

Figure 1. Trends of age-standardized cancer incidence rates for five major sites and male- and female-specific sites (standard population: world population).

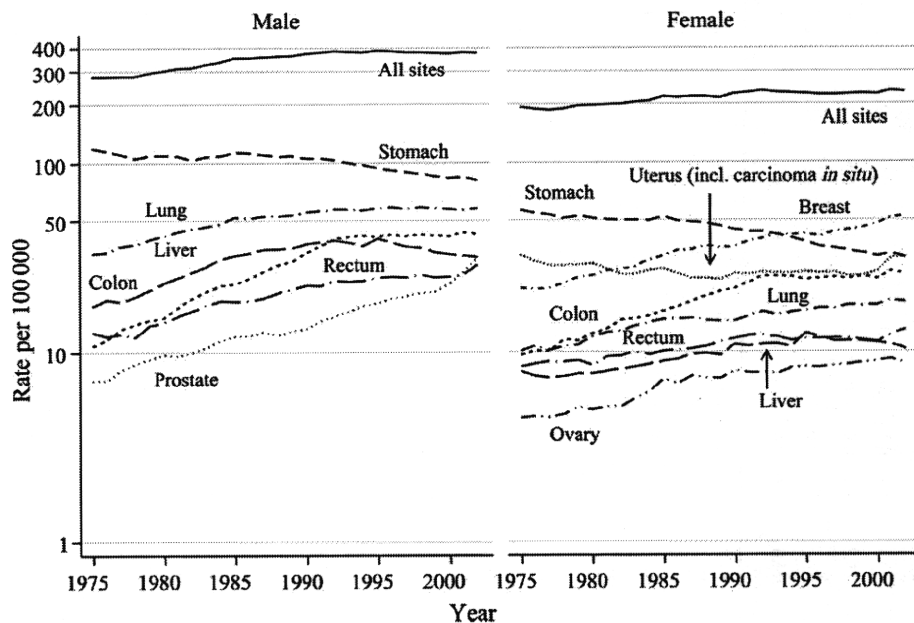


Figure 2. Trends of age-standardized cancer incidence rates for five major sites and male- and female-specific sites (standard population: 1985 Japanese model population).

Regional differences in population-based cancer survival between six prefectures in Japan: Application of relative survival models with funnel plots

Yuri Ito,^{1,5} Akiko Ioka,¹ Hideaki Tsukuma,¹ Wakiko Ajiki,² Tomoyuki Sugimoto,³ Bernard Rachet⁴ and Michel P. Coleman⁴

¹Department of Cancer Control and Statistics, Osaka Medical Center for Cancer and Cardiovascular Diseases, Osaka; ²Cancer Information Services and Surveillance Division, Center for Cancer Control and Information Services, National Cancer Center, Tokyo; ³Department of Biomedical Statistics, Osaka University Graduate School of Medicine, Osaka, Japan; ⁴Non-Communicable Disease Epidemiology Unit, London School of Hygiene and Tropical Medicine, London, UK

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We used new methods to examine differences in population-based cancer survival between six prefectures in Japan, after adjustment for age and stage at diagnosis. We applied regression models for relative survival to data from population-based cancer registries covering each prefecture for patients diagnosed with stomach, lung, or breast cancer during 1993–1996. Funnel plots were used to display the excess hazard ratio (EHR) for each prefecture, defined as the excess hazard of death from each cancer within 5 years of diagnosis relative to the mean excess hazard (in excess of national background mortality by age and sex) in all six prefectures combined. The contribution of age and stage to the EHR in each prefecture was assessed from differences in deviance-based R^2 between the various models. No significant differences were seen between prefectures in 5-year survival from breast cancer. For cancers of the stomach and lung, EHR in Osaka prefecture were above the upper 95% control limits. For stomach cancer, the age- and stage-adjusted EHR in Osaka were 1.29 for men and 1.43 for women, compared with Fukui and Yamagata. Differences in the stage at diagnosis of stomach cancer appeared to explain most of this excess hazard (61.3% for men, 56.8% for women), whereas differences in age at diagnosis explained very little (0.8%, 1.3%). This approach offers the potential to quantify the impact of differences in stage at diagnosis on time trends and regional differences in cancer survival. It underlines the utility of population-based cancer registries for improving cancer control. (*Cancer Sci* 2009; 100: 1306–1311)

The Japanese Government launched the Fundamental Planning of Cancer Control Promotion based on the Fundamental Bill on Cancer Control in June 2007. One of the mainstays of this new strategy was to 'narrow the inequalities of cancer medical services'. Monitoring cancer survival among the prefectures of Japan is important, both to evaluate progress toward this goal and as a contribution to the next Cancer Control Plan or regional cancer control planning. Wide regional differences in cancer survival in Japan have been reported, but the findings were only adjusted by age at diagnosis.⁽¹⁾

Multivariable models of relative survival have increasingly been used to quantify the impact of various prognostic factors (e.g. country, hospital, calendar period, age).^(2–4) Funnel plots, mostly used in meta-analyses, have been used more recently as additional tools for such comparisons.^(5–7) In the present study, we combined multivariable relative survival models with the funnel plot approach,⁽⁸⁾ to investigate differences in population-based cancer survival between six prefectures in Japan. The role of age and stage at diagnosis was evaluated for cancers of the stomach, lung, and breast (women).

Materials and Methods

Patients. The collaborative study of cancer survival⁽⁹⁾ collated data from 11 prefectural cancer registries on some 373 000

cancer patients diagnosed between 1993 and 1996. The national cancer survival figures were estimated on 279 469 records from the seven registries (Yamagata, Miyagi, Niigata, Osaka, Fukui, Tottori, and Nagasaki) that met the quality requirements (death certificate only cases less than 25%; death certificate notification less than 30%; vital status unknown for less than 5% of patients).⁽⁹⁾

These data formed the basis of the analyses reported here, but the data from the Tottori registry (4% of the total) were excluded because tumor stage was missing. Overall, 84 350 cases diagnosed with a first, primary, invasive malignant tumor of the stomach (ICD-10⁽¹⁰⁾ code C16), lung (C33–C34), or breast (C50; only women) between 1993 and 1996 and followed up for at least 5 years were considered as eligible for survival analysis. Of these, we excluded 11 874 patients (14.1% of those eligible) for whom the tumor stage at diagnosis was unknown, and 72 476 patients (85.9%) were included in the survival analyses.

Methods. We first applied relative survival models to examine differences in cancer survival between the six prefectures. The adjusted excess hazard of death for each prefecture was then compared with the grand mean using the funnel plot approach.

In a second step, focussing on the prefecture with the lowest survival, we assessed the influence of age and stage at diagnosis on survival using the R^2 measure to estimate the proportion of variation explained by each variable.

Regional differences in survival up to 5 years since diagnosis: the funnel plots. The excess hazard ratios (EHR) of death from each cancer within 5 years of diagnosis were estimated for each prefecture with a Poisson regression model for relative survival,⁽¹¹⁾ adjusting first for age, then for age and stage combined. The expected (background) mortality, which is removed from the observed overall mortality, was obtained from complete (single-year-of-age) national life tables.⁽¹²⁾ The contrasts used in the model were modified such that the excess hazard of each prefecture was compared to the overall mean hazard of death in excess of the national background mortality. This 'grand mean' across the six prefectures represents the 'target' in the funnel plots,^(7,8) that is, the excess hazard of death against which the hazard among cancer patients in each prefecture was compared. Both 95 and 99.8% control limits were estimated according to the 'precision', represented by the inverse variance of the grand mean, and displayed on the x -axis of the funnel plots. An excess hazard outside the 95 (dotted lines) or 99.8% (dashed lines) control limits means that the excess hazard of death from that cancer in that prefecture was considerably higher (if above the limits) or lower (if below) than the risk of death from that cancer in all the prefectures combined.

Evaluation of the role played by prognostic factors on the lowest survival. We then focused on the prefecture with the lowest

⁵To whom correspondence should be addressed. E-mail: itou-yu2@mc.pref.osaka.jp

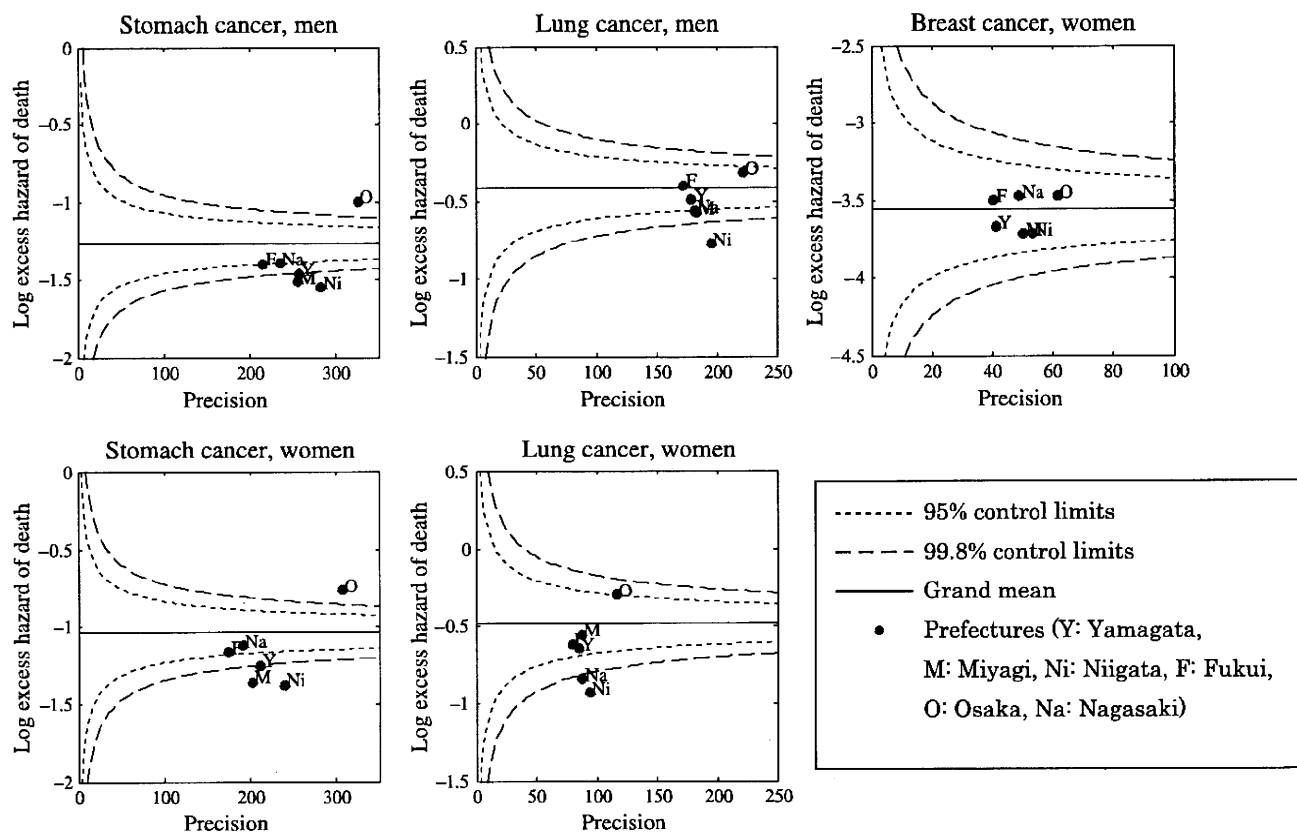


Fig. 1. Funnel plots of the age-adjusted log excess hazard of death within 5 years of diagnosis, by prefecture: cancers of the stomach, lung, and breast. Precision (x-axis) is the inverse of the variance of the age-adjusted log excess hazard of death. The target ('grand mean') is the average of the log excess hazard of death across the six prefectures

survival for each cancer and evaluated the role of age and tumor stage at diagnosis using R^2 measures for the Poisson regression model, based on deviance residuals.⁽¹³⁾ We used four models to quantify the effect of adjusting the excess hazard for age and stage. Model 1 comprised the follow-up time (0-, 0.25-, 0.5-, 1-, 2-, and 3–5 years since diagnosis) and the region. In model 2, age at diagnosis was added to model 1, whereas model 3 consisted of model 1 plus stage at diagnosis. Model 4 included both age and stage. The effect of age adjustment was defined as the difference in R^2 between model 4 (adjusted for both age and stage) and model 3 (adjusted for stage). The effect of adjusting the excess hazard for stage was represented by the difference in R^2 between model 4 (age and stage) and model 2 (age).

Results

Stomach cancer. Five-year relative survival was lower in Osaka than in the other five prefectures for both sexes (data not shown). After adjustment for age at diagnosis, the excess hazard of death in Osaka was above the upper 99.8% control limit (Fig. 1). Additional adjustment for stage at diagnosis reduced the excess hazard in Osaka slightly, but it was still above the upper 95% control limit for both sexes (Fig. 2). Some realignment of the prefectural excess hazards was also observed. The data from Miyagi and Niigata showed a significantly low excess hazard of death from stomach cancer. In Miyagi, this persisted after adjustment for both age and stage (Figs 1, 2).

We examined further the role of age and stage on the lower survival in Osaka. Cancer patients in Osaka tended to be diagnosed at a younger age and, for stomach cancer, at a more advanced stage (Table 1). We further restricted the analysis to

those cancer registries that conducted active follow up of cancer patients, namely Osaka, Yamagata, and Fukui.

In this restricted analysis, the excess hazard of death for both sexes in Osaka was still significantly higher than in the comparison group of Yamagata and Fukui combined (Table 2: model 1). The EHR barely changed after adjustment for age (model 2). The EHR fell after accounting for stage (models 3 and 4), but it was still significantly high. We estimated that differences in age at diagnosis explained as little as 0.8% in men and 1.3% in women of the difference in cancer survival between Osaka and Yamagata and Fukui combined (Table 3). By contrast, differences in tumor stage appeared to explain 61.3 and 56.8% of the survival differences in men and women respectively (Table 3). This mainly reflects a higher proportion of patients with advanced stage (Table 1), particularly for regional disease (data not shown).

Lung cancer. Age-adjusted excess hazards were lower than the 99.8% control limit in both sexes in Niigata and among women in Nagasaki (Fig. 1). These populations had a higher proportion of localized tumors (Table 1) and, after additional adjustment for tumor stage, the excess hazards of death were all within the 95% control limits except for men in Miyagi prefecture (Fig. 2).

Breast cancer. No outlier was found among the six prefectures for 5-year relative survival or the excess hazard of death from breast cancer within 5 years of diagnosis (Figs 1, 2).

Discussion

Analysis of population-based cancer data showed wide differences in 5-year relative survival from stomach cancer between the six prefectures, after adjustment for age and stage. Patients in Osaka

Table 1. Characteristics of cancer patients diagnosed between 1993 and 1996 in six prefectures in Japan: selected cancers

| | | Prefecture | | | | | | | | | | | | Total | |
|----------------------------|--------------------------------------|------------|-------|---------|-------|-----------|-------|-----------|-------|-----------|-------|-----------|-------|------------|-------|
| | | Yamagata | | Fukui | | Osaka | | Niigata | | Miyagi | | Nagasaki | | | |
| Resident population (1995) | | 1 256 958 | | 826 996 | | 8 797 268 | | 2 488 364 | | 2 328 739 | | 1 544 934 | | 17 243 259 | |
| Stomach | | | | | | | | | | | | | | | |
| Men | Incidence (per million) [†] | 111.8 | | 104.3 | | 74.2 | | 113.5 | | 97.7 | | 82.3 | | 87.1 | |
| | Mortality (per million) [‡] | 48.5 | | 37.5 | | 47.5 | | 49.3 | | 42.8 | | 37.5 | | 42.1 | |
| Age (years) | | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| 15-44 | | 157 | 4.5 | 87 | 4.7 | 466 | 4.5 | 263 | 4.6 | 177 | 5.2 | 125 | 5.5 | 1275 | 4.7 |
| 45-54 | | 389 | 11.2 | 208 | 11.1 | 1582 | 15.4 | 658 | 11.5 | 437 | 12.9 | 233 | 10.2 | 3507 | 13.0 |
| 55-64 | | 908 | 26.0 | 484 | 25.9 | 3212 | 31.3 | 1637 | 28.6 | 992 | 29.2 | 636 | 27.9 | 7869 | 29.1 |
| 65-74 | | 1308 | 37.5 | 649 | 34.7 | 3170 | 30.9 | 2082 | 36.4 | 1215 | 35.8 | 813 | 35.6 | 9237 | 34.2 |
| 75-99 | | 724 | 20.8 | 441 | 23.6 | 1830 | 17.8 | 1082 | 18.9 | 577 | 17.0 | 474 | 20.8 | 5128 | 19.0 |
| Stage | | | | | | | | | | | | | | | |
| Localized | | 2007 | 57.6 | 1040 | 55.6 | 4830 | 47.1 | 3391 | 59.3 | 1914 | 56.3 | 1193 | 52.3 | 14 375 | 53.2 |
| Regional | | 941 | 27.0 | 499 | 26.7 | 3442 | 33.5 | 1619 | 28.3 | 919 | 27.0 | 716 | 31.4 | 8136 | 30.1 |
| Distant | | 538 | 15.4 | 330 | 17.7 | 1988 | 19.4 | 712 | 12.4 | 565 | 16.6 | 372 | 16.3 | 4505 | 16.7 |
| Total | | 3486 | 100.0 | 1869 | 100.0 | 10260 | 100.0 | 5722 | 100.0 | 3398 | 100.0 | 2281 | 100.0 | 27 016 | 100.0 |
| Women | Incidence (per million) [†] | 48.5 | | 44.0 | | 28.2 | | 40.8 | | 35.2 | | 34.4 | | 33.7 | |
| | Mortality (per million) [‡] | 22.0 | | 17.8 | | 17.9 | | 17.5 | | 14.9 | | 14.4 | | 16.4 | |
| Age (years) | | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| 15-44 | | 110 | 5.9 | 84 | 7.9 | 438 | 8.7 | 215 | 7.5 | 170 | 10.4 | 107 | 9.1 | 1124 | 8.3 |
| 45-54 | | 138 | 7.4 | 109 | 10.3 | 876 | 17.4 | 309 | 10.8 | 210 | 12.8 | 134 | 11.4 | 1776 | 13.0 |
| 55-64 | | 354 | 19.1 | 208 | 19.6 | 1118 | 22.3 | 610 | 21.4 | 330 | 20.1 | 243 | 20.7 | 2863 | 21.0 |
| 65-74 | | 690 | 37.2 | 312 | 29.4 | 1371 | 27.3 | 951 | 33.3 | 545 | 33.3 | 362 | 30.8 | 4231 | 31.1 |
| 75-99 | | 565 | 30.4 | 348 | 32.8 | 1221 | 24.3 | 772 | 27.0 | 384 | 23.4 | 330 | 28.1 | 3620 | 26.6 |
| Stage | | | | | | | | | | | | | | | |
| Localized | | 1018 | 54.8 | 526 | 49.6 | 2198 | 43.8 | 1668 | 58.4 | 841 | 51.3 | 590 | 50.2 | 6841 | 50.2 |
| Regional | | 526 | 28.3 | 351 | 33.1 | 1761 | 35.1 | 841 | 29.4 | 495 | 30.2 | 371 | 31.5 | 4345 | 31.9 |
| Distant | | 313 | 16.9 | 184 | 17.3 | 1065 | 21.2 | 348 | 12.2 | 303 | 18.5 | 215 | 18.3 | 2428 | 17.8 |
| Total | | 1857 | 100.0 | 1061 | 100.0 | 5024 | 100.0 | 2857 | 100.0 | 1639 | 100.0 | 1176 | 100.0 | 13 614 | 100.0 |
| Lung | | | | | | | | | | | | | | | |
| Men | Incidence (per million) [†] | 51.8 | | 56.8 | | 65.0 | | 63.4 | | 60.3 | | 68.8 | | 55.9 | |
| | Mortality (per million) [‡] | 45.7 | | 50.8 | | 57.9 | | 47.8 | | 50.8 | | 55.3 | | 47.3 | |
| Age (years) | | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| 15-44 | | 22 | 1.8 | 21 | 2.2 | 179 | 2.7 | 41 | 1.7 | 35 | 2.7 | 36 | 2.8 | 334 | 2.4 |
| 45-54 | | 63 | 5.1 | 50 | 5.3 | 696 | 10.4 | 180 | 7.3 | 101 | 7.8 | 92 | 7.2 | 1182 | 8.5 |
| 55-64 | | 263 | 21.3 | 184 | 19.5 | 1636 | 24.4 | 509 | 20.5 | 275 | 21.4 | 256 | 19.9 | 3123 | 22.4 |
| 65-74 | | 517 | 41.8 | 386 | 40.9 | 2514 | 37.5 | 1077 | 43.5 | 587 | 45.6 | 565 | 44.0 | 5646 | 40.5 |
| 75-99 | | 372 | 30.1 | 303 | 32.1 | 1680 | 25.1 | 671 | 27.1 | 290 | 22.5 | 335 | 26.1 | 3651 | 26.2 |
| Stage | | | | | | | | | | | | | | | |
| Localized | | 236 | 19.1 | 240 | 25.4 | 1209 | 18.0 | 808 | 32.6 | 245 | 19.0 | 320 | 24.9 | 3058 | 21.9 |
| Regional | | 444 | 35.9 | 372 | 39.4 | 2826 | 42.1 | 986 | 39.8 | 485 | 37.7 | 507 | 39.5 | 5620 | 40.3 |
| Distant | | 557 | 45.0 | 332 | 35.2 | 2670 | 39.8 | 684 | 27.6 | 558 | 43.3 | 457 | 35.6 | 5258 | 37.7 |
| Total | | 1237 | 100.0 | 944 | 100.0 | 6705 | 100.0 | 2478 | 100.0 | 1288 | 100.0 | 1284 | 100.0 | 13 936 | 100.0 |
| Women | Incidence (per million) [†] | 15.6 | | 14.9 | | 19.0 | | 17.4 | | 16.0 | | 19.2 | | 16.8 | |
| | Mortality (per million) [‡] | 12.0 | | 9.4 | | 17.1 | | 10.5 | | 10.8 | | 14.1 | | 12.6 | |
| Age (years) | | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| 15-44 | | 17 | 3.7 | 13 | 3.8 | 101 | 3.9 | 24 | 2.9 | 19 | 4.4 | 23 | 4.4 | 197 | 3.8 |
| 45-54 | | 44 | 9.6 | 26 | 7.6 | 309 | 12.1 | 77 | 9.3 | 48 | 11.0 | 43 | 8.3 | 547 | 10.6 |
| 55-64 | | 97 | 21.1 | 61 | 17.9 | 526 | 20.5 | 177 | 21.3 | 104 | 23.9 | 117 | 22.5 | 1082 | 21.0 |
| 65-74 | | 156 | 33.9 | 119 | 35.0 | 814 | 31.8 | 310 | 37.3 | 156 | 35.8 | 195 | 37.4 | 1750 | 34.0 |
| 75-99 | | 146 | 31.7 | 121 | 35.6 | 813 | 31.7 | 242 | 29.2 | 109 | 25.0 | 143 | 27.4 | 1574 | 30.6 |
| Stage | | | | | | | | | | | | | | | |
| Localized | | 133 | 28.9 | 110 | 32.4 | 514 | 20.1 | 344 | 41.4 | 109 | 25.0 | 178 | 34.2 | 1388 | 27.0 |
| Regional | | 112 | 24.3 | 114 | 33.5 | 1003 | 39.1 | 250 | 30.1 | 131 | 30.0 | 160 | 30.7 | 1770 | 34.4 |
| Distant | | 215 | 46.7 | 116 | 34.1 | 1046 | 40.8 | 236 | 28.4 | 196 | 45.0 | 183 | 35.1 | 1992 | 38.7 |
| Total | | 460 | 100.0 | 340 | 100.0 | 2563 | 100.0 | 830 | 100.0 | 436 | 100.0 | 521 | 100.0 | 5150 | 100.0 |

Table 1. Continued

| | Prefecture | | | | | | | | | | | | Total | | | |
|---------------|--------------------------------------|--|-------|-------|-------|-------|---------|-------|--------|-------|----------|-------|-------|-------|-------|-------|
| | Yamagata | | Fukui | | Osaka | | Niigata | | Miyagi | | Nagasaki | | | | | |
| Breast | | | | | | | | | | | | | | | | |
| Women | Incidence (per million) [†] | | 43.5 | | 40.3 | | 41.6 | | 38.8 | | 53.5 | | 43.1 | | 43.6 | |
| | Mortality (per million) [‡] | | 9.2 | | 9.6 | | 12.0 | | 8.3 | | 9.8 | | 9.7 | | 10.4 | |
| | Age (years) | | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| | 15-44 | | 189 | 19.9 | 152 | 20.2 | 1174 | 19.7 | 511 | 23.9 | 371 | 21.5 | 272 | 22.1 | 2669 | 20.9 |
| | 45-54 | | 247 | 25.9 | 232 | 30.9 | 2121 | 35.6 | 647 | 30.2 | 536 | 31.0 | 352 | 28.6 | 4135 | 32.4 |
| | 55-64 | | 201 | 21.1 | 156 | 20.7 | 1330 | 22.3 | 424 | 19.8 | 389 | 22.5 | 240 | 19.5 | 2740 | 21.5 |
| | 65-74 | | 210 | 22.1 | 135 | 18.0 | 840 | 14.1 | 389 | 18.2 | 305 | 17.7 | 254 | 20.6 | 2133 | 16.7 |
| | 75-99 | | 105 | 11.0 | 77 | 10.2 | 489 | 8.2 | 171 | 8.0 | 127 | 7.3 | 114 | 9.3 | 1083 | 8.5 |
| | Stage | | | | | | | | | | | | | | | |
| | Localized | | 563 | 59.1 | 439 | 58.4 | 3275 | 55.0 | 1215 | 56.7 | 930 | 53.8 | 641 | 52.0 | 7063 | 55.4 |
| | Regional | | 320 | 33.6 | 263 | 35.0 | 2324 | 39.0 | 827 | 38.6 | 686 | 39.7 | 521 | 42.3 | 4941 | 38.7 |
| | Distant | | 69 | 7.2 | 50 | 6.6 | 355 | 6.0 | 100 | 4.7 | 112 | 6.5 | 70 | 5.7 | 756 | 5.9 |
| | Total | | 952 | 100.0 | 752 | 100.0 | 5954 | 100.0 | 2142 | 100.0 | 1728 | 100.0 | 1232 | 100.0 | 12760 | 100.0 |

[†]The age-adjusted incidence rates per 100 000 (Standard Population: Japanese 1985 model population) in 1998 (the estimation of the incidence in each prefecture was based on the collaborative study of cancer incidence in Japan⁽²¹⁾) and the total incidence was estimated using data from the 12 population-based cancer registries in Japan⁽²²⁾).

[‡]Age-adjusted mortality rate per 100 000 (Std. Pop.: 1985 Japanese model population) in 1998 (data from vital statistics of Japan⁽²³⁾).

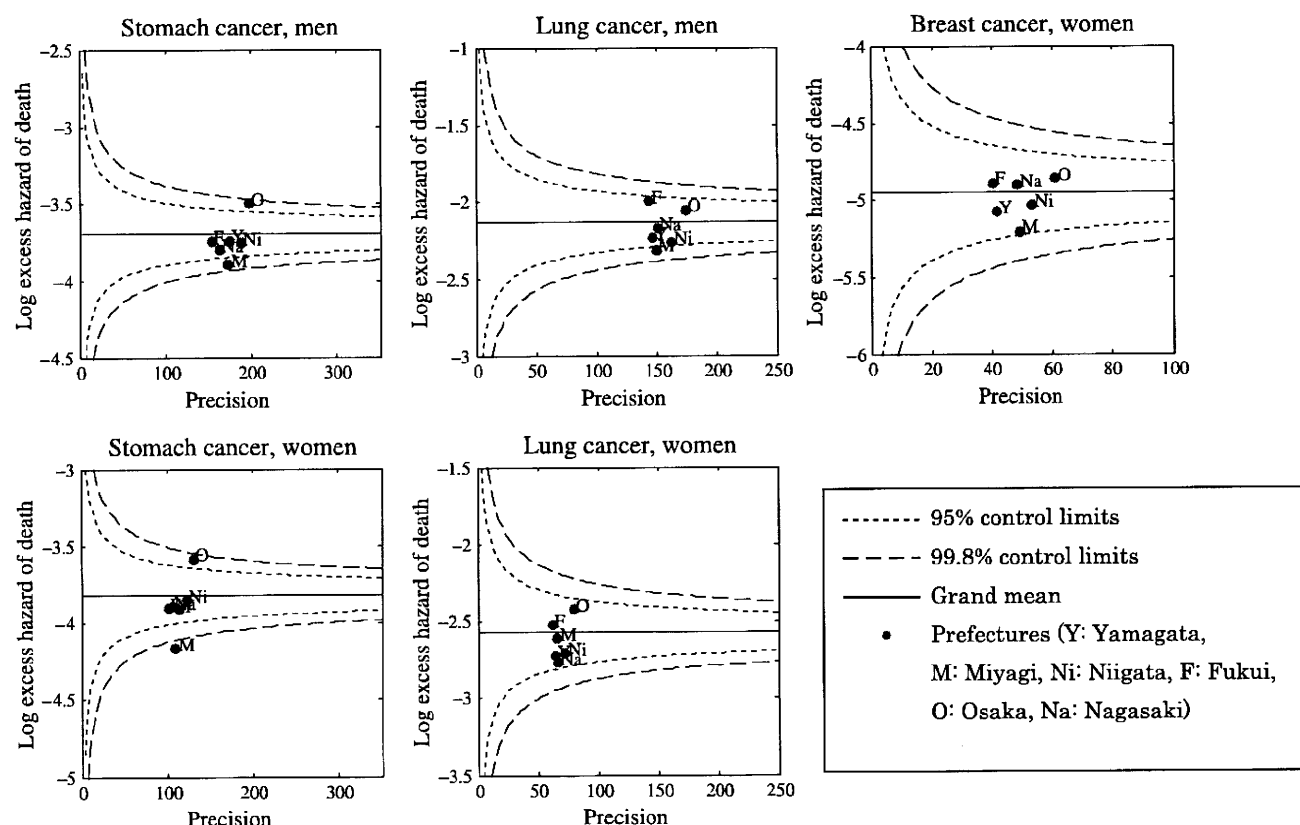


Fig. 2. Funnel plots of the age- and stage-adjusted log excess hazard of death within 5 years of diagnosis, by prefecture: cancers of the stomach, lung, and breast. Precision (x-axis) is the inverse of the variance of the age- and stage-adjusted log excess hazard of death. The target ('grand mean') is the average of the log excess hazard of death across the six prefectures

prefecture had higher than average excess mortality attributable to stomach cancer, whereas lower excess mortality was seen in Miyagi prefecture. Additional analyses restricted to three prefectures showed that more advanced stage at stomach cancer

diagnosis accounted for approximately 60% of the excess hazard of death in Osaka.

Many cancer screening programmes (stomach, lung, breast, cervix, colorectal, even prostate cancer) have been implemented

Table 2. Stomach cancer: excess hazard ratio (EHR) of death within five years since diagnosis in Osaka relative to Yamagata and Fukui combined: patients diagnosed 1993–1996

| | No. patients | Model 1 Follow-up time and region | | Model 2 Model 1 + age at diagnosis | | Model 3 Model 1 + stage at diagnosis | | Model 4 Model 1 + age and stage | |
|------------------|--------------|---|-----------|--|-----------|--|-------------|---------------------------------------|-------------|
| | | EHR | 95% CI | EHR | 95% CI | EHR | 95% CI | EHR | 95% CI |
| Men | | | | | | | | | |
| Region | | | | | | | | | |
| Yamagata + Fukui | | 5355 | | 1.00 | | 1.00 | | 1.00 | |
| Osaka | 10 260 | 1.53 | 1.44–1.62 | 1.59 | 1.50–1.68 | 1.26 | 1.19–1.33 | 1.29 | 1.22–1.36 |
| Age group | | | | | | | | | |
| 15–59 | 4858 | | | 1.00 | | | | 1.00 | |
| 60–69 | 5508 | | | 1.29 | 1.21–1.37 | | | 1.16 | 1.09–1.24 |
| 70–99 | 5249 | | | 1.77 | 1.66–1.88 | | | 1.42 | 1.33–1.52 |
| Stage | | | | | | | | | |
| Localized | 7877 | | | | | 1.00 | | 1.00 | |
| Regional | 4882 | | | | | 12.43 | 11.07–13.95 | 11.54 | 11.07–13.95 |
| Distant | 2856 | | | | | 47.02 | 41.78–52.90 | 42.77 | 41.78–52.90 |
| Women | | | | | | | | | |
| Region | | | | | | | | | |
| Yamagata + Fukui | 2918 | 1.00 | | 1.00 | | 1.00 | | 1.00 | |
| Osaka | 5024 | 1.55 | 1.44–1.68 | 1.65 | 1.53–1.78 | 1.34 | 1.25–1.45 | 1.43 | 1.32–1.54 |
| Age group | | | | | | | | | |
| 15–59 | 2522 | | | 1.00 | | | | 1.00 | |
| 60–69 | 2057 | | | 1.09 | 0.99–1.20 | | | 1.12 | 1.02–1.24 |
| 70–99 | 3363 | | | 1.70 | 1.57–1.85 | | | 1.52 | 1.40–1.65 |
| Stage | | | | | | | | | |
| Localized | 3742 | | | | | 1.00 | | 1.00 | |
| Regional | 2638 | | | | | 12.90 | 10.96–15.17 | 11.69 | 10.03–13.63 |
| Distant | 1562 | | | | | 49.43 | 41.85–58.38 | 44.19 | 37.75–51.73 |

CI, confidence interval.

Table 3. Summary of the excess hazard of death for stomach cancer patients in Osaka compared with Fukui + Yamagata

| Model | Variables included in model | Men | | Women | |
|-------|--------------------------------|------|----------------|-------|----------------|
| | | EHR | R ² | EHR | R ² |
| 1 | Follow up, region | 1.53 | 0.344 | 1.55 | 0.380 |
| 2 | + Age | 1.59 | 0.364 | 1.65 | 0.403 |
| 3 | + Stage | 1.26 | 0.970 | 1.34 | 0.958 |
| 4 | + Age and stage | 1.29 | 0.978 | 1.43 | 0.971 |

The effect of age (difference in R² between model 4 and model 3: see text) was 0.8 and 1.3% in men and women respectively. The effect of stage (difference in R² between model 4 and model 2) was 61.3 and 56.8% in men and women respectively. EHR, excess hazard ratio.

in Japan with public resources, but they have often not been well organized, with deficient management, poor definition of the target population, low participation (e.g. stomach cancer screening uptake 43.2% in Yamagata, 28.8% in Fukui, 17.9% in Osaka),⁽¹⁴⁾ and poor quality control. Although such issues have not yet been fully documented, the uptake or quality of screening may have been worse in Osaka, by far the most populous prefecture examined here (Table 1).

The proportion of records excluded from analysis because of missing data on stage varied widely by prefecture. The inclusion of cases with missing stage in unadjusted analyses did not, however, eliminate regional differences in stomach cancer survival. Stage distribution is an indication of early detection of cancer, but it does not explain the lower overall survival in Osaka: stage-specific survival was also lower. Patients with regional disease and, to a lesser degree, those with localized cancer,

had much lower survival in Osaka prefecture than in Yamagata and Fukui.

Regional disparities in health care management could play a major role in the remaining differences in stomach cancer survival. First, differential cancer screening coverage between Osaka and Yamagata-Fukui was likely to produce lead-time bias and/or length bias and might explain some of the differences in survival. Second, only 25% of cancer patients in Osaka were treated in the designated cancer care hospitals, whereas this proportion reached 70–80% in Fukui and Yamagata.⁽¹⁵⁾ Third, lower 5-year survival has been reported for cancer patients treated in low-volume hospitals:^(16–19) in Osaka, a higher proportion of cases was treated in such hospitals.

Significant differences between prefectures in the age-adjusted EHR for lung cancer disappeared after adjustment for stage. We infer that the differences in lung cancer survival arose mainly from differences in stage at diagnosis. In particular, cancer patients in Niigata and Nagasaki were on average diagnosed at an earlier stage than those in other prefectures. The high proportion of localized cases in Niigata could be explained by the high participation in screening. In Miyagi, the survival of localized cases was much higher than in other prefectures (data not shown), which could be due to lead-time bias and/or length bias among screen-detected cases. Niigata and Miyagi are two of the prefectures that have promoted cancer screening the most.

By contrast, no large disparities in survival were observed for breast cancer while all six prefectures achieved high survival on an international scale.⁽⁵⁾ Such observations show that regional differences in survival are not inevitable and that the overall organization of health care (from early diagnosis and screening through to treatment) can reach a uniformly high standard. It also demonstrates that the differences in survival observed

for the other cancers were not simply the result of a complex data artefact.

This is to our knowledge the first report of differences in population-based cancer survival in Japan using multivariable relative survival models, whereas crude survival (e.g. estimated with Cox proportional hazard models) does not account for the differences in background mortality. We did not control for background mortality by prefecture because it was shown to vary very little.⁽²⁰⁾

The contrast used here for the funnel plots enabled us to examine the distribution of the excess hazard of death from each cancer in each prefecture in relation to an overall mean excess hazard, after adjustment for age and stage at diagnosis. This approach also enabled us to take into account the differences in precision of the estimates arising from the wide differences in the population of each prefecture.

This cancer survival study was limited to six prefectures. Population-based cancer registration is present in 35 of the 47 prefectures and one city in Japan, but the quality of registration and follow up is often too poor and the proportion of records with missing information on stage too high for systematic survival analysis. Even in the six prefectures that met the predetermined quality criteria, there were some unresolved data management issues. Furthermore, we limited the additional analysis on three prefectures with similar follow-up procedure in order to make the results more comparable.

Analysis of secular trends in these regional disparities in survival, using more recent data, will enable us to improve these

investigations. Comparable approaches could also be applied to examine differences in cancer survival between smaller administrative geographies within a given prefecture, such as second-level medical care districts.

High-quality cancer registries with individual follow-up information are a key requirement for effective cancer control. The infrastructure of cancer registration in Japan has lagged behind that in European countries, Canada, and the USA. Systematic analysis of the data from a network of cancer registries is indispensable for monitoring improvements in cancer survival, for assessing equity in the outcome of cancer care, and for implementing and evaluating cancer control policies.

We showed that the use of the multivariable relative survival model combined with funnel plot approach was useful for assessing the regional disparities in cancer survival. It enabled us to quantify the impact of differential age and stage distributions on these regional inequalities. Our study illustrates the value of population-based cancer registries for improving cancer control.

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Epidemiology Note

Cancer Incidence and Incidence Rates in Japan in 2003: Based on Data from 13 Population-based Cancer Registries in the Monitoring of Cancer Incidence in Japan (MCIJ) Project

Tomohiro Matsuda¹, Tomomi Marugame¹, Ken-ichi Kamo², Kota Katanoda¹, Wakiko Ajiki¹, Tomotaka Sobue¹ and The Japan Cancer Surveillance Research Group

¹Cancer Information Services and Surveillance Division, Center for Cancer Control and Information Services, National Cancer Center, Tokyo and ²Division of Mathematics, School of Medicine, Liberal Arts and Sciences, Sapporo Medical University, Hokkaido, Japan

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The Japan Cancer Surveillance Research Group is involved in cancer monitoring in Japan (1–3). This group estimated the cancer incidence in 2003 as part of the Monitoring of Cancer Incidence in Japan (MCIJ) project, on the basis of data collected from 13 of 31 population-based cancer registries: Miyagi, Yamagata, Chiba, Kanagawa, Niigata, Fukui, Shiga, Osaka, Tottori, Okayama, Hiroshima, Saga and Nagasaki. If data from all 31 registries were used, this would have led to a large underestimation of national cancer incidence because of under-registration. The methods of registry selection, estimation of incidence and the limitations of these methods have been explained in previous studies (4–6). There were two major methodologic changes in the present study: (i) this was the first time we invited all 31 population-based cancer registries in Japan to participate, and from these we selected the 13 cancer registries with high-quality data in order to estimate the national incidence, and (ii) in consideration of timeliness, we did not apply the moving average which calculates the annual mean incidence rates of a year by using preceding and following years, and we used 2003 data alone for the national estimation. Because of the enlargement of the coverage area, Hiroshima prefecture was newly selected as one of the registries with high-quality data for the national estimation, but the other registries remained since the previous estimations. In 2007, we estimated incidences with and without the moving average based on the same registry data to compare the two methods. In conclusion, the estimated incidence without the moving average was comparatively unstable from year to year, but the gaps of the incidence numbers between the two

estimations were subtle. These new methods therefore do not bring about changes in the estimated incidence numbers.

The number of incidences, crude rates, age-standardized rates and completeness of registration in 2003 are shown in Table 1, and the age-specific number of incidences and the rates according to sex and primary site are shown in Tables 2 and 3. The total number of incidences in Japan for 2003 was estimated as 620 011 (C00–C96). The time trends of age-standardized incidence rates for the five major sites and male- and female-specific sites in 1975–2003 are shown in Fig. 1 (standard population: the world population) and in Fig. 2 (standard population: the 1985 Japanese model population). The leading cancer site according to the crude and age-standardized incidence rates was the stomach for men and breast for women, as shown in Figs 1 and 2. The apparent increase in age-standardized incidence rates in 2003 is considered to be caused primarily by the development of hospital-based cancer registry in designated cancer care hospitals. The estimated cancer incidence data in Japan by sex, site, 5-year age group and calendar year during the period 1975–2003 are available as a booklet (7) and as an electronic database on the website (<http://ganjoho.ncc.go.jp/professional/statistics/statistics.html>).

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For reprints and all correspondence: Tomohiro Matsuda, Cancer Information Services and Surveillance Division, Center for Cancer Control and Information Services, National Cancer Center, 5-1-1 Tsukiji, Chuo-ku, Tokyo 104-0045, Japan. E-mail: tomatsud@ncc.go.jp

Table 1. Incidence, completeness of reporting and accuracy of diagnosis in Japan according to sex and primary site, 2003

| Primary sites | ICD-10th | Number of incidence | Crude rate ^a | Age-standardized rate ^a | | Completeness of reporting | | Accuracy of diagnosis | |
|-----------------------------------|------------------|---------------------|-------------------------|------------------------------------|--------------------------------|---------------------------|------|-----------------------|--|
| | | | | World population | Japanese 1985 model population | DCO/I (%) | I/M | MV/I (%) | |
| Male | | | | | | | | | |
| All sites (incl. CIS) | C00–C96, D00–D09 | 372 374 | 597.7 | 288.0 | 409.8 | 16.5 | 1.99 | 74.8 | |
| All sites | C00–C96 | 364 072 | 584.3 | 281.4 | 400.5 | 16.8 | 1.95 | 74.4 | |
| Lip, oral cavity and pharynx | C00–C14 | 7835 | 12.6 | 6.7 | 9.1 | 11.7 | 1.94 | 81.0 | |
| Esophagus | C15 | 13 658 | 21.9 | 10.8 | 15.1 | 15.5 | 1.45 | 78.3 | |
| Stomach | C16 | 73 798 | 118.4 | 57.1 | 81.1 | 13.8 | 2.30 | 82.4 | |
| Colon | C18 | 35 262 | 56.6 | 27.0 | 38.5 | 11.9 | 2.74 | 82.6 | |
| Rectum and anus | C19, C20 | 21 892 | 35.1 | 18.0 | 24.8 | 11.1 | 2.68 | 84.2 | |
| Liver | C22 | 29 126 | 46.7 | 22.7 | 31.9 | 25.2 | 1.25 | 38.4 | |
| Gallbladder etc. | C23, C24 | 8755 | 14.1 | 6.1 | 9.2 | 27.2 | 1.20 | 46.0 | |
| Pancreas | C25 | 12 511 | 20.1 | 9.5 | 13.7 | 28.7 | 1.11 | 37.0 | |
| Larynx | C32 | 3921 | 6.3 | 3.1 | 4.3 | 7.3 | 4.24 | 88.5 | |
| Trachea, bronchus and lung | C33, C34 | 55 928 | 89.8 | 39.6 | 59.5 | 24.2 | 1.34 | 69.8 | |
| Skin | C43, C44 | 3325 | 5.3 | 2.6 | 3.6 | 7.1 | 6.08 | 90.6 | |
| Prostate | C61 | 40 062 | 64.3 | 27.3 | 41.4 | 9.5 | 4.76 | 85.7 | |
| Bladder | C67 | 12 646 | 20.3 | 9.3 | 13.6 | 11.1 | 3.40 | 84.7 | |
| Kidney, renal pelvis, ureter etc. | C64–C66, C68 | 8217 | 13.2 | 6.7 | 9.3 | 16.0 | 2.27 | 74.3 | |
| Brain and nervous system | C70–C72 | 2571 | 4.1 | 3.1 | 3.5 | 27.5 | 2.95 | 65.3 | |
| Thyroid | C73 | 2023 | 3.2 | 2.0 | 2.6 | 5.9 | 4.53 | 90.2 | |
| Malignant lymphoma | C81–C85, C96 | 12 881 | 20.7 | 11.6 | 15.5 | 17.0 | 2.65 | 79.9 | |
| Multiple myeloma | C88–C90 | 2251 | 3.6 | 1.6 | 2.4 | 30.6 | 1.20 | 65.8 | |
| All leukaemias | C91–C95 | 5606 | 9.0 | 5.8 | 7.0 | 25.3 | 1.37 | 82.9 | |
| Female | | | | | | | | | |
| All sites (incl. CIS) | C00–C96, D00–D09 | 269 220 | 412.2 | 193.9 | 260.8 | 17.1 | 2.20 | 73.6 | |
| All site | C00–C96 | 255 939 | 391.9 | 179.3 | 242.5 | 17.9 | 2.09 | 72.4 | |

Continued

Table 1. Continued

| Primary sites | ICD-10th | Number of incidence | Crude rate ^a | Age-standardized rate ^b | | Completeness of reporting | | Accuracy of diagnosis | |
|-----------------------------------|--------------|---------------------|-------------------------|------------------------------------|--------------------------------|---------------------------|------|-----------------------|------|
| | | | | World population | Japanese 1985 model population | DCO/I (%) | I/M | MV/I (%) | I/M |
| Lip, oral cavity and pharynx | C00-C14 | 3180 | 4.9 | 2.2 | 2.9 | 15.0 | 2.01 | 76.6 | 2.01 |
| Esophagus | C15 | 2742 | 4.2 | 1.7 | 2.3 | 20.0 | 1.66 | 69.3 | 1.66 |
| Stomach | C16 | 36 525 | 55.9 | 22.1 | 31.2 | 17.9 | 2.10 | 78.3 | 2.10 |
| Colon | C18 | 29 859 | 45.7 | 17.4 | 24.7 | 15.8 | 2.30 | 77.1 | 2.30 |
| Rectum and anus | C19, C20 | 11 902 | 18.2 | 7.9 | 10.9 | 13.1 | 2.43 | 81.5 | 2.43 |
| Liver | C22 | 13 535 | 20.7 | 7.0 | 10.4 | 29.3 | 1.26 | 32.8 | 1.26 |
| Gallbladder etc. | C23, C24 | 10 200 | 15.6 | 4.7 | 7.1 | 32.3 | 1.18 | 40.5 | 1.18 |
| Pancreas | C25 | 10 371 | 15.9 | 5.5 | 7.9 | 34.0 | 1.05 | 30.1 | 1.05 |
| Larynx | C32 | 448 | 0.7 | 0.3 | 0.4 | 3.8 | 7.34 | 91.4 | 7.34 |
| Trachea, bronchus and lung | C33, C34 | 22 817 | 34.9 | 12.8 | 18.4 | 25.1 | 1.51 | 66.5 | 1.51 |
| Skin | C43, C44 | 4497 | 6.9 | 2.5 | 3.4 | 9.6 | 8.52 | 89.2 | 8.52 |
| Breast (incl. CIS) | C50, D05 | 45 716 | 70.0 | 43.4 | 56.1 | 5.6 | 4.66 | 90.5 | 4.66 |
| Uterus (incl. CIS) | C53-C55, D06 | 24 240 | 37.1 | 25.5 | 32.3 | 7.4 | 4.57 | 88.9 | 4.57 |
| Uterus (only invasive) | C53-C55 | 17 285 | 26.5 | 16.1 | 20.8 | 10.0 | 3.26 | 85.7 | 3.26 |
| Cervix uteri | C53 | 8674 | 13.3 | 8.8 | 11.3 | 7.1 | 3.65 | 89.4 | 3.65 |
| Corpus uteri | C54 | 7430 | 11.4 | 6.5 | 8.5 | 5.6 | 5.41 | 89.6 | 5.41 |
| Ovary | C56 | 7946 | 12.2 | 7.2 | 9.2 | 17.2 | 1.88 | 77.0 | 1.88 |
| Bladder | C67 | 3713 | 5.7 | 1.8 | 2.7 | 18.8 | 2.19 | 74.5 | 2.19 |
| Kidney, renal pelvis, ureter etc. | C64-C66, C68 | 4689 | 7.2 | 3.0 | 4.1 | 18.3 | 2.38 | 71.7 | 2.38 |
| Brain and nervous system | C70-C72 | 2034 | 3.1 | 1.8 | 2.1 | 24.6 | 3.10 | 60.2 | 3.10 |
| Thyroid | C73 | 6046 | 9.3 | 5.6 | 7.2 | 7.6 | 6.17 | 87.4 | 6.17 |
| Malignant lymphoma | C81-C85, C96 | 8592 | 13.2 | 6.1 | 8.2 | 16.8 | 2.36 | 80.8 | 2.36 |
| Multiple myeloma | C88-C90 | 2234 | 3.4 | 1.2 | 1.7 | 34.4 | 1.23 | 62.3 | 1.23 |
| All leukaemias | C91-C95 | 3951 | 6.0 | 3.8 | 4.3 | 25.2 | 1.35 | 81.0 | 1.35 |

ICD-10th, International Classification of Disease, 10th Revision; DCO/I, proportion of cases with the death certificate only to incident cases; I/M, number of incidence/number of deaths; MV/I, proportion of microscopically verified cases to incident cases; CIS, carcinoma *in situ*.

^aPer 100 000 population.

Table 2. Age-specific incidence in Japan according to sex and primary site, 2003

| Primary sites | ICD-10th | All ages Age group (years) | | | | | | | | | | | | | | | | | | |
|-----------------------------------|------------------|----------------------------|-----|-------|-------|-------|-------|-------|-------|-------|-------|--------|--------|--------|--------|--------|--------|--------|--------|--------|
| | | 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85+ | |
| Male | | | | | | | | | | | | | | | | | | | | |
| All sites (incl. CIS) | C00-C96, D00-D09 | 372 374 | 401 | 290 | 190 | 416 | 656 | 1021 | 1510 | 2353 | 4422 | 7922 | 18 940 | 29 913 | 44 332 | 57 691 | 72 125 | 63 779 | 36 791 | 29 622 |
| All sites | C00-C96 | 364 072 | 401 | 290 | 190 | 405 | 650 | 1020 | 1497 | 2310 | 4213 | 7732 | 18 421 | 29 054 | 43 110 | 56 281 | 70 601 | 62 386 | 36 217 | 29 294 |
| Lip, oral cavity and pharynx | C00-C14 | 7835 | 2 | 0 | 2 | 8 | 34 | 39 | 99 | 127 | 117 | 316 | 626 | 924 | 1180 | 1342 | 1220 | 910 | 543 | 346 |
| Esophagus | C15 | 13 658 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 14 | 93 | 317 | 850 | 1629 | 2351 | 2281 | 2621 | 1945 | 981 | 576 |
| Stomach | C16 | 73 798 | 0 | 0 | 0 | 17 | 47 | 70 | 154 | 281 | 878 | 1741 | 4439 | 6714 | 9286 | 12 022 | 14 013 | 12 042 | 6472 | 5622 |
| Colon | C18 | 35 262 | 0 | 3 | 0 | 8 | 18 | 54 | 120 | 204 | 339 | 713 | 1698 | 2905 | 4591 | 5634 | 7014 | 5589 | 3432 | 2940 |
| Rectum and anus | C19, C20 | 21 892 | 0 | 0 | 1 | 8 | 5 | 15 | 83 | 158 | 420 | 709 | 1582 | 2564 | 3380 | 3828 | 3652 | 2925 | 1445 | 1117 |
| Liver | C22 | 29 126 | 11 | 2 | 3 | 0 | 19 | 12 | 33 | 82 | 266 | 573 | 1792 | 2714 | 4018 | 5290 | 6146 | 4455 | 2127 | 1583 |
| Gallbladder etc. | C23, C24 | 8755 | 0 | 0 | 0 | 0 | 0 | 1 | 4 | 23 | 57 | 79 | 294 | 410 | 820 | 1137 | 1483 | 1697 | 1438 | 1312 |
| Pancreas | C25 | 12 511 | 0 | 0 | 0 | 0 | 14 | 4 | 1 | 41 | 157 | 194 | 727 | 1081 | 1666 | 1880 | 2247 | 2119 | 1365 | 1015 |
| Larynx | C32 | 3921 | 0 | 0 | 0 | 0 | 19 | 0 | 0 | 6 | 31 | 72 | 229 | 434 | 604 | 713 | 746 | 616 | 304 | 147 |
| Trachea, bronchus and lung | C33, C34 | 55 928 | 0 | 0 | 0 | 1 | 5 | 3 | 68 | 175 | 296 | 820 | 1944 | 3549 | 5091 | 7296 | 11 701 | 11 923 | 7446 | 5610 |
| Skin | C43, C44 | 3325 | 0 | 0 | 3 | 0 | 13 | 42 | 68 | 50 | 46 | 77 | 107 | 148 | 349 | 358 | 572 | 590 | 364 | 538 |
| Prostate | C61 | 40 062 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 9 | 58 | 430 | 1251 | 3704 | 6719 | 9914 | 9291 | 4852 | 3834 |
| Bladder | C67 | 12 646 | 7 | 0 | 0 | 10 | 4 | 23 | 32 | 101 | 92 | 229 | 645 | 862 | 1196 | 1544 | 2623 | 2287 | 1520 | 1471 |
| Kidney, renal pelvis, ureter etc. | C64-C66, C68 | 8217 | 14 | 5 | 0 | 0 | 26 | 50 | 35 | 70 | 164 | 280 | 648 | 834 | 932 | 1226 | 1487 | 1223 | 760 | 463 |
| Brain and nervous system | C70-C72 | 2571 | 67 | 111 | 18 | 45 | 85 | 72 | 88 | 84 | 139 | 146 | 230 | 149 | 319 | 313 | 290 | 202 | 105 | 108 |
| Thyroid | C73 | 2023 | 0 | 3 | 0 | 1 | 34 | 49 | 44 | 126 | 88 | 137 | 245 | 215 | 224 | 188 | 270 | 193 | 117 | 89 |
| Malignant lymphoma | C81-C85, C96 | 12 881 | 12 | 38 | 76 | 96 | 113 | 123 | 175 | 307 | 528 | 680 | 791 | 1184 | 1415 | 2002 | 1705 | 1680 | 1107 | 849 |
| Multiple myeloma | C88-C90 | 2251 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 8 | 10 | 33 | 88 | 184 | 240 | 344 | 349 | 450 | 304 | 237 |
| All leukaemias | C91-C95 | 5606 | 138 | 94 | 50 | 77 | 73 | 162 | 142 | 81 | 200 | 211 | 319 | 459 | 518 | 795 | 844 | 699 | 390 | 354 |
| Female | | | | | | | | | | | | | | | | | | | | |
| All sites (incl. CIS) | C00-C96, D00-D09 | 269 220 | 397 | 219 | 202 | 332 | 821 | 1909 | 4996 | 6722 | 9210 | 13 421 | 19 959 | 22 867 | 25 392 | 28 998 | 34 319 | 34 339 | 29 314 | 35 803 |
| All site | C00-C96 | 255 939 | 397 | 219 | 202 | 315 | 612 | 1301 | 3433 | 5118 | 7788 | 12 156 | 18 900 | 21 931 | 24 287 | 28 108 | 33 190 | 33 601 | 28 888 | 35 493 |

Continued

Table 2. Continued

| Primary sites | ICD-10th | All ages Age group (years) | | | | | | | | | | | | | | | | | | |
|-----------------------------------|--------------|----------------------------|-----|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|------|------|
| | | 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85+ | |
| Lip, oral cavity and pharynx | C00-C14 | 3180 | 0 | 0 | 2 | 18 | 42 | 23 | 33 | 56 | 74 | 100 | 219 | 248 | 332 | 370 | 363 | 468 | 385 | 447 |
| Esophagus | C15 | 2742 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 14 | 13 | 123 | 140 | 243 | 250 | 378 | 392 | 335 | 323 | 530 |
| Stomach | C16 | 36525 | 0 | 0 | 0 | 2 | 17 | 70 | 234 | 418 | 783 | 1101 | 1851 | 2752 | 3010 | 4149 | 5208 | 5706 | 4850 | 6374 |
| Colon | C18 | 29859 | 0 | 0 | 0 | 2 | 11 | 36 | 121 | 214 | 346 | 634 | 1480 | 2021 | 2853 | 3709 | 4420 | 4681 | 4120 | 5211 |
| Rectum and anus | C19, C20 | 11902 | 0 | 0 | 0 | 0 | 0 | 12 | 62 | 120 | 239 | 414 | 852 | 1162 | 1444 | 1511 | 1695 | 1602 | 1264 | 1525 |
| Liver | C22 | 13535 | 1 | 0 | 11 | 0 | 0 | 12 | 13 | 10 | 36 | 68 | 246 | 575 | 946 | 1989 | 2754 | 2677 | 2228 | 1969 |
| Gallbladder etc. | C23-C24 | 10200 | 0 | 0 | 0 | 4 | 0 | 0 | 6 | 4 | 44 | 108 | 229 | 337 | 609 | 894 | 1274 | 1758 | 2086 | 2847 |
| Pancreas | C25 | 10371 | 0 | 0 | 0 | 0 | 0 | 6 | 6 | 33 | 69 | 197 | 394 | 551 | 860 | 1080 | 1583 | 1619 | 1637 | 2336 |
| Larynx | C32 | 448 | 0 | 0 | 2 | 0 | 0 | 0 | 7 | 2 | 0 | 38 | 2 | 37 | 59 | 83 | 47 | 92 | 39 | 40 |
| Trachea, bronchus and lung | C33, C34 | 22817 | 5 | 0 | 0 | 5 | 0 | 36 | 35 | 126 | 190 | 417 | 955 | 1525 | 2005 | 2774 | 3558 | 3831 | 3272 | 4083 |
| Skin | C43, C44 | 4497 | 10 | 0 | 10 | 7 | 15 | 13 | 24 | 98 | 56 | 90 | 137 | 168 | 250 | 512 | 441 | 561 | 734 | 1371 |
| Breast (incl. CIS) | C50, D05 | 45716 | 0 | 0 | 0 | 0 | 29 | 222 | 934 | 1986 | 3547 | 5722 | 6882 | 5832 | 5657 | 4570 | 3724 | 3098 | 2009 | 1504 |
| Uterus (incl. CIS) | C53-C55, D06 | 24240 | 0 | 0 | 0 | 0 | 268 | 835 | 2479 | 2529 | 2299 | 2167 | 2432 | 2876 | 2030 | 1557 | 1609 | 1360 | 899 | 892 |
| Uterus (only invasive) | C53-C55 | 17285 | 0 | 0 | 0 | 2 | 77 | 259 | 988 | 1114 | 1146 | 1408 | 1978 | 2557 | 1791 | 1377 | 1531 | 1291 | 879 | 887 |
| Cervix uteri | C53 | 8674 | 0 | 0 | 0 | 2 | 74 | 223 | 791 | 889 | 870 | 832 | 753 | 879 | 701 | 613 | 600 | 552 | 443 | 452 |
| Corpus uteri | C54 | 7430 | 0 | 0 | 0 | 0 | 3 | 29 | 193 | 203 | 245 | 520 | 1148 | 1577 | 997 | 661 | 817 | 606 | 248 | 183 |
| Ovary | C56 | 7946 | 0 | 0 | 20 | 40 | 47 | 150 | 182 | 258 | 412 | 683 | 1183 | 1183 | 801 | 695 | 761 | 536 | 488 | 507 |
| Bladder | C67 | 3713 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 14 | 10 | 42 | 78 | 136 | 197 | 403 | 608 | 659 | 684 | 880 |
| Kidney, renal pelvis, ureter etc. | C64-C66, C68 | 4689 | 17 | 8 | 8 | 4 | 2 | 3 | 26 | 25 | 111 | 95 | 348 | 345 | 441 | 559 | 693 | 737 | 593 | 674 |
| Brain and nervous system | C70-C72 | 2034 | 53 | 27 | 27 | 21 | 9 | 28 | 106 | 43 | 46 | 54 | 79 | 156 | 233 | 223 | 217 | 208 | 225 | 279 |
| Thyroid | C73 | 6046 | 0 | 0 | 11 | 21 | 89 | 133 | 233 | 325 | 339 | 448 | 715 | 716 | 723 | 591 | 704 | 443 | 225 | 330 |
| Malignant lymphoma | C81-C85, C96 | 8592 | 19 | 33 | 13 | 45 | 81 | 86 | 117 | 113 | 217 | 282 | 592 | 637 | 808 | 918 | 1471 | 1248 | 969 | 943 |
| Multiple myeloma | C88-C90 | 2234 | 0 | 0 | 0 | 0 | 0 | 0 | 9 | 11 | 33 | 20 | 81 | 84 | 200 | 215 | 375 | 378 | 368 | 460 |
| All leukaemias | C91-C95 | 3951 | 114 | 98 | 32 | 68 | 81 | 44 | 108 | 96 | 97 | 147 | 289 | 321 | 319 | 411 | 483 | 476 | 378 | 389 |

Table 3. Age-specific incidence rate per 100 000 population in Japan according to sex and primary site, 2003

| Primary sites | ICD-10th | All ages Age group (years) | | | | | | | | | | | | | | | | | | |
|-----------------------------------|------------------|----------------------------|------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|--------|--------|--------|--------|--------|--------|
| | | 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85+ | |
| Male | | | | | | | | | | | | | | | | | | | | |
| All sites (incl. CIS) | C00-C96, D00-D09 | 597.7 | 13.5 | 9.5 | 6.1 | 11.6 | 16.3 | 22.1 | 30.8 | 55.2 | 111.9 | 199.2 | 379.7 | 661.4 | 1100.6 | 1643.2 | 2488.8 | 3093.1 | 3541.0 | 3954.9 |
| All sites | C00-C96 | 584.3 | 13.5 | 9.5 | 6.1 | 11.3 | 16.2 | 22.0 | 30.6 | 54.2 | 106.6 | 194.5 | 369.3 | 642.4 | 1070.3 | 1603.0 | 2436.2 | 3025.5 | 3485.8 | 3911.1 |
| Lip, oral cavity and pharynx | C00-C14 | 12.6 | 0.1 | 0.0 | 0.1 | 0.2 | 0.8 | 0.8 | 2.0 | 3.0 | 3.0 | 7.9 | 12.6 | 20.4 | 29.3 | 38.2 | 42.1 | 44.1 | 52.3 | 46.2 |
| Esophagus | C15 | 21.9 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.3 | 2.4 | 8.0 | 17.0 | 36.0 | 58.4 | 65.0 | 90.4 | 94.3 | 94.4 | 76.9 |
| Stomach | C16 | 118.4 | 0.0 | 0.0 | 0.0 | 0.5 | 1.2 | 1.5 | 3.1 | 6.6 | 22.2 | 43.8 | 89.0 | 148.4 | 230.5 | 342.4 | 483.5 | 584.0 | 622.9 | 750.6 |
| Colon | C18 | 56.6 | 0.0 | 0.1 | 0.0 | 0.2 | 0.4 | 1.2 | 2.5 | 4.8 | 8.6 | 17.9 | 34.0 | 64.2 | 114.0 | 160.5 | 242.0 | 271.0 | 330.3 | 392.5 |
| Rectum and anus | C19, C20 | 35.1 | 0.0 | 0.0 | 0.0 | 0.2 | 0.1 | 0.3 | 1.7 | 3.7 | 10.6 | 17.8 | 31.7 | 56.7 | 83.9 | 109.0 | 126.0 | 141.9 | 139.1 | 149.1 |
| Liver | C22 | 46.7 | 0.4 | 0.1 | 0.1 | 0.0 | 0.5 | 0.3 | 0.7 | 1.9 | 6.7 | 14.4 | 35.9 | 60.0 | 99.8 | 150.7 | 212.1 | 216.1 | 204.7 | 211.3 |
| Gallbladder etc. | C23, C24 | 14.1 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.5 | 1.4 | 2.0 | 5.9 | 9.1 | 20.4 | 32.4 | 51.2 | 82.3 | 138.4 | 175.2 |
| Pancreas | C25 | 20.1 | 0.0 | 0.0 | 0.0 | 0.0 | 0.3 | 0.1 | 0.0 | 1.0 | 4.0 | 4.9 | 14.6 | 23.9 | 41.4 | 53.5 | 77.5 | 102.8 | 131.4 | 135.5 |
| Larynx | C32 | 6.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.5 | 0.0 | 0.0 | 0.1 | 0.8 | 1.8 | 4.6 | 9.6 | 15.0 | 20.3 | 25.7 | 29.9 | 29.3 | 19.6 |
| Trachea, bronchus and lung | C33, C34 | 89.8 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.1 | 1.4 | 4.1 | 7.5 | 20.6 | 39.0 | 78.5 | 126.4 | 207.8 | 403.8 | 578.2 | 716.7 | 749.0 |
| Skin | C43, C44 | 5.3 | 0.0 | 0.0 | 0.1 | 0.0 | 0.3 | 0.9 | 1.4 | 1.2 | 1.2 | 1.9 | 2.1 | 3.3 | 8.7 | 10.2 | 19.7 | 28.6 | 35.0 | 71.8 |
| Prostate | C61 | 64.3 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.2 | 1.5 | 8.6 | 27.7 | 92.0 | 191.4 | 342.1 | 450.6 | 467.0 | 511.9 |
| Bladder | C67 | 20.3 | 0.2 | 0.0 | 0.0 | 0.3 | 0.1 | 0.5 | 0.7 | 2.4 | 2.3 | 5.8 | 12.9 | 19.1 | 29.7 | 44.0 | 90.5 | 110.9 | 146.3 | 196.4 |
| Kidney, renal pelvis, ureter etc. | C64-C66, C68 | 13.2 | 0.5 | 0.2 | 0.0 | 0.0 | 0.6 | 1.1 | 0.7 | 1.6 | 4.1 | 7.0 | 13.0 | 18.4 | 23.1 | 34.9 | 51.3 | 59.3 | 73.1 | 61.8 |
| Brain and nervous system | C70-C72 | 4.1 | 2.3 | 3.6 | 0.6 | 1.3 | 2.1 | 1.6 | 1.8 | 2.0 | 3.5 | 3.7 | 4.6 | 3.3 | 7.9 | 8.9 | 10.0 | 9.8 | 10.1 | 14.4 |
| Thyroid | C73 | 3.2 | 0.0 | 0.1 | 0.0 | 0.0 | 0.8 | 1.1 | 0.9 | 3.0 | 2.2 | 3.4 | 4.9 | 4.8 | 5.6 | 5.4 | 9.3 | 9.4 | 11.3 | 11.9 |
| Malignant lymphoma | C81-C85, C96 | 20.7 | 0.4 | 1.2 | 2.4 | 2.7 | 2.8 | 2.7 | 3.6 | 7.2 | 13.4 | 17.1 | 15.9 | 26.2 | 35.1 | 57.0 | 58.8 | 81.5 | 106.5 | 113.4 |
| Multiple myeloma | C88-C90 | 3.6 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.2 | 0.3 | 0.8 | 1.8 | 4.1 | 6.0 | 9.8 | 12.0 | 21.8 | 29.3 | 31.6 |
| All leukaemias | C91-C95 | 9.0 | 4.6 | 3.1 | 1.6 | 2.1 | 1.8 | 3.5 | 2.9 | 1.9 | 5.1 | 5.3 | 6.4 | 10.1 | 12.9 | 22.6 | 29.1 | 33.9 | 37.5 | 47.3 |
| Female | | | | | | | | | | | | | | | | | | | | |
| All sites (incl. CIS) | C00-C96, D00-D09 | 412.2 | 14.1 | 7.5 | 6.8 | 9.7 | 21.4 | 42.6 | 104.0 | 159.9 | 235.7 | 339.5 | 397.2 | 492.1 | 594.0 | 744.7 | 991.9 | 1211.3 | 1479.0 | 1904.4 |
| All site | C00-C96 | 391.9 | 14.1 | 7.5 | 6.8 | 9.2 | 16.0 | 29.1 | 71.5 | 121.8 | 199.3 | 307.5 | 376.1 | 471.9 | 568.1 | 721.8 | 959.2 | 1185.2 | 1457.5 | 1887.9 |

Continued

Table 3. Continued

| Primary sites | ICD-10th | All ages Age group (years) | | | | | | | | | | | | | | | | | | | | | |
|-----------------------------------|--------------|----------------------------|-----|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|------|------|------|
| | | 0-4 | 5-9 | 10-14 | 15-19 | 20-24 | 25-29 | 30-34 | 35-39 | 40-44 | 45-49 | 50-54 | 55-59 | 60-64 | 65-69 | 70-74 | 75-79 | 80-84 | 85+ | | | | |
| Lip, oral cavity and pharynx | C00-C14 | 4.9 | 0.0 | 0.0 | 0.1 | 0.5 | 1.1 | 1.1 | 0.5 | 1.1 | 0.5 | 0.7 | 1.3 | 1.9 | 2.5 | 4.4 | 5.3 | 7.8 | 9.5 | 10.5 | 16.5 | 19.4 | 23.8 |
| Esophagus | C15 | 4.2 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.3 | 0.3 | 3.1 | 2.8 | 5.2 | 5.8 | 9.7 | 11.3 | 11.8 | 16.3 | 28.2 |
| Stomach | C16 | 55.9 | 0.0 | 0.0 | 0.0 | 0.1 | 0.4 | 1.6 | 4.9 | 9.9 | 20.0 | 27.9 | 36.8 | 59.2 | 70.4 | 106.5 | 150.5 | 201.3 | 244.7 | 339.0 | | | |
| Colon | C18 | 45.7 | 0.0 | 0.0 | 0.0 | 0.1 | 0.3 | 0.8 | 2.5 | 5.1 | 8.9 | 16.0 | 29.5 | 43.5 | 66.7 | 95.2 | 127.7 | 165.1 | 207.9 | 277.2 | | | |
| Rectum and anus | C19, C20 | 18.2 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.3 | 1.3 | 2.9 | 6.1 | 10.5 | 17.0 | 25.0 | 33.8 | 38.8 | 49.0 | 56.5 | 63.8 | 81.1 | | | |
| Liver | C22 | 20.7 | 0.0 | 0.0 | 0.4 | 0.0 | 0.0 | 0.3 | 0.3 | 0.2 | 0.9 | 1.7 | 4.9 | 12.4 | 22.1 | 51.1 | 79.6 | 94.4 | 112.4 | 104.7 | | | |
| Gallbladder etc. | C23, C24 | 15.6 | 0.0 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.1 | 0.1 | 1.1 | 2.7 | 4.6 | 7.3 | 14.2 | 23.0 | 36.8 | 62.0 | 105.2 | 151.4 | | | |
| Pancreas | C25 | 15.9 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.1 | 0.8 | 1.8 | 5.0 | 7.8 | 11.9 | 20.1 | 27.7 | 45.8 | 57.1 | 82.6 | 124.3 | | | |
| Larynx | C32 | 0.7 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.8 | 1.4 | 2.1 | 1.4 | 3.2 | 2.0 | 2.1 | | |
| Trachea, bronchus and lung | C33, C34 | 34.9 | 0.2 | 0.0 | 0.0 | 0.1 | 0.0 | 0.8 | 0.7 | 3.0 | 4.9 | 10.5 | 19.0 | 32.8 | 46.9 | 71.2 | 102.8 | 135.1 | 165.1 | 217.2 | | | |
| Skin | C43, C44 | 6.9 | 0.4 | 0.0 | 0.3 | 0.2 | 0.4 | 0.3 | 0.5 | 2.3 | 1.4 | 2.3 | 2.7 | 3.6 | 5.8 | 13.1 | 12.7 | 19.8 | 37.0 | 72.9 | | | |
| Breast (incl. CIS) | C50, D05 | 70.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.8 | 5.0 | 19.4 | 47.3 | 90.8 | 144.8 | 137.0 | 125.5 | 132.3 | 117.4 | 107.6 | 109.3 | 101.4 | 80.0 | | | |
| Uterus (incl. CIS) | C53-C55, D06 | 37.1 | 0.0 | 0.0 | 0.0 | 0.2 | 7.0 | 18.7 | 51.6 | 60.2 | 58.8 | 54.8 | 48.4 | 61.9 | 47.5 | 40.0 | 46.5 | 48.0 | 45.4 | 47.4 | | | |
| Uterus (only invasive) | C53-C55 | 26.5 | 0.0 | 0.0 | 0.0 | 0.1 | 2.0 | 5.8 | 20.6 | 26.5 | 29.3 | 35.6 | 39.4 | 55.0 | 41.9 | 35.4 | 44.2 | 45.5 | 44.3 | 47.2 | | | |
| Cervix uteri | C53 | 13.3 | 0.0 | 0.0 | 0.0 | 0.1 | 1.9 | 5.0 | 16.5 | 21.2 | 22.3 | 21.0 | 15.0 | 18.9 | 16.4 | 15.7 | 17.3 | 19.5 | 22.4 | 24.0 | | | |
| Corpus uteri | C54 | 11.4 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.6 | 4.0 | 4.8 | 6.3 | 13.2 | 22.8 | 33.9 | 23.3 | 17.0 | 23.6 | 21.4 | 12.5 | 9.7 | | | |
| Ovary | C56 | 12.2 | 0.0 | 0.0 | 0.7 | 1.2 | 1.2 | 3.4 | 3.8 | 6.1 | 10.5 | 17.3 | 23.5 | 25.5 | 18.7 | 17.8 | 22.0 | 18.9 | 24.6 | 27.0 | | | |
| Bladder | C67 | 5.7 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.3 | 0.3 | 1.1 | 1.6 | 2.9 | 4.6 | 10.3 | 17.6 | 23.2 | 34.5 | 46.8 | | | |
| Kidney, renal pelvis, ureter etc. | C64-C66, C68 | 7.2 | 0.6 | 0.3 | 0.3 | 0.1 | 0.1 | 0.1 | 0.5 | 0.6 | 2.8 | 2.4 | 6.9 | 7.4 | 10.3 | 14.4 | 20.0 | 26.0 | 29.9 | 35.9 | | | |
| Brain and nervous system | C70-C72 | 3.1 | 1.9 | 0.9 | 0.9 | 0.6 | 0.2 | 0.6 | 2.2 | 1.0 | 1.2 | 1.4 | 1.6 | 3.4 | 5.5 | 5.7 | 6.3 | 7.3 | 11.4 | 14.8 | | | |
| Thyroid | C73 | 9.3 | 0.0 | 0.0 | 0.4 | 0.6 | 2.3 | 3.0 | 4.9 | 7.7 | 8.7 | 11.3 | 14.2 | 15.4 | 16.9 | 15.2 | 20.3 | 15.6 | 11.4 | 17.6 | | | |
| Malignant lymphoma | C81-C85, C96 | 13.2 | 0.7 | 1.1 | 0.4 | 1.3 | 2.1 | 1.9 | 2.4 | 2.7 | 5.6 | 7.1 | 11.8 | 13.7 | 18.9 | 23.6 | 42.5 | 44.0 | 48.9 | 50.2 | | | |
| Multiple myeloma | C88-C90 | 3.4 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.2 | 0.3 | 0.8 | 0.5 | 1.6 | 1.8 | 4.7 | 5.5 | 10.8 | 13.3 | 18.6 | 24.5 | | | |
| All leukaemias | C91-C95 | 6.0 | 4.0 | 3.4 | 1.1 | 2.0 | 2.1 | 1.0 | 2.2 | 2.3 | 2.5 | 3.7 | 5.8 | 6.9 | 7.5 | 10.6 | 14.0 | 16.8 | 19.1 | 20.7 | | | |

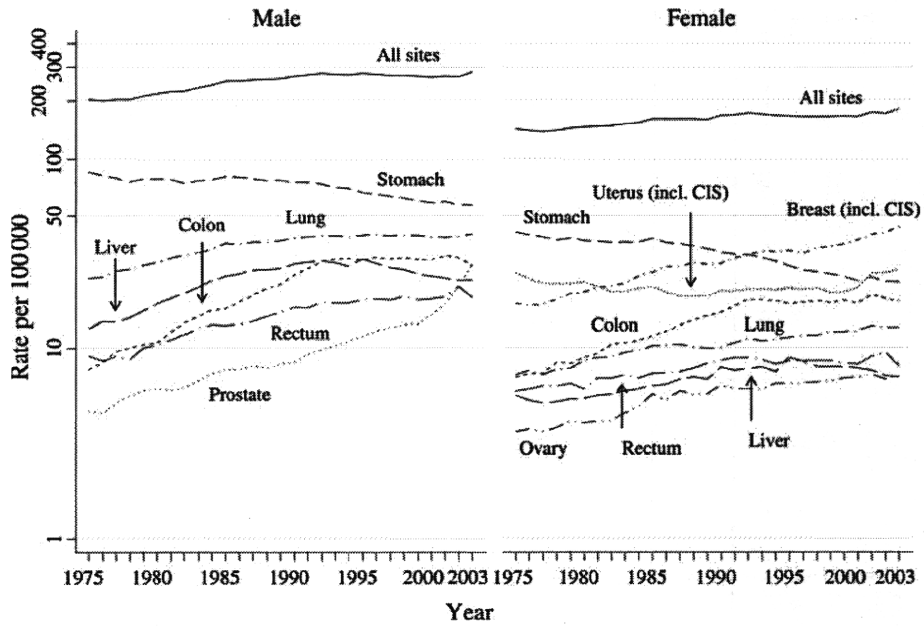


Figure 1. Trends of age-standardized cancer incidence rates for five major sites and specific sites for each sex (standard population: the world population). CIS, carcinoma *in situ*.

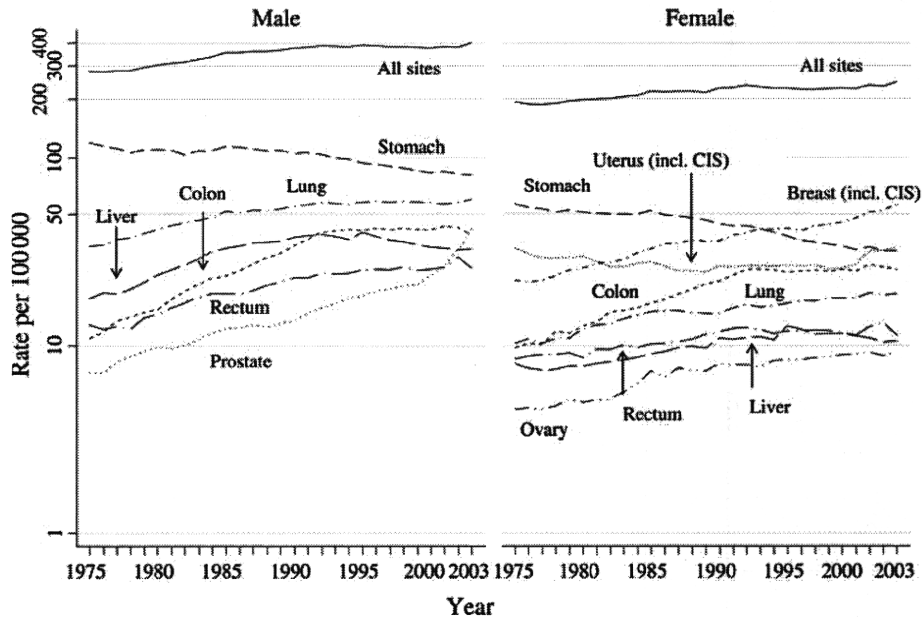


Figure 2. Trends of age-standardized cancer incidence rates for five major sites and specific sites for each sex (standard population: 1985 Japanese model population)

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Conflict of interest statement

None declared.

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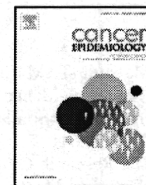
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Do the Japanese feel more suspicious about cancer registration than the British?

Tomohiro Matsuda*, Tomomi Marugame, Wakiko Ajiki, Tomotaka Sobue

Population-based Cancer Registry Section, Cancer Information Services and Surveillance Division, Center for Cancer Control and Information Services, National Cancer Center, 5-1-1 Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

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ABSTRACT

Background: Cancer registration is indispensable, providing useful statistical measures for the appropriate evaluation of cancer control programs and medical treatment or screening. **Methods:** Following the British national survey on attitudes toward cancer registration, we conducted an investigation to correctly evaluate the general opinion of the Japanese population in this regard. We randomly recruited 3000 men and women aged 20–69 years from a research database. **Results:** Only 4% of all respondents had heard about the cancer registry system before the investigation. However, 77% of respondents thought that cancer registration was useful. Forty-three percent of respondents answered, regardless of the strictness of the data protection, that privacy had been violated if the registration occurred without an individual explanation. Compared with the British survey results, Japanese people seemed to be more suspicious about the largely unknown system of cancer registry. Nonetheless, it is noteworthy that Japanese respondents did not show active opposition to cancer registration; they tended to choose “I don’t know” instead of “no” to questions asking if they supported the registry system. Multivariate analysis showed that male sex, older age, and living in the southern region were the factors significantly associated with support for cancer registration. **Conclusions:** We can seek society’s understanding toward cancer registration by actively utilizing information from cancer registries, by using examples of how data are actually used that have wide appeal, and by educating the public on how the data are treated under the complete privacy policy.

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1. Introduction

1.1. Cancer registration in Japan

Registration of cancer cases is indispensable. It provides useful statistical measures for the appropriate evaluation of cancer control programs and medical treatment or screening. The Japanese cancer registration system has been running for more than 50 years, with the first population-based cancer registry having been started in Miyagi prefecture in 1951 [1]. Although cancer registries were in place in 35 of the 47 prefectures as of June 2008 [2], Japan lags behind Europe and the USA in completeness and timeliness of the registry system. In the Cancer Incidence in Five Continents vol. IX, for example, only seven Japanese registries published data [3]. The following reasons for this delay have been postulated: (1) cancer is not a reportable disease in Japan, and therefore the government is not actively engaged in the registration system; (2) hospital medical information systems are still being developed, and treating doctors are excessively burdened with cancer-recording tasks; and (3) medical institutions and the

public do not sufficiently understand the cancer registry system. Moreover, collection of cancer incidence data from medical institutions is sometimes considered a violation of privacy, although submission of patient data to the cancer registry is exempt from the Private Information Protection Law [4].

1.2. Results of prior surveys on cancer registries in other countries and in Japan

The British national survey on cancer registration, organized by the research group of Dr. Coleman of the London School of Hygiene and Tropical Medicine, was published in 2006 [5]. The survey examined the public’s perception of the use of personal medical data by the national cancer registry. It concluded that the British people were supportive of cancer registration and were generous in supplying personal information used for the public interest, but only if this information was manipulated under strict conditions.

In Japan, the Cancer Control Act was approved in 2006 and the Basic Plan to Promote Cancer Control Program was implemented in 2007, and these policies recognize cancer registration as a central and important component for cancer control. Several surveys on attitude toward cancer registration have since been conducted in Japan. In the “Public opinion survey on cancer controls” organized by the Cabinet Office, 85.6% of the respondents “did not know about

* Corresponding author.

E-mail address: tomatsud@ncc.go.jp (T. Matsuda).

cancer registration" [6]. One question gave a simple explanation of the cancer registration system in Japan and in foreign countries, and asked how the respondents felt about a nationwide cancer registry. Only half of the respondents (54.6%) thought that such a system was necessary. In the "Public opinion poll on health and the aged society" conducted by the Mainichi Newspaper [7], the questionnaire asked: "A cancer registry system that registers the patient's name, date of birth, and medical information is enshrined in law in Europe and the United States. The data provide information about the extent and patterns of cancer and are used to evaluate treatment. What do you think of the cancer registry system?" Of those who responded, 18% answered, "it is necessary to enshrine the system in law because it is in our interests," and 62% answered, "cases should be registered only when patients give consent". Moreover, 15% answered "cancers should not have to be registered".

These survey results might suggest that Japanese people generally consider cancer registries to be unnecessary, and that this attitude is an obstacle to the development of cancer registration in Japan. However, the response rate of about 50% for these surveys indicates probable recruitment bias in that only people who are interested in cancer or in politics are likely to have answered. In addition since most people are unfamiliar with the topic of cancer registration, they are therefore obliged to answer the questions without sufficient information. The negative presentation of the question, such as "cancer registration is not included in the Cancer Control Act" and the answer choice that "priority should be put on protection of personal information, and cancer should be registered only if patients themselves agree" easily evoke anxiety, and could lead to the results lacking validity.

We therefore need to reinvestigate opinion regarding cancer registration, to resolve the above-mentioned problem and to correctly evaluate the general opinion of the Japanese population. Moreover, a different investigative perspective from that of journalists or administrative officers is needed. The present study aimed to: (1) increase the response rate to avoid recruitment bias, (2) add objective and sufficient explanation about "cancer registration" to the questions, and (3) use a validated, internationally comparable questionnaire in order to assess the Japanese situation objectively.

2. Methods

2.1. Recruitment and questionnaire

For participant recruitment we used the database of Nikkei Research Ltd., in which about 140,000 people are registered as research monitors. These monitors are paid to be engaged in various types of research according to the study objectives. Mindful of the importance of a high response rate, we decided to use this service. We stratified individuals by sex, age, and address according to the proportions of the most recent National Census. Finally 3000 men and women aged from 20 to 69 were recruited at random from the database according to these proportions.

We carefully translated the questionnaire that was used for the British survey so as not to change the intention of the original questions [5], and added two questions which were regarded as important in Japan (Q7 and Q8). Back translation of the Japanese version into English was performed by a professional translator. The research team verified that the two English versions maintained the same meaning for each question. The questionnaire was composed of 17 questions and was mailed to participants in December 2007.

2.2. Statistical methods

A confidence interval of 95% was calculated for each answer. Correlations between the answers and socio-demographic vari-

Table 1
Background of the respondents.

| | n | % |
|---|------|-------|
| Sex | | |
| Male | 1164 | 47.9 |
| Female | 1265 | 52.1 |
| Total | 2429 | 100.0 |
| Age (years) | | |
| 20–29 | 384 | 15.9 |
| 30–39 | 495 | 20.4 |
| 40–49 | 465 | 19.2 |
| 50–59 | 588 | 24.3 |
| 60–69 | 490 | 20.2 |
| Total | 2422 | 100.0 |
| Marital status | | |
| Spouse | 1807 | 74.4 |
| No spouse | 621 | 25.6 |
| Total | 2428 | 100.0 |
| Children | | |
| Yes | 1741 | 76.0 |
| No | 649 | 28.3 |
| Total | 2290 | 100.0 |
| Region | | |
| Hokkaido, Tohoku | 305 | 12.6 |
| Kanto | 832 | 34.3 |
| Chubu | 363 | 15.0 |
| Kinki | 415 | 17.1 |
| Chugoku, Shikoku | 238 | 9.8 |
| Kyushu, Okinawa | 274 | 11.3 |
| Total | 2427 | 100.0 |
| Occupation | | |
| Company employee/executive | 900 | 37.3 |
| Public officer | 143 | 5.9 |
| House husband/ wife | 452 | 18.7 |
| Self-employed | 153 | 6.3 |
| Freelance professional (MD, lawyer, etc.) | 45 | 1.9 |
| Part-time worker | 347 | 14.4 |
| Retired/unemployed | 250 | 10.4 |
| Others | 122 | 5.1 |
| Total | 2412 | 100.0 |
| Educational background | | |
| Junior high school | 92 | 3.8 |
| High school | 783 | 32.3 |
| College | 520 | 21.4 |
| University/graduate school | 1031 | 42.5 |
| Total | 2426 | 100.0 |
| Household income | | |
| ≤4 million yen | 567 | 23.8 |
| 4–8 million yen | 993 | 41.6 |
| >8 million yen | 826 | 34.6 |
| Total | 2386 | 100.0 |

ables were examined by chi-square test. Attitude towards cancer registration and privacy protection were enquired about in Q8, and respondents answered this question by means of a Likert-type scale (1–5). For this discrete variable, an ordered logit model was employed to test for a significant effect of respondents' background factors, while controlling for each variable. The ordered logit model predicts the probability of an event occurring, allowing for more than two ordered response categories in a dependent variable. The model makes the proportional odds assumption for being in a chosen category or higher compared to being in a lower category. In addition we obtained modeled cut-off points between ordered categories allowing us to interpret the respondents' preference for each answer.

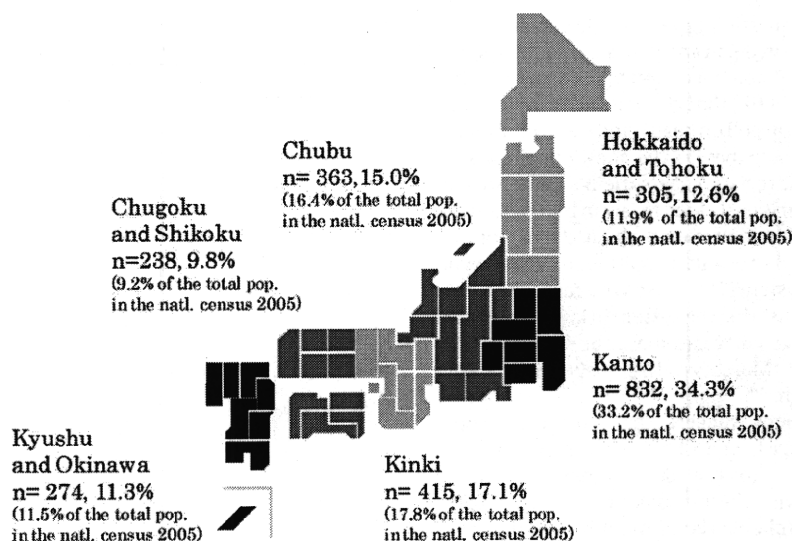


Fig. 1. Geographical distribution of the respondents.

3. Results

3.1. Respondents

A valid response was obtained from 2430 people, giving a response rate of 81.0%. Table 1 shows the socio-demographic background of respondents. When we analyzed attributes of those who responded to questions, male to female proportion was 47.9:52.1; 16% were in their 20 s, 20% were in their 30 s, 19% were in their 40 s, 24% were in their 50 s, and 20% were in their 60 s. Geographical distribution of the respondents is shown in Fig. 1. The distribution of the respondents was close to the population distribution according to the 2005 national census. No significant difference was found in participation in the study according to these socio-demographic variables.

3.2. British and Japanese results

Table 2 shows the results for each question for the present Japanese respondents and the original British respondents. A few of the Japanese respondents (9%) felt that their privacy was violated when they received invitations to cancer screening (Q1). Four percent of all respondents in Japan had heard about cancer registries before reading the questionnaire, whereas this proportion in the UK was 17% (Q2). However, among Japanese respondents, 77% thought the cancer registry system was useful, while 3% answered that it was not (Q3). On the other hand, 95% of British respondents considered the cancer registry system useful. Regarding support for a new law that required medical information of cancer patients to be registered (Q4), more than 30% of Japanese respondents answered "I don't know," although nearly 60% supported such a law. In contrast, 81% of British respondents supported such a law.

In Japan, 43% answered that, regardless of the strictness of data protection, privacy had been violated if the registration occurred without an individual explanation (Q5), while over 80% of the British respondents replied that privacy had not been violated in this situation. The largest difference in response between the two countries was seen for this question. The proportion of Japanese respondents who believed privacy had been violated when individuals were contacted for research participation based on the cancer registry list decreased to 24% (Q6).

In Q7, an original question in the present study, 57% of respondents stated that residents of prefectures that had a registry system would be at an unfair advantage if this system was not available elsewhere (Table 3). For Q8, which asked about the balance between the violation of privacy and the usefulness of cancer registration, the mode of responses was 4. Answers were slightly skewed toward recognition of the system's usefulness.

3.3. Relationship between responses and socio-economic background

An overview of the relationship between responses and socio-economic background of the subjects is presented in Table 4. Because we conducted univariate analysis, all variables on socio-economic background were related to the question answers.

When compared with women, male respondents were more likely to believe that cancer registration provides useful information. Men were also more likely to support a new law to enforce cancer registration, and they were less likely to report invasion of privacy in Q5 and 6. Moreover, the number of respondents who felt that provision of information to a cancer registry constituted a violation of privacy decreased with age in both sexes (Fig. 2).

In Q5, a geographical difference was seen when respondents were divided into six regions. In the Kanto region, which includes the capital, Tokyo, 37.9% of respondents did not feel that their privacy was violated by provision of information to a cancer registry. The variation according to geographical region was remarkable; this proportion was 49.6% in the Kyushu and Okinawa area, in the south of Japan.

As for profession of the respondents, 85.3% of public officers answered "yes" in Q3, and this proportion was the highest. In contrast, home makers and part-time workers were less likely to answer "yes" (73.9% and 70.0%, respectively). Self-employed people and the unemployed/retired were most supportive of the cancer registration: 67.3% and 64.4%, respectively, answered "yes" to Q4. These groups were also less likely to report violation of privacy in response to Q5 (36.0% and 28.8%, respectively). Freelance professionals (doctors, lawyers, etc.) were significantly more aware of the cancer registry system; 15.6% answered that they had heard of it. At the same time, 51.1% of this group thought that registration without individual explanation violated their privacy (Q5). Respondents with higher levels of education (university/graduate school) tended to have positive opinions about cancer registration in Q5 and 6.

Table 2
Results of the surveys in Japan and the UK.

| | Yes | | | No | | | Don't know | | |
|---|------|-----|--------|------|-----|--------|------------|----|--------|
| | n | % | 95% CI | n | % | 95% CI | n | % | 95% CI |
| Q1. Many people get letters from their primary care trust (previously called the health authority) about screening tests for cancer, such as cervical smear tests or bowel cancer screening. If your primary care trust sent you a letter inviting you to a screening test, do you think this would be an invasion of your privacy? (corresponding to Q3 in the UK study) | | | | | | | | | |
| Japan | 209 | 9 | 7–10 | 2037 | 84 | 82–85 | 179 | 7 | 6–8 |
| UK | 93 | 3 | 2–4 | 2740 | 95 | 94–97 | 39 | 1 | 1–2 |
| JP-UK | | 6 | | | -11 | | | 6 | |
| Q2. In Japan we have regional cancer registries, which are confidential databases of people who have cancer. Information is held under strict security. Have you ever heard of a cancer registry before? (corresponding to Q4 in the UK study) | | | | | | | | | |
| Japan | 103 | 4 | 3–5 | 2254 | 93 | 92–94 | 72 | 3 | 2–4 |
| UK | 479 | 17 | 15–18 | 2362 | 82 | 81–84 | 32 | 1 | 1–2 |
| JP-UK | | -13 | | | 11 | | | 2 | |
| Q3. The cancer registry is the only reliable source of information for monitoring trends in the risk of getting cancer and trends in cancer survival. The information is used to compare the effectiveness of cancer treatment around the country, and to evaluate the success of cancer screening programs. Do you think this is useful information for us to have in this country? (corresponding to Q5 in the UK study) | | | | | | | | | |
| Japan | 1863 | 77 | 75–78 | 75 | 3 | 2–4 | 491 | 20 | 19–22 |
| UK | 2737 | 95 | 94–96 | 68 | 2 | 2–3 | 69 | 2 | 2–3 |
| JP-UK | | -18 | | | 1 | | | 18 | |
| Q4. In the USA, Denmark, Sweden, South Korea, and many other countries, all cases of cancer have to be notified to the cancer registry by law. In the future, there may need to be a similar law in Japan, to ensure that the cancer registries continue to have the information needed for monitoring cancer in Japan. Would you support a new law that meant all cases of cancer have to be notified to the cancer registries? (corresponding to Q6 in the UK study) | | | | | | | | | |
| Japan | 1423 | 59 | 57–61 | 258 | 11 | 9–12 | 748 | 31 | 29–33 |
| UK | 2335 | 81 | 79–83 | 343 | 12 | 10–13 | 194 | 7 | 6–8 |
| JP-UK | | -22 | | | -1 | | | 24 | |
| Q5. Currently, survival rates from cancer can only be compared between regions of the country by knowing cancer patients' names and addresses. If you had cancer and your name and address was included automatically in the cancer registries, to be held confidentially and under strict security, do you think this would be an invasion of your privacy? (corresponding to Q8 in the UK study) | | | | | | | | | |
| Japan | 1033 | 43 | 41–44 | 1029 | 42 | 40–44 | 366 | 15 | 14–17 |
| UK | 446 | 16 | 14–17 | 2326 | 81 | 79–83 | 101 | 4 | 3–4 |
| JP-UK | | 27 | | | -39 | | | 11 | |
| Q6. Finally, suppose that a research group from a university medical school wanted to do research with people who had a particular type of cancer. If you had cancer and the cancer registries sent you a letter, via your doctor, asking if you wanted to take part in the research, do you think this would be an invasion of your privacy? (corresponding to Q9 in the UK study) | | | | | | | | | |
| Japan | 594 | 24 | 23–26 | 1486 | 61 | 59–63 | 348 | 14 | 13–16 |
| UK | 261 | 9 | 8–10 | 2508 | 87 | 86–89 | 104 | 4 | 3–5 |
| JP-UK | | 15 | | | -26 | | | 10 | |
| Q16. Have any members of your immediate family (for instance, parents, children, husband/wife/partner, brothers, sisters) ever had cancer? (corresponding to Q2 in the UK study) | | | | | | | | | |
| Japan | 1056 | 44 | 42–45 | 1340 | 55 | 53–57 | 24 | 1 | 1–1 |
| UK | 1298 | 45 | 43–47 | 1528 | 53 | 51–56 | 50 | 2 | 1–2 |
| JP-UK | | -1 | | | 2 | | | -1 | |
| Q17. Could I please start by asking if you have, or you have ever had, cancer? (corresponding to Q1 in the UK study) | | | | | | | | | |
| Japan | 96 | 4 | 3–5 | 2274 | 94 | 93–95 | 49 | 2 | 1–3 |
| UK | 174 | 6 | 5–7 | 2701 | 94 | 93–95 | - | - | - |
| JP-UK | | -2 | | | 0 | | | - | |

Cancer experience, either of the individual or their family, was related to awareness of the cancer registry system (6.0% for “without experience” and 8.3% for “with an experience”, respectively). Cancer experience also seemed to be related to a positive

opinion of cancer registration in Q5 and 6; however, this correlation disappeared when age was adjusted for.

In Q8, we performed ordered logit modeling in order to calculate the adjusted odds ratio (OR) of the respondents'

Table 3
Results for Q7 and Q8 (original questions in the Japanese questionnaire).

| | Yes | | | No | | | | | | Don't know | | |
|--|------|----|--------|-----|-----|--------|-----|----|-----|------------|--------|--|
| | n | % | 95% CI | n | % | 95% CI | | | n | % | 95% CI | |
| Q7. Suppose that there is no cancer registry in your region which is monitoring trends in the risk of getting cancer and trends in cancer survival. Do you feel that other regions have an unfair advantage by using their cancer registry information for evaluation of regional cancer screening and treatment, or for cancer control? | | | | | | | | | | | | |
| | 1393 | 57 | 55–59 | 631 | 26 | 24–28 | | | 401 | 17 | 16–18 | |
| I think this is an invasion of our privacy | | | | | | | | | | | | |
| | 1 | | | 2 | | | 3 | | 4 | | 5 | |
| | n | % | n | % | n | % | n | % | n | % | | |
| Q8. Cancer registries are reliable information sources for cancer control, as they allow us to compare the outcomes of treatment and to evaluate anti-cancer programs by providing cancer patients' names and addresses. What would you think if this were done without the individual consent of the patients? Please circle the number that best represents your opinion. | | | | | | | | | | | | |
| | 314 | 13 | 542 | 22 | 545 | 22 | 658 | 27 | 362 | 15 | | |