and compared to the estimated European value for 2004.

**Methods:**

The recent sources of incidence data are available in the: Cancer Registry of Slovenia (Institute of Oncology, Ljubljana, Slovenia), Croatian National Cancer Registry (Croatian National Institute of Public Health, Zagreb, Croatia) Tumorregister Tirol (IET-Institut für klinische Epidemiologie der TILAK GmbH, Innsbruck, Austria). The incidence data for man and woman are analysed separately.

**Results and Conclusions:**

The incidence values / 100000 in 1999 was the highest in Tirol (79 for woman and 88 for man), in Croatia this was (24,6 for woman and 43,8 for man). The lowest incidence values were in Slovenia ( 16,3 for woman and 32,5 for man). In the year 2003 the data are the following: in Tirol (Austria) the incidence values were 54 (for woman) and 76 (for man). In Croatia this was 20,6 for woman and 33,0 for man. In Slovenia the incidence values were: 18,7 for woman and 29,1 for man. In general the incidence values are decreased. It is interesting to compare these data with the estimated number of incident case in Europe in 2004 being 68,2 for woman and 102,8 for man. The decrease may be related to improvement in preservation and storage of food, as well as this also represent the changes in the prevalence of H. Pylori as a possible risk factor for stomach cancer.

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**O-03**

**Trends in colorectal cancer incidence and mortality in the Netherlands since 1975 by period and birth cohort**

Authors: LN van Steenberg MSc1, VEPP Lemmens MSc2 , WJ Louwman MSc1, JWW Coebergh MD PhD1,2

Affiliation of Authors: 1Eindhoven Cancer Registry, Comprehensive Cancer Centre South, Eindhoven, the Netherlands  
2Department of Public health, Erasmus University Medical Centre, Rotterdam, the Netherlands

**Objectives:**

Preceding any future colorectal cancer (CRC) mass screening we examined trends in CRC incidence and mortality by gender, and subsite in the southern Netherlands, an area well served by endoscopy since the 1980's.

**Methods:**

All patients with primary CRC registered between 1975 and 2004 in the Eindhoven Cancer Registry area were included. (n=23,450) Age-period-cohort analysis was performed to explain the origin of the trends of CRC incidence and mortality.

**Results:**

Incidence rates of colon cancer increased since 1975 from 23/100,000 in both genders to about 38/100,000 in males and 30/100,000 in females in 2004. Rectal cancer incidence remained relatively stable at about 25/100,000 in males and 15/100,000 in females. The CRC incidence increased for male patients born in subsequent birth cohorts between 1900 and 1955 ( $p=0.010$ ). A birth cohort effect was found in the incidence of left sided colon cancer for males with a marked increase in relative risk for the birth cohorts 1900 to 1960. (RR1900: 0.8 (95%CI 0.6-1.0), RR1960: 1.6 (95%CI 0.9-2.8), reference: 1910-1919) Mortality rates for CRC decreased since 1975, which was more pronounced for rectal than for colon cancer. (RR 1975-1979:1.32 (95%CI 1.19-1.46), RR 2000-2004: 1.00, reference period)

**Conclusion:**

Cohort effects affected temporal trends in incidence of CRC, especially in the left sided colon. Trends in mortality were mainly affected by period effects. These results confirm that the changes in CRC incidence could be attributed to lifestyle factors, and the decreasing mortality to improved treatment.

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**O-04**

**Cancer survival analysis as a service for oncological clinics in Hamburg**

Authors: Alice Nennecke\*, Stefan Hentschel\*

Affiliation of Authors:\* Hamburg Cancer Registry  
Authority for Social Affairs, Family, Health and Consumer  
Protection  
Billstraße 80, D-20539 Hamburg, Germany

**Objectives**

Population-based cancer survival analysis constitutes valuable reference material for the evaluation of oncological care. The Hamburg Cancer Registry (HCR) set up a procedure to report survival of cancer patients regularly to the treating institutions. Thus registration data shall be utilized by clinical quality management on behalf of long-term improvements. In return data quality and completeness are to be enhanced. The approach is presented using the example of breast cancer.

**Methods**

In collaboration with clinical oncologists a report structure covering the institution's notifying activity and the survival of its patients was developed. The routine analysis includes observed and relative survival rates of patient cohorts defined by period of diagnosis, sex and treating institution, compared to that of a Hamburg reference patient. Further stratifications by age, stage, etc. are available on request.

**Results**

Population-based survival concerning female breast cancer patients resident in Hamburg and diagnosed since 1995 ranges among that of intra-German and European neighbouring countries (5-year relative survival rate 82%), while the rates relating to several treating institutions vary considerably. The analysis of these results needs cautiousness and clinical knowledge.

**Conclusions**

The evaluation and interpretation of clinic specific cancer survival analysis requires a structured and long-ranging cooperation of population-based cancer registry and treating oncological institution to produce reliable and comparable results.

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**O-10**

**A new software for evaluating the quality of cancer registry data**

Ivan Rashid<sup>1</sup>, Carlotta Buzzoni<sup>2</sup>, Fulvio Ricceri<sup>3</sup>, Stefano Rosso<sup>3</sup>

- 1) Modena Cancer Registry, COM, Modena (Italy)
- 2) Tuscany Cancer Registry, CSPO Florence (Italy).
- 3) Piedmont Cancer Registry, CPO Turin (Italy).

**Objectives.**

Different indicators are commonly used to evaluate quality of a Cancer Registry (CR) such as the mortality/incidence (M/I) ratio and the proportion of DCO and microscopically verified (MV) cases. Before admitting a new CR in the Italian Association (AIRTUM), the above mentioned indicators and other additional parameters were used to verify the reliability of data. These criteria were extended, formalized and finally included in a software, CHECKRT, in order to provide a tool that can be used for a quick and accurate evaluation of CR data.

**Methods.**

CHECKRT was written in Visual Basic 6.0 language. The analysis was divided into 17 check categories and evaluated separately according to cancer type and age group. This lead to a total number of 1.360 different quality checks each associated with a specific score for relevance (benchmark). CR data are compared with a weighted sample from the AIRTUM database. Adjustments for geographical area were also introduced. Fisher's exact test was calculated.

**Results.**

In evaluating Italian CRs, CHECKRT showed satisfactory results in terms of time of computation and quality of reports. The average percentage of passed checks was 95% (range 89-97%) while the mean overall score was 91% of the maximum score (range 82-95%).

**Conclusions.**

CHECKRT proved to be an efficient tool for quality control. CHECKRT can be used not only for newly-established CRs but also for self-evaluation of well established CRs driving continuous improvement processes. The detailed software reports can replace time-consuming manual tasks and provide a more accurate tool also for the evaluation non-Italian CR data.

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**SESSION 3 – ACCESS TO DATA: LEGAL STATUS OF THE EGISTRIES,  
CONFIDENTIALITY AND DATA SECURITY ISSUES**

**O-14**

**The Austrian National Cancer Registry –  
Strengths and Limitations of a Cancer Registration Law**

Author: Monika Hackl

Affiliation of Authors: Statistics Austria, Austria

Population based cancer registries are an important data source for health policy and for scientific research. The aim of this presentation is to explain the legal situation of the Austrian National Cancer Registry and to show how we handle issues like confidentiality and data security. Furthermore the strengths and limitations of a cancer registration law will be discussed.

The Austrian National Cancer Registry is operated by Statistics Austria, which is the National Statistical Institute of Austria. The national law on cancer statistics (1969) prescribes a data collection for cancer cases, including personal information about the patient as well as information about the tumour. The data protection law (2000) and the Federal Statistics Act 2000 (1999) regulate all issues concerning data protection, including data procession, data storage and publication of data.

The regulation of cancer statistics by law results in several strengths and limitations. Due to the legal situation cancer statistics is a long standing project in Austria. Access to data is regulated and the duty of notification allows running a population based registry for a population of more than 8 million. Furthermore cancer statistics is financially independent, implying that neither politics nor economy can influence the data published by the registry. Data are available for all people at the same time.

Austria has to tap the full potential of the law and work hard on public relations. The recent acceptance of the data in Cancer Incidence in Five Continents shows that we are on the right way.

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**O-15**

Confidentiality in cancer registration: the German way

**Authors:** Alexander Katalinic, Rajesh Rawal,

on behalf of the Association of Population-Based Cancer Registries in Germany (GEKID)

**Affiliation of Authors:** Institute for Cancer Epidemiology, University of Luebeck

Cancer registration is regulated by public laws in Germany. Each of the 16 German federal states has its own law, but nearly all of them were derived from a common base model. This base model was implemented in 1995 in a national law, which made it mandatory for all states to compile population-based cancer registries.

Within this model the cancer registry is subdivided into two independent units: the 'data collection office' (CO) and the 'data analysis office' (AO). This separation was done for the data protection due to confidentiality reasons. The CO has the task to collect the notification from doctors, clinics, death certificates etc. and to put the data into a computer system. After this the patients' personal (e.g. name, surname, prior names) data will be encrypted to 22 pseudonymous identification strings. These strings are sent together with the tumour data to the AO. Later on tumour data (and in some cases also the personal data) is deleted in the CO. In the AO a record linkage will be performed on the identification string to find out multiple notifications for a single patient.

As a result of this procedure the 'data analysis office' does not know the personal data of patients and the 'data collection office' has no tumour information. A maximum of data confidentiality is reached.

But this system has high operating expense. Double structures are present. Apparently easy steps in cancer registration such as error correction or follow up are taking much time and efforts.

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# Poster Listings

- P-01      Population CR in Bosnia and Herzegovina: register investigations in cancer incidences  
*Zlatko Puvacic*
- P-02      Cancer incidence in Republika of Srpska  
*Gavric Zivana*
- P-03      Use of Cancer Registry data in Schleswig- Holstein, Germany  
*Alexander Katalinic*
- P-04      Invasive cancers subsequent to breast carcinoma *in situ* in South East England  
*David Robinson*
- P-05      The future burden of cancer in England compared to London: incidence rates and numbers of cases in 2020  
*Victoria Coupland*
- P-06      Cancer inequalities, socio-economic deprivation, London  
*Vivian Mak*

# Abstracts

## Poster Presentations

P-01

### Population Cancer Registry In The Fb&H – Investigation in Cancer Incidence

Authors: Prof dr Zlatko Puvačić, Mr dr Jasna Omanić, Dr Aida Filipović-Hadžiomerađić

Investigation in cancer morbidity of the population in the FB&H present the first study applying methodologies in the Federation of Bosnia and Herzegovina consistent with IARC standards..

The starting year for our investigations was 2004. IACR estimates of cancer morbidity for different types of cancer and population and recognized important risks were used.

The main target of the research investigation was that, from the collected databases we can produce studies on regional distributions, types, aging, long time in the survivals, and estimated treatments.

Our research investigations data in the population FB&H during two investigations years are estimated that rations incidences types cancer per 100000 people were:

Digestive system	48,98
respiratory organs	39,68
reproductive system	25,19
skin and tissues	15,72
Breast	15,46

with bigger incidences cancers diseases in the males and in the aging 65> years.

That investigations results were prepared in relation with FB&H Registry databases and they were compared to the relevant data of our Registry in the Oncology Institute and to EUCAN investigations databases for that year.

Comparing this investigations data and investigations data produced in the pre-ware periods we can say that in the populations of FB&H we still have an increase in cancers incidence.

We hope that IACR who has important resources for epidemiology research, better quality investigation data will be able to support the National Health strategy in FB&H

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**P-02**

**Cancer Incidence in Reublika of Srpska**

Authors: Professor Zivana Gavric, Ph D MD

The malignant diseases represent the main cause for hospitalization, they are at the second place as mortality cause in Republic of Srpska. Introducing the register of malignant diseases we collected data about new discovered cases of cancer from all medical institutions. The data are electronically processed using the CanReg 4 and Epi info 2002. program.

The aim of this paper is to analyze cancer incidence rate toward sex, age, the most frequent location and mortality.

In above mentioned period in Republic of Srpska mortality rates for cancer increased for 18.3% (index 05/01 is 118,3). Mortality rate for cancer in 2005. was 179,4 (220,3 males and 140,6 female per 100 000). Proportion male-female was 60:40. In the same year 45,6% of new cases died. In Republika of Srpska in 2005 cancer (16,0%) is amongst the leading causes of hospitalization together with cardiovascular diseases (15,7%). Male incidence rates (55,2%) was 285,7 per 100 000 and ASR 211,0 per 100 000, and female incidence rates (44,8%) was 227,6 per 100 000 and ASR 151,1 per 100 000 (without skin cancer). The highest incidence rate for males was bronchus and 66% died in the same year and breast cancer incidence was at the first place for female and 22% died in the same year.

The most frequent cancers among the male population are malignant neoplasm of trachea, bronchus and lung, which increases steadily by the age 40-44 year, then after 65 year have characteristics of expansion. Among the female population malignant neoplasm of breast increases steadily by the age 25-29 year, then age 54-64 year characterize small decrease, and significantly increases after 65 year.

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**P-03**

**Use of cancer registry data in Schleswig-Holstein, Germany**

Authors: Alexander Katalinic, Ron Pritzkeleit, Rajesh Rawal

Affiliation of Authors: Institute for Cancer Epidemiology, University of Luebeck, Beckergrube 43-47, 23552 Luebeck, Germany, [alexander.katalinic@cancer-sh.de](mailto:alexander.katalinic@cancer-sh.de)

Cancer registration started in 1998 in Schleswig-Holstein, the northernmost state in Germany with a target population of 2.8 million inhabitants. On the basis of a public cancer registration law, including mandatory notification, a complete cancer registration was reached in 2001.

The data are regularly used for several purposes:

- yearly reports of incidence and mortality for all notifying doctors (~3 300)
- internet platform with reports and database
- small area analyses induced by politics or citizens (e.g. leukaemia and nuclear power plant)
- allocation of patients for case control studies (e.g. study for hormone intake and ovarian cancer)
- allocation of cohorts with selected cancers (e.g. public health study on 5 000 patients with breast, prostate or skin cancer)
- evaluation of early detection programs (skin cancer screening, quality assurance in breast cancer)

The cancer registry of Schleswig-Holstein could show its usefulness in the past years (even under the hard German data protection issues). Therefore long-term financing of the registry (0.5 € per inhabitant) could be assured by the government.

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**P-04**

**Invasive cancers subsequent to breast carcinoma *in situ* in South East England**

David Robinson, King's College London, Thames Cancer Registry, UK  
Lars Holmberg, King's College London, UK  
Henrik Møller, King's College London, Thames Cancer Registry, UK

**Objectives**

To investigate the occurrence of invasive cancers following a diagnosis of breast carcinoma *in situ* (BCIS), and the effects of treatment on such occurrences.

**Methods**

13,269 cases of breast carcinoma *in situ* diagnosed between 1971 and 2003 were analysed for the occurrence of subsequent cancers by comparing observed with expected numbers, using female age/calendar period specific incidence rates for South East England. Ipsilateral and contralateral subsequent breast cancers were considered separately. The effects of treatment were explored using Cox regression.

**Results**

A greater than expected number of subsequent cancers was found for two sites: breast (standardised incidence ratio (SIR) 1.98; 95% confidence interval (CI) 1.82 - 2.16) and corpus uteri (SIR 1.43; 95% CI 1.13 - 1.79). For subsequent ipsilateral breast cancer, the excess was independent of the time since diagnosis of BCIS, whereas for subsequent contralateral breast cancer there was a steady decline in excess over time. In the first year post-diagnosis, there was a significant excess of ipsilateral breast cancers in women diagnosed with lobular carcinoma *in situ*, but not for ductal carcinoma *in situ*. For subsequent uterine cancer, the excess became statistically significant only at > 5 years post BCIS diagnosis, consistent with a treatment effect, with the risk significantly increased in women receiving hormone therapy (hazard ratio 3.01; 95% CI 1.88 - 4.82).

**Conclusions**

Women diagnosed with BCIS have a moderately increased risk of both ipsilateral and contralateral subsequent breast cancers. Those receiving hormone therapy are at increased risk of subsequent uterine cancer.

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**P-05**

**The future burden of cancer in England compared to London: Incidence rates and numbers of new cases in 2020.**

Authors: Coupland V, Møller H, Fairley L, Okello C, Green M, Forman D, Møller B, Bray F

Affiliation of Authors: Thames Cancer Registry, UK; Northern and Yorkshire Cancer and Information Service, UK; Department of Health, UK; Cancer Registry of Norway, Norway

**Objectives:**

The aim of the project was to compare the estimated future burden of cancer in England and London with regards to numbers of cases and age-standardised incidence rates.

**Methods:**

The future numbers of cancer cases and future age-standardised incidence rates were projected for England using cancer registration data between 1974 and 2003 and official population projections from the Office of National Statistics up to 2023. The London projections were based on registration data between 1985 and 2003 and population projections from the Greater London Authority up to 2024. Both sets of data were analysed using an age-period-cohort model developed for an analysis of cancer trends and projections in the Nordic countries (BJC 2007; 96:1484-8).

**Results:**

For all cancers combined (excl. non-melanoma skin cancer) age-standardised rates were seen to decrease in males and increase slightly in females in England whereas in London a decrease in rates was seen in both sexes. In England, the number of cancer cases was seen to increase from 224,000 in 2001 to around 299,000 in 2020, an overall increase of 33% (36% in males and 30% in females). In London, the number of cases was still expected to increase, but to a lesser extent from 27,000 in 2002 to 28,500 in 2022, an increase of 5% (8% in males and 2% in females).

**Conclusions:**

The main reason for these increases is associated with increasing populations. The population for England is estimated to increase in the middle age to older age groups (40+) whereas London shows an increase in middle-aged (30-69) returning to similar levels between 2001 and 2022 in the 70+ groups. Projections of the future burden of cancer are mainly sensitive to the demographic population trends and are therefore likely to be different in cities compared to whole countries.

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**P-06**

**Cancer Inequalities in London**

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**Objectives:**

To establish the association between socio-economic deprivation and cancer incidence, mortality and survival in London.

**Methods:**

Details of cancer patients resident in London diagnosed between 2000 and 2004 were extracted from the Thames Cancer Registry database. Patients were assigned to socio-economic deprivation quintiles based on the area of residence using the income domain of the Indices of Deprivation 2004.

We calculated age-standardised incidence and mortality rates for 15 major cancer sites for the socio-economic deprivation groups, 55 primary care trusts and 5 cancer networks area of residence. We used period analysis to calculate the relative survival estimates by socio-economic deprivation groups and by cancer network of residence. We presented these as maps and graphs to show the variation by area of residence.

**Results:**

Age-standardised incidence and mortality rates increased with the level of socio-economic deprivation for cancer of the head and neck, oesophagus, stomach, lung, cervix and bladder. Age-standardised incidence and mortality rates decreased with the level of socio-economic deprivation for cancer of the breast, prostate and melanoma of the skin. Overall, the differences between the most deprived and the most affluent were largest in the incidence of lung cancer and the mortality of cervical cancer.

Relative survival decreased with increased level of socio-economic deprivation, particularly for cancer of the head and neck, uterus, bladder, breast and prostate.

The variations in incidence, mortality and survival by cancer network were mainly driven by the level of socio-economic deprivation in these areas.

**Conclusions:**

Our study demonstrated important variations in cancer occurrence and outcomes within a diverse administrative unit. The findings on the variations in incidence, mortality and survival between the socio-economic deprivation groups could be used to address health inequalities in London.

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