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Why did treatment rates for colorectal cancer in South East England fall between 1982 and 1988? The effect of case ascertainment and registration bias

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Abstract

Background We had two aims in undertaking this study, as follows: (1) to describe regional and district trends in incidence and treatment for colorectal cancer in South East England from 1982 to 1988; (2) to examine the effect of registration practice and case ascertainment on district variations in incidence and treatment using data on death certificate only (DCO) registrations, mortality and stage.

Methods We included all cases registered by the Thames cancer registry diagnosed with colon or rectal cancer between 1982 and 1988 and resident in 28 districts in the two South Thames regions. Indirect standardized incidence ratios were calculated for the districts and a χ^2 test for trend was carried out.

Results In the SE England regional analysis, between 1982 and 1988 there was a significant increase in the incidence of cases of colon and rectal cancer in the over-75s, but treatment rates remained unchanged. Treatment rates fell significantly in the under-65s although incidence rates remained unchanged. Age is a strong predictor of non-treatment. Between 1982 and 1988 the relative risk of not receiving treatment increased for all ages over 65 years. DCO registrations accounted for 22 per cent and 15 per cent of all colon and rectal cancer cases, respectively, between 1982 and 1988. The proportions rose (between 1982 and 1988) from 10 and 8 per cent to 25 and 19 per cent in colon and rectal cancer, respectively. DCO registration rates increased over time and in all age groups in South East England for both colon and rectal cancer between 1982 and 1988, but the largest increase was in the over-75s. Thirty-two per cent of colon and 25 per cent of rectal cases were unstaged. Although the proportion of unstaged cases remained constant over time, they were increasingly the result of DCO registrations. Errors in the registry staging data rendered those cases which were staged unusable.

In the district analysis, there were significant variations in age-standardized incidence, treatment and DCO registration ratios across the 28 districts for men and women with colon and rectal cancer between 1982 and 1988. DCO registrations show a negative correlation with treatment for both colon and rectal cancer ($p < 0.05$) and with incidence for only rectal cancer.

Conclusions We report significant differences in age-standardized incidence and treatment ratios across 28 districts in South East England, some of which can be accounted for by differences in registration practice. There is a complex relationship between DCO registrations and incidence and treatment for both colon and rectal cancer. DCO registrations are a good proxy for under-ascertainment of incidence in rectal cancer but not colon cancer, and are a good proxy for under-ascertainment of treatment in both colon and rectal cancers. Information from the cancer registry can be used to examine registration and treatment rates across districts. However, if variations are to be adequately explained, meticulous data collection on stage and quality control are essential.

Background

In the United Kingdom, concerns about the completeness and reliability of national cancer registry data have generally restricted their use in the evaluation of health care. However, recent changes to the structure of the UK National Health Service (NHS), together with the introduction of clinical audit, have stimulated new interest in this valuable but underused data source. The Office of Population Censuses and Surveys (OPCS) publishes annual age-standardized registration rates for all major cancers in England and Wales,[1] but treatment rates are not published as treatment data are collected by only a few registries in England and Wales.

In this paper we set out to explore incidence and

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treatment rates using data from the Thames cancer registry (TCR), the largest population-based registry in Europe, which covers 14·1 million residents. Our findings are similar to those of studies of coronary heart disease using routine hospital statistics: that there are age and geographic differences in treatment rates for some groups of the population.[2,3] We consider below three major sources of bias which could explain the observed age and geographic differences in incidence and treatment for colorectal cancer. These relate to differences in the clinical processes of medical care (e.g. screening programmes), case ascertainment, and differences in the registration process.

Case ascertainment

Rates of cancer incidence and treatment are as dependent on the accuracy of the population denominator as numerator data.[4] Shifting population denominators, e.g. as a result of migration, could have a differential impact on area-based rates; however, denominator error has not been studied with respect to cancer registry data.

Numerator error can result from incompleteness of case ascertainment. Alternative data sources, such as pathology records, have been used to measure the completeness of registration. They indicate that around 90 per cent of all cancers are ascertained by the UK regional cancer registries.[4–8] These findings have also been confirmed using the ratio of new cases to deaths as an indirect proxy measure of ascertainment.[9]

Registration practice

Numerator error can also result from differences across and within registries in the sources of data used for registration. All UK registries rely on death certificate notifications to initiate registrations, to update registrations and to search for clinical details on previously unregistered cases. Where no details are found, the death certificate becomes the only source of information. However, the death certificate registration is incomplete as it contains no information on date of diagnosis, stage, histology or treatment. This means that where death certificates form the sole basis for registration, errors in the numerator can occur where data are missing. Thus areas with high numbers of death certificate only (DCO) registrations might be expected to have low treatment rates.

Process of care

Case ascertainment can also be affected by the clinical processes of care. For example, in districts where clinicians have a particular interest in early ascertainment, e.g. screening, incidence and treatment rates might increase. Stage is one measure of the process of care: districts with screening or early intervention programmes might be expected to have a greater proportion of early stage cases than districts without.

This paper looks at incidence and treatment rates for colorectal cancer in the 28 health districts in South East England and considers the impact of access to medical care, registration practice, and case ascertainment on the observed variations using as proxy measures stage, death certificate rates and the ratio of new cases to deaths for each of these respective factors.

Methods

All cases registered by the TCR diagnosed with colon or rectal cancer between 1982 and 1988 and resident in 28 districts in the two South Thames regions in South East England were included in the study. There were 8744 cases of rectal cancer and 15077 cases of colon cancer. Data from the two North Thames regions were excluded because they only amalgamated with the South Thames registry in 1985.

The TCR covers a population of seven million in the two South Thames regions.[10,11] Peripatetic cancer registry clerks trained by the registry retrieve data from case notes using a structured proforma which records sociodemographic details, stage, site and tumour type as well as the first six months planned treatment. Death notifications are flagged via OPCS, which means that there may be some under-ascertainment of mortality. Data are entered centrally onto the main computer.

Baseline regional data for SE England

Annual age-specific incidence, treatment and DCO registration rates were calculated for all cases in the South Thames regions between 1982 and 1988. Regional and district denominator data were obtained from OPCS population estimates.

The cancer registry collects simple information on the first six months of initial planned treatment carried out in hospital. Treatment proportions were analysed in four categories: no treatment, surgery alone, surgery and adjuvant therapy and chemotherapy or radiotherapy alone.

District variations

Incidence

Using cancer registry data and mid-year population

estimates for the 28 districts, indirect standardized incidence ratios for each of the 28 districts were calculated. Age-specific rates (for each variable under observation) for colon and rectum were calculated for the two Thames regions (using mid-year population estimates for the years 1982–1988). A χ^2 test for trend was carried out to see whether incidence rates were changed over time. Rates were applied to the mid-year population estimates of each district to obtain expected numbers of cases and standardized incidence ratios were calculated. Ninety-five per cent confidence intervals for each standardized incidence ratio were calculated using the methods described by Gardner and Altman.[12]

Treatment

Age-standardized treatment and non-treatment ratios were calculated by district for colon and rectum using the methods for standardized incidence ratios described above. As no data on treatment are available for DCO cases, standardized treatment ratios were calculated without DCOs.

Explanatory factors

Access to medical care – stage

Of the several staging systems for colorectal cancer the most commonly used is the modified Dukes' classification. Tumours are categorized into four groups: stage A, the tumour is confined to the bowel wall; stage B, extension through the bowel wall; stage C, lymph node involvement; stage D, spread to other organs. The cancer registry uses its own staging system to compare survival for all cancers, which it was thought possible to convert to Dukes' staging. As there are no national staging data, Dukes' staging proportions for the two South Thames regions were compared with data from Dukes' original clinical series and the Birmingham cancer registry.[13,14]

The Thames cancer registry also subdivides total unstaged cases into two categories: those diagnosed before death (NK1) and those diagnosed after death, i.e. by DCO registrations (NK2). The two stage unknown categories NK1 and NK2 were analysed first as a proportion of all registrations between 1982 and 1988. The proportions of unstaged registrations were analysed over time, as were DCO registrations as a proportion of unstaged cases.

Registration process – DCO registrations

Age-standardized DCO registration ratios were calculated for each district using indirect standardization as described above and then correlated with treatment and incidence ratios using Pearson's correlation coefficient.

Case ascertainment – incidence to mortality ratios

We took an indirect measure of each district's completeness of case ascertainment using the ratio of registrations to deaths. A high ratio would indicate those districts with the most complete ascertainment.

Results

Regional baseline data

Between 1982 and 1988 there was a significant increase in the incidence of cases of colon and rectal cancer in the over-75s, but treatment rates remained unchanged. Treatment rates fell significantly in the under-65s, but incidence remained unchanged. DCO registration rates rose significantly in all age groups for both colon and rectal cancer (Table 1).

Treatment

Overall treatment proportions are shown for colon and rectum for the two regions combined between 1982 and 1988 (Fig. 1). Sixty-eight per cent of patients with colon cancer and 75 per cent of patients with rectal cancer receive treatment; the most common modality of treatment is surgery, and 14 per cent of rectal patients and 7 per cent of colon patients receive adjuvant therapy. Age was a strong predictor of non-treatment, between 1982 and 1988 the relative risk of not receiving treatment rising at all ages over 65 (Table 2).

District variations

Incidence/registrations

There are significant variations in the age-standardized incidence ratios across the 28 districts in the South Thames regions for men and women with colon and rectal cancer (Fig. 2).

Treatment

There are significant variations in the standardized treatment ratios across the 28 districts in the South Thames regions for men and women with colon and rectal cancer (Fig. 3). Treatment was highly correlated with incidence for both colon and rectal cancer ($R = 0{\cdot}93$ and $0{\cdot}95$, respectively).

Explanatory factors

Access to medical care – stage

Thirty-two per cent of colon and 25 per cent of rectal

TABLE 1 Colorectal cancer in the South Thames regions, 1982–1988; age-specific rates for incidence, registrations receiving treatment and DCO registrations, by year of diagnosis (per 100 000 of the population)

	Colon cancer cases				Rectal cancer cases			
		Age group				Age group		
Year	*n* (cases)	<65	65–74	75+	*n* (cases)	<65	65–74	75+
Incidence								
1982	2003	9·9	94·3	187·6	1138	5·8	56·4	99·4
1983	1996	9·2	96·5	186·6	1195	6·1	60·0	102·6
1984	2126	9·1	105·2	203·3	1255	6·2	61·7	112·2
1985	2203	9·8	94·8	215·6	1256	6·0	64·5	106·7
1986	2142	9·6	95·1	203·2	1232	5·5	61·6	109·8
1987	2178	9·2	102·2	207·4	1228	5·7	63·5	102·3
1988	2159	8·6	94·3	214·0	1217	5·6	54·7	110·7
p (tr)		NS	NS	<0·01		NS	NS	<0·01
Treatment								
1982	1709	8·5	76·9	121·5	1004	5·3	47·5	70·4
1983	1777	7·9	72 9	112·4	1065	5·4	50·5	71·7
1984	1964	7·3	78·4	112·0	1142	5·2	50·6	67·7
1985	2002	7·9	66·8	121·8	1151	5·1	50·8	66·9
1986	1940	7·9	72·4	117·6	1104	4·8	48·3	70·6
1987	1976	6·9	72·7	110·2	1104	4·7	49·5	59·0
1988	1962	6·3	71·0	121·9	1109	4·8	44·9	66·0
p (tr)		<0·01	NS	NS		<0·02	NS	NS
DCOs								
1982	198	0·5	6·1	23·4	89	0·2	3·1	11·4
1983	369	0·8	14·4	41·8	121	0·4	4·2	13·4
1984	559	1·5	20·7	65·4	221	0·6	8·1	26·1
1985	552	1·4	19·9	64·4	233	0·6	8·5	28·1
1986	478	1·5	17·0	52·6	194	0·4	8·9	21·0
1987	609	1 9	21·1	68·4	242	0·7	8·7	27·3
1988	548	1·7	16·2	63·1	235	0·6	6·9	29·2
p (tr)		<0·01	<0·01	<0·01		<0·01	<0·01	<0·01

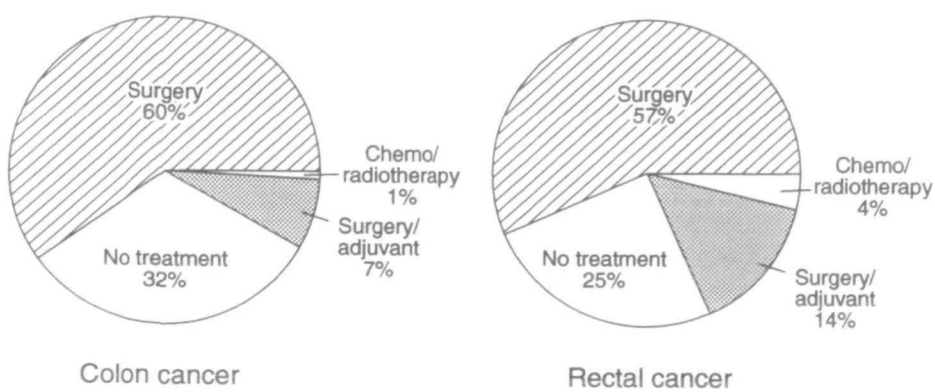

FIGURE 1 Treatment patterns for colon and rectal cancer (all districts, STCR 1982–1988).

cancer cases in the TCR are unstaged. The proportion and number of unstaged to total cases is much higher in the 75-plus age group for both sites (Table 3).

There are no national staging data, but a comparison of South Thames staging proportions with the Birmingham registry and various clinical series reveals that the cancer registry records high proportions of stage A and very much lower proportions for stages B and C (Table 4). These differences were found to be statistically significant ($p < 0{\cdot}0001$).

Although the proportion of total unstaged cases NK remains relatively constant over time, an increasing proportion of cases entered onto the registry is diagnosed after death (NK2) from DCO returns between 1982 and 1988, for both colon and rectal cancer (Fig. 4).

Registration process – DCO registrations

DCO registrations accounted for 22 per cent and 15 per cent of all colon and rectum cancer cases, respectively. The proportions rose between 1982 and 1988 from 10 per cent and 8 per cent to 25 per cent and 19 per cent in colon and rectal cancer, respectively (Fig. 4). DCO registration rates increased over time and in all age groups in the South Thames regions for both colon and rectal cancer between 1982 and 1988, but the largest increase was in the over-75s (Table 1).

The variations observed across districts in the age-standardized DCO registration ratios give a significant negative correlation ($p < 0{\cdot}001$) with colon and rectal treatment, i.e. districts with high DCO returns have lower treatment rates for both colon and rectum. A significant negative correlation was also found between DCOs and incidence for rectal cancer ($p < 0{\cdot}05$) (Table 6).

Case ascertainment – incidence to mortality ratios

Ratios of registrations to deaths by health district of residence are listed in Table 5, which shows significant positive correlations between these ratios and colon cancer registration ($p < 0{\cdot}0001$). No significant association was found between registrations to deaths ratios and standardized registration ratios for rectal cancer or standardized treatment ratios for colon cancer.

Discussion

This study shows that treatment rates for colorectal cancer not only failed to keep pace with rising incidence in the over-75s but fell significantly in the under-65s in South East England from 1982 to 1988. For the whole time period the relative risk of not receiving treatment increased with age. Variations in age-standardized incidence and treatment ratios for cancer of the colon and rectum across the 28 districts in South East England indicate that district factors might be important in explaining the regional treatment trends. The use of proxy factors for case ascertainment and registration practice was an attempt to elucidate their respective contributions to treatment trends.

Registration practice

The fall in treatment rates in South East England was accompanied by a dramatic increase in DCO registrations. The upward trend in DCO registration rates almost mirrors the observed downward trend in treatment rates over the same time period in the over-75s, raising the possibility that the 'fall' could be entirely artefactual. The greater risk of not receiving

TABLE 2 Colorectal cancer in the South Thames regions, 1982–1988; relative risk of not receiving treatment, by age group; cases registered by death certificate only have been excluded

Age group	*n* (cases)	% untreated	Relative risk of not receiving treatment (95% CIs)
Colon			
0–64	3047	6·1	1
65–74	3468	8·9	1·46 (1·04, 2·04)
75+	4978	19·7	3·23 (2·42, 4·31)
All ages	11 493		
Rectum			
0–64	2023	5·2	1
65–74	2301	8·2	1·58 (1·11, 2·26)
75+	2862	19·1	3·67 (2·71, 4·96)
All ages	7186		

treatment borne by the elderly is to some extent a greater risk of not being registered from case notes.

Twenty-two per cent of colon cases and 16 per cent of rectal cancer cases were registered as DCO returns for 1982–1988 in South East England; however, from 1982 to 1988 the proportion of DCO registrations more than doubled from 10 per cent to 25 per cent in colon cancer and from 8 per cent to 19 per cent in rectal cancer. The TCR, which in 1983 was compelled for financial reasons to abandon retrospective follow-up of death certificates, has now reinstituted its follow-up policies.

Across the districts, districts with high death certificate registration ratios were associated with low treatment ratios. Taking $100 \times r^2$ as a measure of the proportion of the total variation in treatment ratios owing to DCO registrations, DCOs explained 32 per cent and 39 per cent of the variation in treatment for colon and rectum, respectively. The high DCO ratios in some districts may not be surprising, given the under-ascertainment of treatment data owing to failure of retrospective follow-up of death certificates.[15] This has been confirmed in a separate case-note study, where we found that some districts achieve better case-note retrieval of death certificate cases.[16] As only a third of

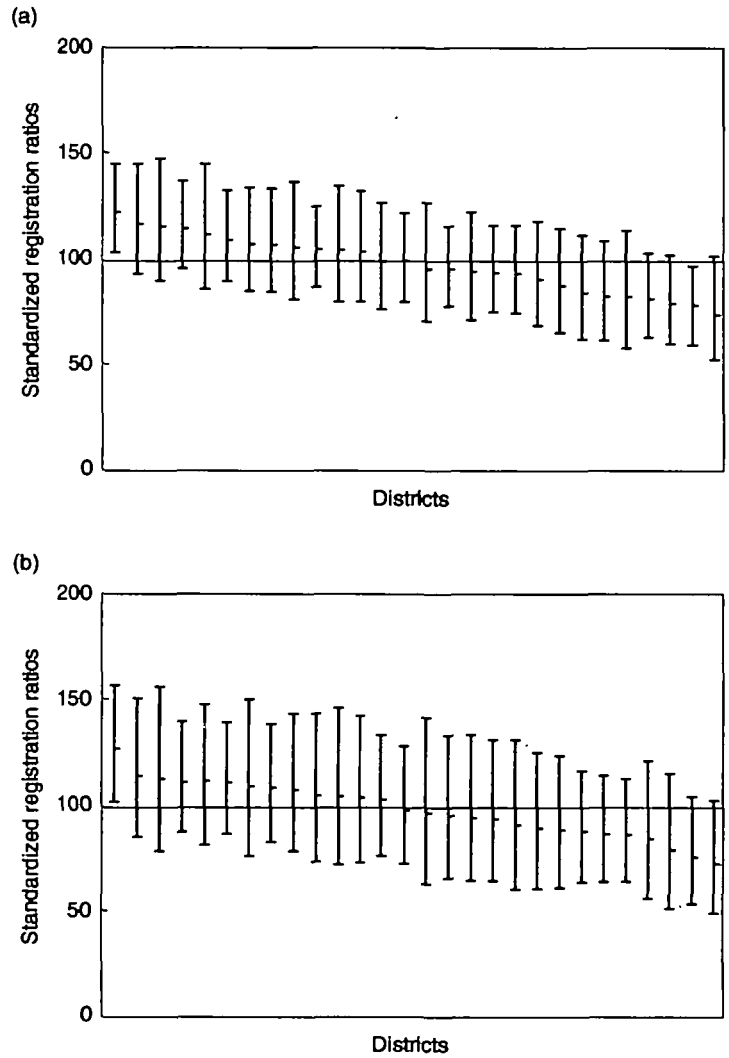

FIGURE 2 (a) Standardized incidence ratios for colon cancer (all districts in the South Thames Regions 1982–1988 including 95 per cent confidence intervals). (b) Standardized incidence ratios for rectal cancer (all districts in the South Thames Regions 1982–1988 including 95 per cent confidence intervals).

the variation can be accounted for by DCOs, other factors yet to be accounted for, such as case ascertainment or access to care, may give rise to district variations in treatment.

When we attempted to use stage as a proxy measure to examine case ascertainment we found two major sources of bias. First, the high proportion of unstaged cases, 32 per cent and 25 per cent for colon and rectum, respectively, will bias any attempts to look at stage differences across districts. Second, those cases which were staged show disproportionately high numbers of early cancers, which do not accord with data from other registries. This we showed subsequently to be due to problems with the cancer registry staging system, which have since been rectified. The absence of clinical staging data made it impossible to look at case ascertainment as an explanation for differences in registration and treatment across districts. In the absence of clinical staging data to link stage to treatment it is not possible to ascertain whether district treatment policies are contributing to observed treatment trends.

The ratio of registrations to deaths is often used as an indirect measure of case ascertainment. However, the

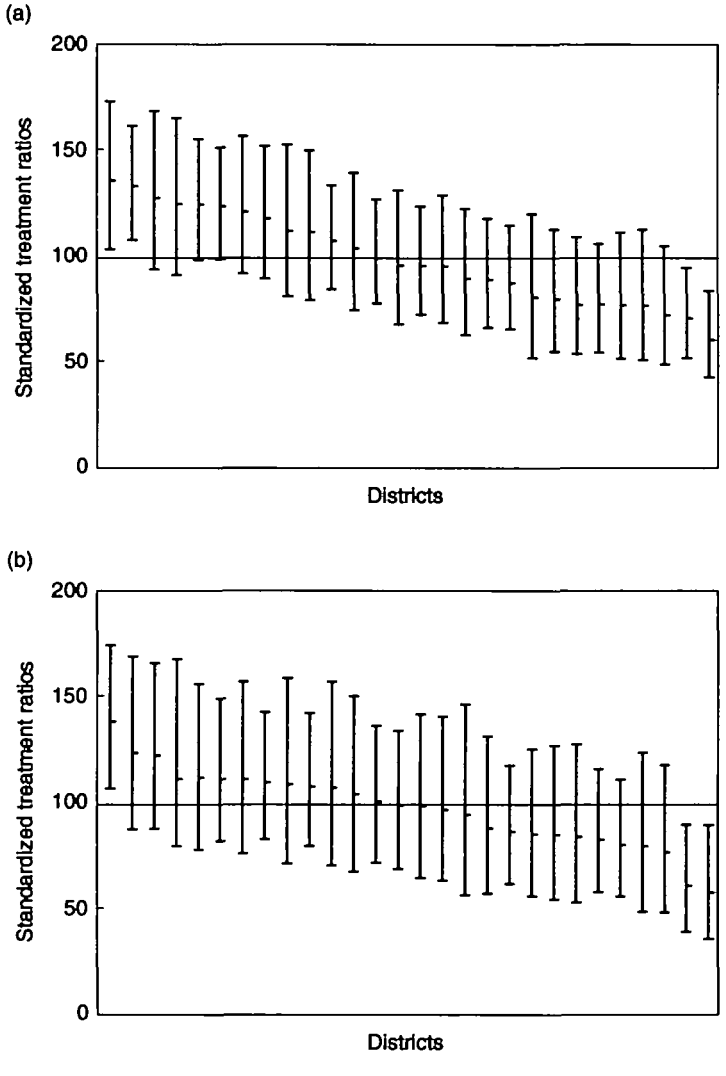

FIGURE 3 (a) Standardized treatment ratios for colon cancer (all districts in the South Thames Regions 1982–1988 including 95 per cent confidence intervals). (b) Standardized treatment ratios for rectal cancer (all districts in the South Thames Regions 1982–1988 including 95 per cent confidence intervals).

TABLE 3 Colorectal cancer in the South Thames regions, pooled years 1982–1988; numbers of patients for whom no Dukes' stage is given (includes DCO registrations)

Age group	*n*	per cent
0–64	1032	28·89
65–75	1192	28·21
75+	2547	36·34
Total	4771	32·22
Rectum		
0–64	449	20·25
65–75	575	21·95
75+	1084	29·42
Total	2108	24·74

TABLE 4 Dukes' stage distribution (per cent) of all staged registrations

	Birmingham (1957–1985)		South Thames (1982–1988)	
	Colon	Rectum	Colon	Rectum
Dukes' A	11	17	64	67
Dukes' B	53	43	12	13
Dukes' C	36	40	24	20

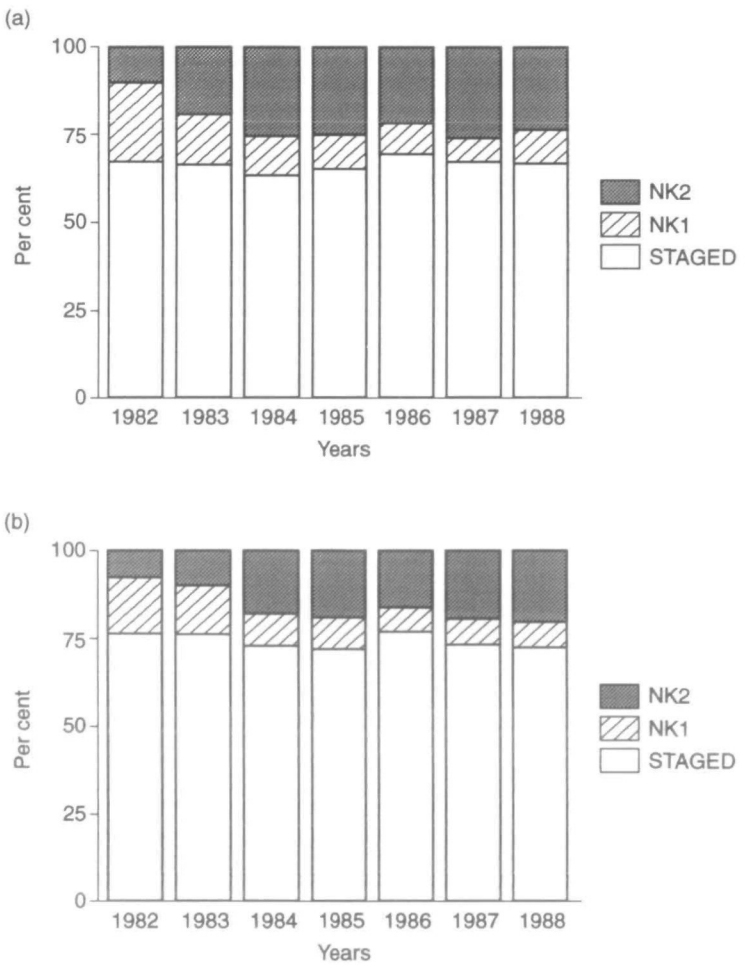

FIGURE 4 (a) Trend in STCR colon cancer registrations (1982–1988). (b) Trend in STCR rectal cancer registrations (1982–1988).

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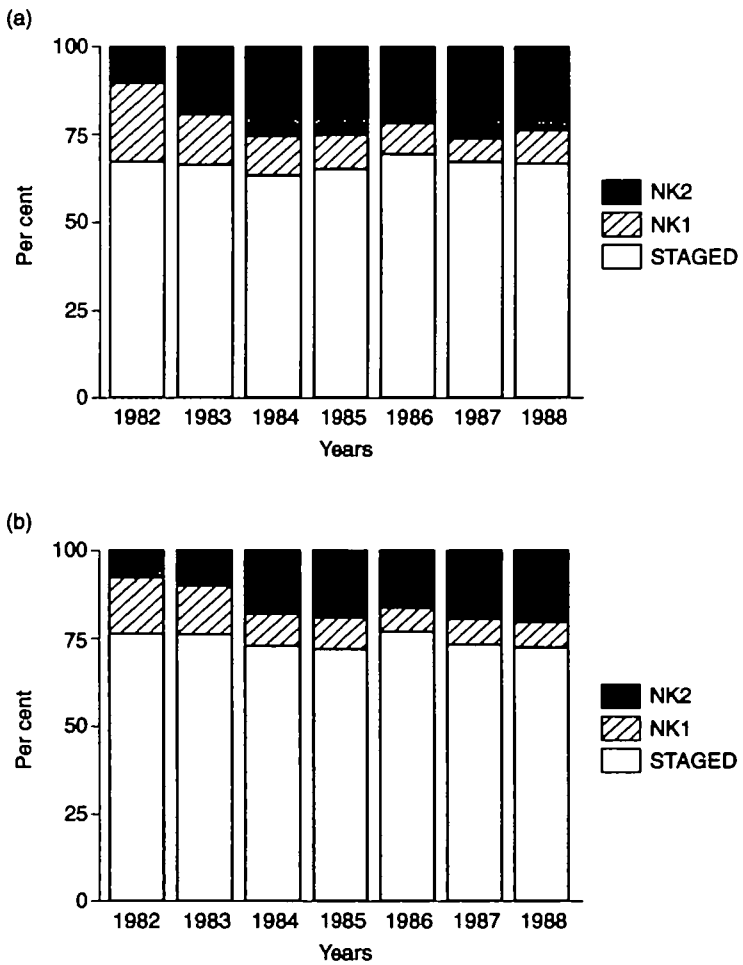

FIGURE 4 (a) Trend in STCR colon cancer registrations (1982–1988). (b) Trend in STCR rectal cancer registrations (1982–1988).

TABLE 5 Colorectal cancer in the South Thames regions 1982–1988; ratios of incidence (total registrations) to mortality, by DHA of residence and tumour site

District of residence	Colon cancer	Rectal cancer
Brighton	1·33	1·41
Eastbourne	1·35	1·42
Hastings	1·31	1·32
South East Kent	1·30	1·30
Canterbury and Thanet	1·34	1 34
Dartford and Gravesham	1·21	1·39
Maidstone	1·23	1·25
Medway	1·16	1·25
Tunbridge Wells	1·24	1·31
Bexley	1·33	1·28
Greenwich	1·40	1·28
Bromley	1·25	1·33
West Lambeth	1·27	1·26
Camberwell	1·46	1·39
Lewisham and North Southwark	1·33	1·26
North West Surrey	1·31	1·40
West Surrey and North East Hampshire	1·27	1 24
South West Surrey	1·47	1·54
Mid Surrey	1·32	1·30
East Surrey	1·36	1·42
Chichester	1·37	1·32
Mid Downs	1·26	1·37
Worthing	1·42	1·42
Croydon	1 39	1·32
Kingston and Esher	1·46	1·37
Richmond, Twickenham and Roehampton	1·36	1·29
Wandsworth	1·30	1·30
Merton and Sutton	1·32	1·35

Correlation analysis of registration to mortality ratios against standardized registration ratios: $r = 0.77$, $p < 0.0001$ for colon; $r = 0.32$, NS for rectum.

TABLE 6 Colorectal cancer in the South Thames regions, 1982–1988; correlation of standardized ratios

Variables correlated	Colon	Rectum
Registration, treatment		
r	0·93	0·95
p	< 0·0001	< 0·0001
Registration, DCO		
r	−0·25	−0·38
p	NS	0·04
Treatment, DCO		
r	−0·56	−0·62
p	< 0·005	< 0·005

variation in colon cancer incidence across districts could not be explained by this measure, although rectal cancer registrations could. This contrasts with the DCO measure discussed above, where DCOs explained 15 per cent and 6 per cent of the variation in incident cases (registration rates) of rectal and colon cancer, respectively, but reached significance only for rectal cancer (figures based on $100 \times r^2$). The difference in the amount of variation which can be explained by death certificates for colon and rectal cancer may lie in the different mode of presentation of the two cancers. Colon cancer is more likely to present at an advanced stage, so death certificates are more likely to be a measure of lateness of presentation rather than under-ascertainment owing to registration practice. In contrast, rectal cancer is more likely to present at an earlier stage, and so should have a greater chance of being registered; thus death certificate registrations may be a better proxy for under-ascertainment of incident cases.

Conclusion

The fall in treatment rates for colorectal cancer which took place in South East England coincided with a dramatic rise in DCO registrations. It seems likely that some of the district variation in treatment and the lower relative risk of receiving treatment in older age is due to the failure of follow-up of death certificate registrations. Death certificate registrations are not a good indirect measure of ascertainment for colorectal cancer; they are, however, a useful quality measure for data completeness, especially for treatment. Further work is required to determine the factors associated with death certificate registrations and their use as a measure of the completeness of registration data.

Our data also show that 29·5 per cent of all registrations are unstaged. This meant that we could not evaluate the effect of clinical practice on case ascertainment and treatment trends. We endorse previous recommendations that stage should be collected routinely by cancer registries. However, the evaluation of cancer care cannot become a reality unless cancer registries use compatible clinical staging systems and data are recorded accurately in the case notes.

Acknowledgements

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