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Epidemiology Note

Cancer Incidence and Incidence Rates in Japan in 2004: Based on Data from 14 Population-based Cancer Registries in the Monitoring of Cancer Incidence in Japan (MCIJ) Project

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The Japan Cancer Surveillance Research Group estimated the cancer incidence in 2004 as part of the Monitoring of Cancer Incidence in Japan (MCIJ) project, on the basis of data collected from 14 of 31 population-based cancer registries. The total number of incidences in Japan for 2004 was estimated as 623 275 (C00–C96). The leading cancer site according to the crude and age-standardized incidence rates was the stomach for men and breast for women. The apparent increase in age-standardized incidence rates in 2003 was calmed down in 2004.

Key words: cancer incidence – incidence estimates – cancer registry – Japan

The Japan Cancer Surveillance Research Group is involved in cancer monitoring in Japan since 2000 (1–4). This group estimated the cancer incidence in 2004 as part of the Monitoring of Cancer Incidence in Japan (MCIJ) project, on the basis of data collected from 14 of 31 population-based cancer registries: Miyagi, Yamagata, Chiba, Kanagawa, Niigata, Fukui, Shiga, Osaka, Tottori, Okayama, Hiroshima, Saga, Kumamoto 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 (5–7). As is mentioned in the last article, there were two major methodological changes in the MCIJ2003, and we maintained these changes in the present study: (i) we invited all 31 population-based cancer registries in Japan to participate, and from these, we selected the 14 cancer registries with high-quality data in order to estimate the national incidence, and (ii) we used 2004 data alone for the national estimation. For this year, Kumamoto 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.

The number of incidences, crude rates, age-standardized rates and completeness of registration in 2004 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 2004 was estimated as 623 275 (C00–C96). The time trends of age-standardized incidence rates for the five major sites and male- and female-specific sites in 1975–2004 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 the breast for women, as shown in Figs 1 and 2. The apparent increase in age-standardized incidence rates in 2003 because of development of hospital-based cancer registry in designated cancer care hospitals was calmed down in 2004. The estimated cancer incidence data in Japan by sex, site, 5-year age group and calendar year during the period 1975–2004 are available as a booklet and as an electronic database on the website (only available in Japanese, http://ganjoho.jp/professional/statistics/monita.html).

Table 1. Incidence, completeness of reporting and accuracy of diagnosis in Japan according to sex and primary site, 2004

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	372 913	598.6	282.3	400.4	17.1	1.93	73.8
All sites	C00–C96	362 149	581.3	273.9	388.6	17.6	1.88	73.2
Lip, oral cavity and pharynx	C00–C14	7136	11.5	6.0	8.1	14.1	1.77	79.7
Esophagus	C15	15 215	24.4	11.8	16.4	15.4	1.62	78.8
Stomach	C16	73 950	118.7	56.4	79.6	14.1	2.25	82.1
Colon	C18	35 657	57.2	26.7	38.1	12.4	2.68	82.4
Rectum	C19–C20	20 954	33.6	16.7	23.1	10.9	2.46	83.8
Liver	C22	28 172	45.2	21.5	30.2	25.6	1.20	33.7
Gallbladder etc.	C23–C24	9234	14.8	6.3	9.4	27.7	1.24	48.3
Pancreas	C25	13 128	21.1	9.6	13.9	31.3	1.10	33.8
Larynx	C32	3210	5.2	2.5	3.4	9.4	3.33	86.2
Trachea, bronchus and lung	C33–C34	55 984	89.9	38.9	58.1	24.3	1.27	70.2
Melanoma of skin etc.	C43–C44	4298	6.9	3.2	4.6	6.2	7.61	92.7
Prostate	C61	39 321	63.1	26.6	39.7	10.9	4.45	83.6
Bladder	C67	12 012	19.3	8.6	12.6	10.9	3.15	83.5
Kidney, renal pelvis, ureter etc.	C64–C66, C68	9358	15.0	7.5	10.5	15.4	2.43	76.1
Brain and nervous system	C70–C72	2352	3.8	2.6	3.1	29.4	2.58	63.4
Thyroid	C73	1933	3.1	1.8	2.4	8.3	4.53	86.9
Malignant lymphoma	C81–C85, C96	9436	15.1	8.0	10.8	17.4	1.96	82.0
Multiple myeloma	C88, C90	2723	4.4	1.9	2.8	29.4	1.37	64.9
All leukemias	C91–C95	5282	8.5	5.3	6.5	25.3	1.28	85.6
Female								
All sites (incl. CIS)	C00–C96, D00–D09	275 578	421.4	198.7	266.2	17.1	2.17	73.6
All site	C00–C96	261 126	399.3	183.5	247.2	18.0	2.05	72.4
Lip, oral cavity and pharynx	C00–C14	2980	4.6	2.1	2.8	14.7	1.94	78.1
Esophagus	C15	2600	4.0	1.6	2.2	22.4	1.47	70.2

Continued

Table 1. *Continued*

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 (%)
Stomach	C16	35 822	54.8	21.5	30.2	17.8	2.02	78.2
Colon	C18	29 070	44.5	16.9	23.8	16.6	2.21	76.5
Rectum	C19–C20	11 585	17.7	7.7	10.5	14.4	2.30	80.6
Liver	C22	13 343	20.4	7.1	10.3	30.4	1.20	29.7
Gallbladder etc.	C23–C24	10 457	16.0	4.7	7.0	33.3	1.18	40.2
Pancreas	C25	11 314	17.3	5.7	8.4	33.8	1.10	30.3
Larynx	C32	224	0.3	0.1	0.2	13.4	2.87	71.6
Trachea, bronchus and lung	C33–C34	24 122	36.9	13.7	19.5	25.3	1.51	67.3
Melanoma of skin etc.	C43–C44	4326	6.6	2.2	3.2	8.5	7.55	90.7
Breast (incl. CIS)	C50, D05	50 549	77.3	48.1	62.0	5.4	4.80	91.1
Uterus (incl. CIS)	C53–C55, D06	24 422	37.3	26.0	32.6	7.2	4.42	89.7
Uterus (only invasive)	C53–C55	17 603	26.9	16.6	21.4	9.5	3.19	86.9
Cervix uteri	C53	9252	14.1	9.5	12.2	6.8	3.71	89.6
Corpus uteri	C54	7253	11.1	6.5	8.4	5.2	5.05	91.8
Ovary	C56	8655	13.2	8.1	10.3	13.5	1.96	79.3
Bladder	C67	4039	6.2	2.0	2.9	16.9	2.32	74.7
Kidney, renal pelvis, ureter etc.	C64–C66, C68	4374	6.7	2.8	3.8	19.5	2.11	70.2
Brain and nervous system	C70–C72	2220	3.4	2.1	2.4	29.5	3.23	56.5
Thyroid	C73	7062	10.8	6.8	8.5	6.6	7.03	87.7
Malignant lymphoma	C81–C85, C96	8063	12.3	5.8	7.6	17.2	2.22	80.4
Multiple myeloma	C88, C90	2247	3.4	1.2	1.7	31.8	1.17	62.5
All leukemias	C91–C95	3726	5.7	3.3	3.9	25.7	1.28	85.0

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*.

[a] Per 100 000 population.

Table 2. Age-specific incidence in Japan according to sex and primary site, 2004

Primary sites	ICD-10	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	372 913	388	171	210	282	535	1073	1727	2567	3891	8273	18 354	31 956	44 998	57 595	70 712	64 723	36 908	28 550
All sites	C00–C96	362 149	388	171	210	271	527	1056	1674	2438	3752	7980	17 771	30 896	43 301	55 799	68 663	63 034	36 053	28 165
Lip, oral cavity and pharynx	C00–C14	7136	0	0	0	16	15	33	63	58	124	290	602	812	1174	1176	1211	745	460	357
Esophagus	C15	15 215	0	0	0	0	0	1	5	8	65	328	863	1789	2633	2856	2744	2123	1198	602
Stomach	C16	73 950	0	0	5	6	10	154	243	369	739	2004	4117	7271	9433	11 844	14 072	12 063	6418	5202
Colon	C18	35 657	0	0	11	5	25	66	90	260	444	643	1762	2987	4635	5565	6765	6133	3462	2804
Rectum	C19–C20	20 954	0	0	0	0	1	31	61	235	305	558	1480	2740	3137	3508	3543	2808	1388	1159
Liver	C22	28 172	14	5	0	0	1	5	52	150	195	598	1450	2843	3811	5205	6061	4464	1952	1366
Gallbladder etc.	C23–C24	9234	0	0	4	0	0	3	28	39	32	122	292	446	733	1279	1668	1736	1447	1405
Pancreas	C25	13 128	0	1	0	0	0	9	16	31	133	274	765	1129	1555	1845	2340	2276	1535	1219
Larynx	C32	3210	0	0	0	0	0	0	0	8	11	80	166	348	548	555	630	474	228	162
Trachea, bronchus and lung	C33–C34	55 984	0	0	0	6	29	22	77	139	383	857	1952	3779	5646	7304	11 128	12 366	7287	5009
Melanoma of skin etc.	C43–C44	4298	10	0	0	7	20	35	33	51	77	108	179	270	336	520	739	820	522	571
Prostate	C61	39 321	0	0	0	0	0	0	0	21	19	96	549	1533	3952	7200	9284	8525	4534	3608
Bladder	C67	12 012	0	0	1	3	2	20	25	48	97	255	628	884	1171	1341	2224	2293	1668	1352
Kidney, renal pelvis, ureter etc.	C64–C66, C68	9358	20	2	0	0	22	21	53	82	151	442	715	1044	1039	1298	1736	1400	794	539
Brain and nervous system	C70–C72	2352	64	45	44	30	45	67	46	137	144	79	168	186	181	262	320	264	132	138
Thyroid	C73	1933	0	1	4	10	23	36	92	59	102	110	199	233	172	320	189	232	97	54
Malignant lymphoma	C81–C85, C96	9436	22	32	56	49	114	135	96	139	206	335	660	887	902	1296	1361	1392	1010	744
Multiple myeloma	C88, C90	2723	0	0	0	1	0	0	2	17	30	20	119	190	305	348	531	547	324	289
All leukemias	C91–C95	5282	127	71	41	53	67	131	119	165	187	140	334	504	562	611	611	775	462	322
Female																				
All sites (incl. CIS)	C00–C96, D00–D09	275 578	269	147	185	363	741	2395	4846	7321	10 069	13 866	20 044	24 791	27 244	29 778	34 370	34 462	29 140	35 547
All site	C00–C96	261 126	269	147	185	349	493	1514	3227	5874	8633	12 798	19 073	23 745	26 090	28 541	33 221	33 528	28 422	35 017

Continued

Table 2. *Continued*

Primary sites	ICD-10	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	2980	0	8	0	4	18	57	42	47	80	127	172	269	314	272	450	438	294	388
Esophagus	C15	2600	0	0	0	0	0	12	10	8	9	40	167	261	336	341	375	299	320	422
Stomach	C16	35 822	0	0	1	0	52	40	204	411	568	1161	1940	2747	3156	4000	5368	5409	4764	6001
Colon	C18	29 070	0	0	0	5	15	28	124	216	310	591	1507	2040	3161	3338	4365	4558	3966	4846
Rectum	C19–C20	11 585	0	0	0	0	4	10	75	206	194	483	813	1003	1363	1565	1602	1491	1273	1503
Liver	C22	13 343	14	1	0	3	0	4	30	10	45	80	353	624	1049	2066	2710	2558	1924	1872
Gallbladder etc.	C23–C24	10 457	0	0	0	0	0	0	6	15	31	87	247	380	625	967	1286	1796	2070	2947
Pancreas	C25	11 314	0	0	0	0	0	1	12	30	83	131	310	617	804	1350	1725	1936	1990	2325
Larynx	C32	224	0	0	0	0	0	0	0	0	1	0	5	22	21	17	53	55	28	22
Trachea, bronchus and lung	C33–C34	24 122	0	0	1	1	6	27	50	92	300	499	1080	1779	2288	2912	3811	3902	3156	4218
Melanoma of skin etc.	C43–C44	4326	0	2	2	4	7	31	55	55	30	61	126	215	307	340	535	673	659	1224
Breast (incl. CIS)	C50, D05	50 549	1	0	1	0	19	253	1039	2397	4204	6181	6635	6965	6556	5073	4060	3338	2104	1723
Uterus (incl. CIS)	C53–C55, D06	24 422	0	0	2	23	251	1168	2430	2605	2465	1909	2752	2636	1973	1737	1355	1256	788	1072
Uterus (only invasive)	C53–C55	17 603	0	0	2	12	32	334	900	1334	1433	1269	2397	2319	1738	1531	1267	1196	773	1066
Cervix uteri	C53	9252	0	0	0	8	27	297	759	1139	1094	673	994	878	753	645	528	592	385	480
Corpus uteri	C54	7253	0	0	2	4	5	37	134	172	321	560	1323	1371	927	827	657	478	209	226
Ovary	C56	8655	1	1	28	53	91	199	150	404	519	792	1202	1202	917	773	734	697	446	446
Bladder	C67	4039	0	0	0	1	4	0	0	30	22	72	101	248	298	366	628	579	683	1007
Kidney, renal pelvis, ureter etc.	C64–C66, C68	4374	25	6	3	4	2	5	35	29	71	141	244	303	445	508	676	701	560	616
Brain and nervous system	C70–C72	2220	43	22	58	58	11	57	48	68	67	76	180	177	122	265	231	307	197	233
Thyroid	C73	7062	0	0	8	43	130	191	297	327	402	562	761	1155	762	815	602	459	277	271
Malignant lymphoma	C81–C85, C96	8063	8	30	21	40	29	117	101	107	247	292	540	720	889	930	1042	1020	929	1001
Multiple myeloma	C88, C90	2247	0	0	0	0	0	0	3	6	10	19	60	183	163	235	375	522	346	325
All leukemias	C91–C95	3726	91	34	36	74	35	83	60	113	104	162	163	251	364	456	367	515	385	433

Table 3. Age-specific incidence rate per 100 000 population in Japan according to sex and primary site, 2004

Primary sites	ICD-10	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	598.6	13.2	5.6	6.8	8.1	13.5	24.1	34.8	58.9	97.9	210.2	396.2	671.1	1073.2	1653.1	2396.2	2985.4	3266.2	3693.4
All sites	C00–C96	581.3	13.2	5.6	6.8	7.8	13.3	23.7	33.8	55.9	94.4	202.7	383.6	648.8	1032.7	1601.6	2326.8	2907.5	3190.5	3643.6
Lip, oral cavity and pharynx	C00–C14	11.5	0.0	0.0	0.0	0.5	0.4	0.7	1.3	1.3	3.1	7.4	13.0	17.1	28.0	33.8	41.0	34.4	40.7	46.2
Esophagus	C15	24.4	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.2	1.6	8.3	18.6	37.6	62.8	82.0	93.0	97.9	106.0	77.9
Stomach	C16	118.7	0.0	0.0	0.2	0.2	0.3	3.5	4.9	8.5	18.6	50.9	88.9	152.7	225.0	340.0	476.9	556.4	568.0	673.0
Colon	C18	57.2	0.0	0.0	0.4	0.1	0.6	1.5	1.8	6.0	11.2	16.3	38.0	62.7	110.5	159.7	229.2	282.9	306.4	362.7
Rectum	C19–C20	33.6	0.0	0.0	0.0	0.0	0.0	0.7	1.2	5.4	7.7	14.2	31.9	57.5	74.8	100.7	120.1	129.5	122.8	149.9
Liver	C22	45.2	0.5	0.2	0.0	0.0	0.0	0.1	1.0	3.4	4.9	15.2	31.3	59.7	90.9	149.4	205.4	205.9	172.7	176.7
Gallbladder etc.	C23–C24	14.8	0.0	0.0	0.1	0.0	0.0	0.1	0.6	0.9	0.8	3.1	6.3	9.4	17.5	36.7	56.5	80.1	128.1	181.8
Pancreas	C25	21.1	0.0	0.0	0.0	0.0	0.0	0.2	0.3	0.7	3.3	7.0	16.5	23.7	37.1	53.0	79.3	105.0	135.8	157.7
Larynx	C32	5.2	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.2	0.3	2.0	3.6	7.3	13.1	15.9	21.3	21.9	20.2	21.0
Trachea, bronchus and lung	C33–C34	89.9	0.0	0.0	0.0	0.2	0.7	0.5	1.6	3.2	9.6	21.8	42.1	79.4	134.7	209.6	377.1	570.4	644.9	648.0
Melanoma of skin etc.	C43–C44	6.9	0.3	0.0	0.0	0.2	0.5	0.8	0.7	1.2	1.9	2.7	3.9	5.7	8.0	14.9	25.0	37.8	46.2	73.9
Prostate	C61	63.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.5	0.5	2.4	11.8	32.2	94.3	206.7	314.6	393.2	401.2	466.8
Bladder	C67	19.3	0.0	0.0	0.0	0.1	0.1	0.4	0.5	1.1	2.4	6.5	13.6	18.6	27.9	38.5	75.4	105.8	147.6	174.9
Kidney, renal pelvis, ureter etc.	C64–C66, C68	15.0	0.7	0.1	0.0	0.0	0.6	0.5	1.1	1.9	3.8	11.2	15.4	21.9	24.8	37.3	58.8	64.6	70.3	69.7
Brain and nervous system	C70–C72	3.8	2.2	1.5	1.4	0.9	1.1	1.5	0.9	3.1	3.6	2.0	3.6	3.9	4.3	7.5	10.8	12.2	11.7	17.9
Thyroid	C73	3.1	0.0	0.0	0.1	0.3	0.6	0.8	1.9	1.4	2.6	2.8	4.3	4.9	4.1	9.2	6.4	10.7	8.6	7.0
Malignant lymphoma	C81–C85, C96	15.1	0.7	1.1	1.8	1.4	2.9	3.0	1.9	3.2	5.2	8.5	14.2	18.6	21.5	37.2	46.1	64.2	89.4	96.2
Multiple myeloma	C88 C90	4.4	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.4	0.8	0.5	2.6	4.0	7.3	10.0	18.0	25.2	28.7	37.4
All leukemias	C91–C95	8.5	4.3	2.3	1.3	1.5	1.7	2.9	2.4	3.8	4.7	3.6	7.2	10.6	13.4	17.5	20.7	35.7	40.9	41.7
Female																				
All sites (incl. CIS)	C00–C96, D00–D09	421.4	9.6	5.1	6.3	11.0	19.7	55.8	99.7	170.1	256.0	353.9	429.5	508.2	611.0	771.7	977.8	1176.2	1384.3	1811.8
All site	C00–C96	399.3	9.6	5.1	6.3	10.6	13.1	35.3	66.4	136.5	219.5	326.6	408.7	486.8	585.1	739.6	945.1	1144.3	1350.2	1784.8

Continued

Table 3. *Continued*

Primary sites	ICD-10	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	4.6	0.0	0.3	0.0	0.1	0.5	1.3	0.9	1.1	2.0	3.2	3.7	5.5	7.0	7.0	12.8	14.9	14.0	19.8
Esophagus	C15	4.0	0.0	0.0	0.0	0.0	0.0	0.3	0.2	0.2	0.2	1.0	3.6	5.4	7.5	8.8	10.7	10.2	15.2	21.5
Stomach	C16	54.8	0.0	0.0	0.0	0.0	1.4	0.9	4.2	9.6	14.4	29.6	41.6	56.3	70.8	103.7	152.7	184.6	226.3	305.9
Colon	C18	44.5	0.0	0.0	0.0	0.2	0.4	0.7	2.6	5.0	7.9	15.1	32.3	41.8	70.9	86.5	124.2	155.6	188.4	247.0
Rectum	C19–C20	17.7	0.0	0.0	0.0	0.0	0.1	0.2	1.5	4.8	4.9	12.3	17.4	20.6	30.6	40.6	45.6	50.9	60.5	76.6
Liver	C22	20.4	0.5	0.0	0.0	0.1	0.0	0.1	0.6	0.2	1.1	2.0	7.6	12.8	23.5	53.5	77.1	87.3	91.4	95.4
Gallbladder etc.	C23–C24	16.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.3	0.8	2.2	5.3	7.8	14.0	25.1	36.6	61.3	98.3	150.2
Pancreas	C25	17.3	0.0	0.0	0.0	0.0	0.0	0.0	0.2	0.7	2.1	3.3	6.6	12.6	18.0	35.0	49.1	66.1	94.5	118.5
Larynx	C32	0.3	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.5	0.5	0.4	1.5	1.9	1.3	1.1
Trachea, bronchus and lung	C33–C34	36.9	0.0	0.0	0.0	0.0	0.2	0.6	1.0	2.1	7.6	12.7	23.1	36.5	51.3	75.5	108.4	133.2	149.9	215.0
Melanoma of skin etc.	C43–C44	6.6	0.0	0.1	0.1	0.1	0.2	0.7	1.1	1.3	0.8	1.6	2.7	4.4	6.9	8.8	15.2	23.0	31.3	62.4
Breast (incl. CIS)	C50, D05	77.3	0.0	0.0	0.0	0.0	0.5	5.9	21.4	55.7	106.9	157.8	142.2	142.8	147.0	131.5	115.5	113.9	100.0	87.8
Uterus (incl. CIS)	C53–C55, D06	37.3	0.0	0.0	0.1	0.7	6.7	27.2	50.0	60.5	62.7	48.7	59.0	54.0	44.2	45.0	38.5	42.9	37.4	54.6
Uterus (only invasive)	C53–C55	26.9	0.0	0.0	0.1	0.4	0.8	7.8	18.5	31.0	36.4	32.4	51.4	47.5	39.0	39.7	36.0	40.8	36.7	54.3
Cervix uteri	C53	14.1	0.0	0.0	0.0	0.2	0.7	6.9	15.6	26.5	27.8	17.2	21.3	18.0	16.9	16.7	15.0	20.2	18.3	24.5
Corpus uteri	C54	11.1	0.0	0.0	0.1	0.1	0.1	0.9	2.8	4.0	8.2	14.3	28.3	28.1	20.8	21.4	18.7	16.3	9.9	11.5
Ovary	C56	13.2	0.0	0.0	0.9	1.6	2.4	4.6	3.1	9.4	13.2	20.2	25.8	24.6	20.6	20.0	20.9	23.8	21.2	22.7
Bladder	C67	6.2	0.0	0.0	0.0	0.0	0.1	0.0	0.0	0.7	0.6	1.8	2.2	5.1	6.7	9.5	17.9	19.8	32.4	51.3
Kidney, renal pelvis, ureter etc.	C64–C66, C68	6.7	0.9	0.2	0.1	0.1	0.1	0.1	0.7	0.7	1.8	3.6	5.2	6.2	10.0	13.2	19.2	23.9	26.6	31.4
Brain and nervous system	C70–C72	3.4	1.5	0.8	2.0	1.8	0.3	1.3	1.0	1.6	1.7	1.9	3.9	3.6	2.7	6.9	6.6	10.5	9.4	11.9
Thyroid	C73	10.8	0.0	0.0	0.3	1.3	3.4	4.4	6.1	7.6	10.2	14.3	16.3	23.7	17.1	21.1	17.1	15.7	13.2	13.8
Malignant lymphoma	C81–C85, C96	12.3	0.3	1.0	0.7	1.2	0.8	2.7	2.1	2.5	6.3	7.5	11.6	14.8	19.9	24.1	29.6	34.8	44.1	51.0
Multiple myeloma	C88 C90	3.4	0.0	0.0	0.0	0.0	0.0	0.0	0.1	0.1	0.3	0.5	1.3	3.8	3.7	6.1	10.7	17.8	16.4	16.6
All leukemias	C91–C95	5.7	3.3	1.2	1.2	2.2	0.9	1.9	1.2	2.6	2.6	4.1	3.5	5.1	8.2	11.8	10.4	17.6	18.3	22.1

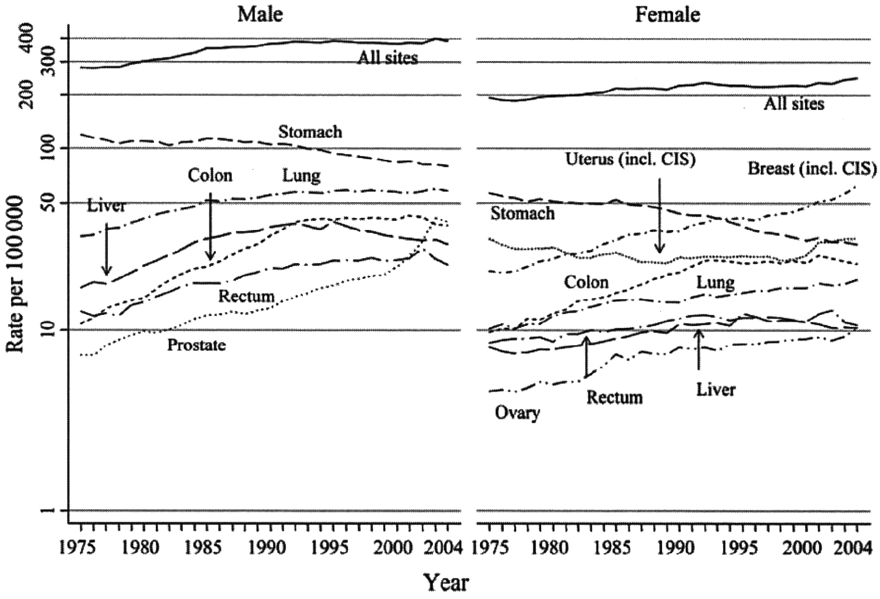

Figure 1. Trends of age-standardized cancer incidence rates for five major sites and specific sites for each sex (standard population: world population). CIS, carcinoma *in situ*.

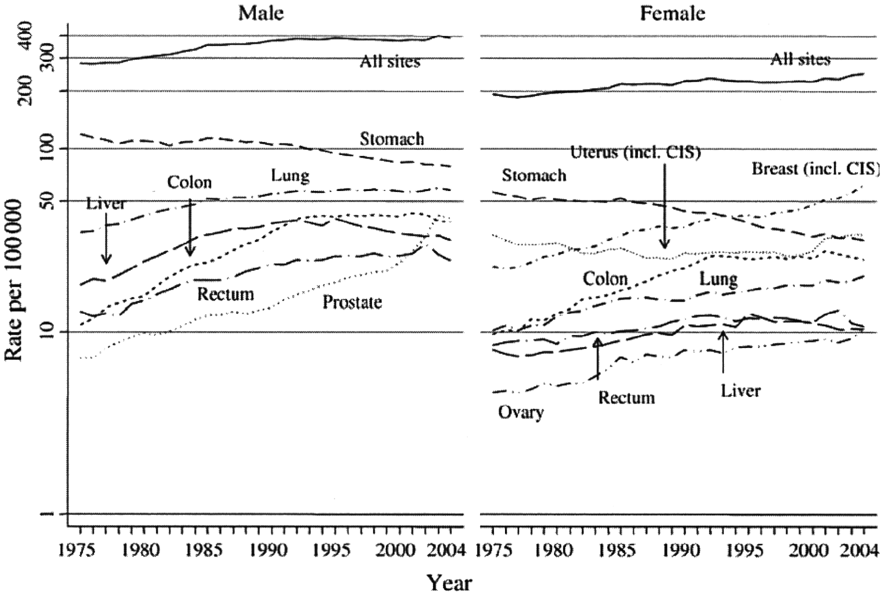

Figure 2. Trends of age-standardized cancer incidence rates for five major sites and specific sites for each sex (standard population: 1985 Japanese model population).

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Conflict of interest statement

None declared.

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

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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.

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

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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 variables 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.

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

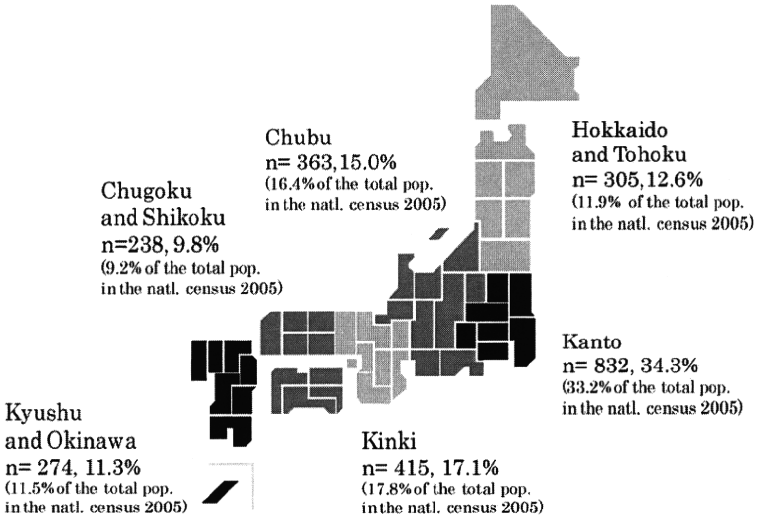


Fig. 1. Geographical distribution of the respondents.

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		I think this is useful information for us to have in this country
	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	

Table 4
Overview of relationship between responses and socio-economic background (%).

	Q2			Q3			Q4			Q5			Q6			Q7		
	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know
Sex																		
Male	4.3	93.0	2.8	80.3	3.3	16.4	62.1	12.7	25.2	40.2	47.0	12.8	25.4	62.4	12.2	25.4	62.4	12.2
Female	4.2	92.6	3.2	73.4	2.9	23.7	55.4	8.7	35.9	44.8	38.1	17.2	23.6	60.1	16.3	23.6	60.1	16.3
		Pr = 0.829			Pr < 0.001			Pr < 0.001			Pr < 0.001			Pr = 0.001			Pr < 0.001	
Age																		
20–29	2.9	93.8	3.4	76.3	3.7	20.1	57.6	10.2	32.3	48.4	38.0	13.5	27.3	55.7	16.9	54.4	26.3	19.3
30–39	3.6	93.1	3.2	77.4	2.8	19.8	57.2	9.7	33.1	46.7	35.6	17.8	30.1	55.8	14.1	60.2	23.5	16.2
40–49	2.4	96.6	1.1	75.9	2.4	21.7	57.0	10.1	32.9	43.7	40.4	15.9	23.9	60.4	15.7	60.0	23.9	16.1
50–59	4.3	92.8	2.9	75.1	3.6	21.3	57.4	10.9	31.7	41.7	43.8	14.5	22.8	63.4	13.8	55.0	27.6	17.4
60–69	7.6	88.2	4.3	79.0	3.1	18.0	63.7	11.8	24.5	33.5	53.2	13.3	18.8	69.1	12.1	57.3	28.6	14.1
Others	16.7	83.3	0.0	100.0	0.0	0.0	83.3	16.7	0.0	50.0	16.7	33.3	33.3	66.7	0.0	83.3	0.0	16.7
		Pr < 0.001			Pr = 0.790			Pr = 0.130			Pr < 0.001			Pr = 0.051			Pr = 0.264	
Marital status																		
Spouse	3.8	93.6	2.6	76.5	3.3	20.2	58.8	10.6	30.6	41.4	43.2	15.4	23.2	62.3	14.6	58.3	25.8	16.0
No spouse	5.5	90.5	4.0	77.3	2.6	20.1	58.1	10.6	31.2	45.9	39.9	14.2	28.1	58.2	13.7	55.1	26.7	18.3
		Pr = 0.037			Pr = 0.687			Pr = 0.949			Pr = 0.153			Pr = 0.367			Pr = 0.296	
No spouse																		
Unmarried	4.2	91.6	4.2	76.9	4.2	18.9	56.6	11.9	31.5	45.5	44.1	10.5	23.8	63.6	12.6	56.6	25.2	18.2
Divorced	7.7	87.2	5.1	89.7	0.0	10.3	71.8	5.1	23.1	30.8	53.9	15.4	18.0	61.5	20.5	50.0	29.0	21.1
Widowed	25.0	63.9	11.1	66.7	2.8	30.6	55.6	8.3	36.1	33.3	41.7	25.0	11.4	68.6	20.0	44.4	36.1	19.4
		Pr < 0.001			Pr = 0.133			Pr = 0.418			Pr = 0.112			Pr = 0.023			Pr = 0.678	
Children																		
Yes	4.1	93.1	2.8	77.0	2.9	20.1	59.4	10.1	30.6	40.5	44.0	15.5	22.9	62.8	14.3	58.1	25.6	16.3
No	4.3	92.5	3.2	77.0	3.4	19.6	57.8	11.1	31.1	47.8	38.7	13.6	28.2	57.6	14.2	55.8	27.1	17.2
		Pr = 0.845			Pr = 0.820			Pr = 0.691			Pr = 0.006			Pr = 0.011			Pr = 0.589	
Profession																		
Company worker/ executive	3.0	94.8	2.2	77.0	2.8	20.2	59.3	12.4	28.4	45.3	41.2	13.5	27.4	59.8	12.8	57.2	26.5	16.3
Public officer	6.3	90.9	2.8	85.3	2.8	11.9	56.6	11.9	31.5	42.7	41.3	16.1	25.9	62.9	11.2	60.8	28.0	11.2
House husband/ wife	4.4	91.8	3.8	73.9	4.2	21.9	54.4	9.1	36.5	46.2	35.4	18.4	20.4	60.4	19.3	58.6	23.5	17.9
Self-employed	3.3	94.1	2.6	79.7	3.9	16.3	67.3	11.1	21.6	36	54.9	9.2	25.7	64.5	9.9	54.9	28.1	17.0
Freelance professional MD, lawyer, etc.	15.6	84.4	0.0	77.8	4.4	17.8	51.1	11.1	37.8	51.1	31.1	17.8	28.9	57.8	13.3	62.2	33.3	4.4
Part-time worker	2.6	93.4	4.0	70.0	3.5	26.5	52.2	7.8	40.1	44.1	37.5	18.4	25.4	59.1	15.6	58.4	23.1	18.5
Pensioner, unemployed	7.6	88.0	4.4	80.8	1.2	18.0	64.4	11.6	24	28.8	57.6	13.6	17.2	68.8	14.0	55.2	28.0	16.8
Others	4.1	94.3	1.6	82.8	3.3	13.9	67.2	7.4	25.4	40.2	47.5	12.3	26.2	59.8	13.9	54.9	27.9	17.2
		Pr = 0.001			Pr = 0.016			Pr < 0.001			Pr < 0.001			Pr = 0.011			Pr = 0.500	
Region																		
Hokkaido/Tohoku	5.6	89.8	4.6	78.7	3.9	17.4	59.7	10.8	29.5	41.3	45.9	12.8	24.6	63.3	12.1	57.1	26.2	16.7
Kanto	4.0	93.4	2.6	77.0	2.6	20.3	57.9	11.8	30.3	45.9	37.9	16.2	27.8	57.8	14.4	56.8	26.2	17.0
Chubu	3.3	93.9	2.8	73.3	3.6	23.1	58.4	11.0	30.6	44.2	41.4	14.4	25.3	62.3	12.4	56.8	26.2	17.1
Kinki	3.6	93.7	2.7	74.5	3.4	22.2	56.9	10.4	32.8	42.7	41.2	16.1	21.7	63.0	15.2	58.1	23.4	18.6
Chugoku/Shikoku	4.6	92.4	3.0	76.8	4.2	19.0	60.3	10.1	29.5	39.7	49.0	11.4	20.2	62.2	17.7	59.7	28.2	12.2
Kyushu/Okinawa	5.5	91.6	2.9	81.4	1.5	17.2	61.0	7.3	31.8	33.9	49.6	16.4	21.2	63.9	15.0	57.9	27.1	15.0
		Pr = 0.699			Pr = 0.303			Pr = 0.838			Pr = 0.009			Pr = 0.147			Pr = 0.788	
Educational background																		
Junior high school	5.4	89.1	5.4	76.1	3.3	20.7	56.5	17.4	26.1	31.5	48.9	19.6	27.2	55.4	17.4	43.5	35.9	20.7
High school	4.6	91.2	4.2	73.0	4.2	22.8	56.4	13.0	30.6	38.5	45.8	15.6	22.6	63.4	14.1	56.4	27.2	16.4
College	4.0	92.1	3.9	74.8	2.3	22.9	55.0	7.7	37.3	45.0	38.7	16.4	23.3	58.8	17.9	58.9	22.7	18.5
University, Graduate school	4.0	94.7	1.4	80.6	2.6	16.8	62.3	9.7	28.0	45.5	40.9	13.6	26.3	61.2	12.5	58.7	26.0	15.4
		Pr = 0.006			Pr = 0.004			Pr < 0.001			Pr = 0.009			Pr = 0.055			Pr = 0.047	

Table 4 (*Continued*)

	Q2			Q3			Q4			Q5			Q6			Q7		
	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know	Yes	No	I don't know
Family ever had cancer?																		
Yes	6.0	91.0	3.0	77.3	3.4	19.3	59.0	9.9	31.2	40.1	45.2	14.7	21.7	65.5	12.8	58.0	26.8	15.2
No	3.0	94.2	2.8	76.9	2.8	20.3	58.6	11.1	30.3	44.1	40.6	15.3	26.3	58.5	15.2	57.1	25.6	17.3
I don't know	0.0	91.7	8.3	54.2	0.0	45.8	45.8	20.8	33.3	62.5	25.0	12.5	37.5	37.5	25.0	58.3	16.7	25.0
		Pr = 0.003			Pr = 0.024			Pr = 0.387			Pr = 0.052			Pr = 0.001			Pr = 0.431	
Ever had cancer?																		
Yes	8.3	90.6	1.0	80.2	2.1	17.7	57.3	13.5	29.2	37.9	42.1	20.0	20.8	69.8	9.4	57.3	30.2	12.5
No	4.0	93.1	2.9	76.8	3.1	20.1	59.0	10.2	30.9	42.6	42.6	14.8	24.4	61.2	14.4	57.6	25.7	16.7
I don't know	8.2	81.6	10.2	71.4	4.1	24.5	49.0	24.5	26.5	44.9	36.7	18.4	32.7	53.1	14.3	54.2	33.3	12.5
		Pr = 0.003			Pr = 0.819			Pr = 0.023			Pr = 0.566			Pr = 0.268			Pr = 0.517	
Income																		
≤4 million yen	6.0	88.2	5.8	75.1	4.6	20.3	55.6	12.7	31.8	39.7	43.6	16.8	22.2	62.4	15.3	53.9	29.0	17.1
4–8 million yen	3.3	94.2	2.5	77.0	2.5	20.5	61.4	9.7	28.9	42.2	43.2	14.6	24.3	60.7	15.0	58.5	25.6	15.8
>8 million yen	4.1	94.3	1.6	78.1	2.9	19.0	58.5	10.4	31.1	44.5	41.3	14.2	25.8	61.6	12.6	59.2	24.7	16.1
Others	0.0	95.2	4.8	61.9	0.0	38.1	38.1	9.5	52.4	57.1	19.1	23.8	42.9	38.1	19.1	38.1	14.3	47.6
		Pr < 0.001			Pr = 0.095			Pr = 0.078			Pr = 0.183			Pr = 0.147			Pr = 0.003	

N.B. Pr values are calculated according to chi^2 test.

background for the answer. The answer on the five-grade Likert scale was employed as the dependent variable. Sex, age, region of residence, family experience of cancer, personal experience of cancer, and awareness of cancer registration, which were all significantly correlated with response to Q8, were used as independent variables. The results are shown in Table 5. Male sex (OR 1.25), older age (OR 1.33), and living in the southern region (OR 1.31) were factors significantly associated with support for cancer registration. Cut-off points were arranged almost linearly, and no clear affinity between the answer categories was observed.

4. Discussion

4.1. Study results

This study clarified the current general opinion on cancer registration in Japan. The questionnaire alone could not fully inform respondents about cancer registration. However, the present results should be more reliable than those of previous surveys because the explanation was given in neutral terms rather than being phrased in a way that creates unrest about privacy.

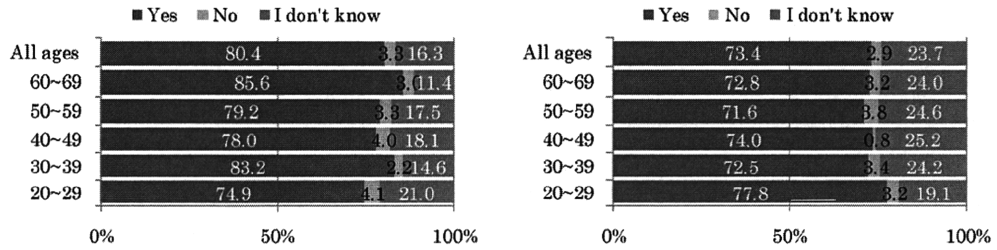
Awareness of the cancer registry system was remarkably low; most Japanese people were unaware of the system, despite increasing media coverage. In the UK study, the awareness was a little higher than in Japan. This is probably because British cancer registries or GPs provide more information on cancer registration to the public. The difference may also be related to frequency to see epidemiological study results based on cancer registration. Nonetheless, nearly 80% of the Japanese respondents answered "cancer registry is useful" when a short explanation on the system was provided.

Compared with the British, Japanese people seemed to be more suspicious about cancer registration according to their responses to Q4 and 5. We speculate that these two questions are correlated in terms of the trade-off that we see in Q8. Japanese respondents appear to believe that they should be informed which contents are transmitted to cancer registries and how this is done. Only when these requirements are satisfied would they agree with legislation of cancer registration. In a general survey on national character in Japan, 41% of the 1001 respondents answered "I am very worried about abuse of my own personal information by someone" [8]. In another international comparative study on information, 55.4% of UK respondents felt assured about the confidentiality of their information, while Japan was positioned at the bottom of the 7 countries surveyed, with only 34.3% of Japanese stating that they felt assured in this regard [9].

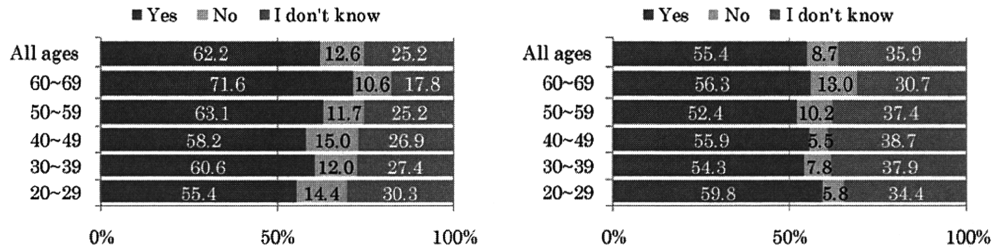
However, it should be noted that Japanese respondents did not show active opposition to cancer registration, as they tended to choose "I don't know" instead of "no". This probably stems from insufficient knowledge of cancer registration in Japan, or to the Japanese tendency to avoid a definitive "yes" or "no" answer. The information in the questionnaire allowed the respondents to consider cancer registration in detail, and to understand its utility. We believe, however, that the general population should receive more education in the long term, in order to form their opinion according to their social position or circumstances.

The tendency to think that cancer registration is an invasion of privacy in Japan may be related to the mass media coverage of the Act for Protection of Computer Processed Personal Data in 2003. Another possibility is the recent prevalence of crime that misuses or leaks personal information. Moreover, differences between the two countries in their attitudes to and understanding of public health and epidemiology and public interest might be another contributing factor.

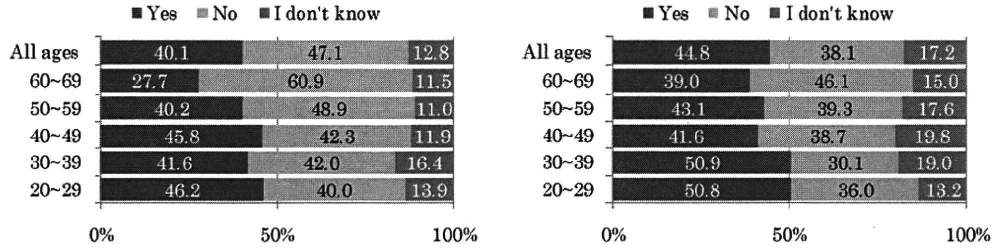
It is interesting that a large difference was seen in the responses to Q1, 5, and 6, although these three questions all covered privacy.



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?



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 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?



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?

Fig. 2. Sex and age differences in the answers to Q3, 4, and 5.

It is already well known that personal information is manipulated by the local administration in the course of civil registration; hence, people may not care about this issue. In both countries, for example, breast and cervical cancer screening are managed by the government, and the population has already received announcements about their health from city halls or health authorities. Even Japanese people are used to receiving such information with a nominative cover letter. On the other hand, cancer registration is an unknown system and people may still be suspicious about it, compared with medical research participation requested through

Table 5
Results of the ordered logit model for the association between response to Q8 and respondents' background factors.

Variables		Odds ratio	S.E.	Pr
$n = 2406$ log likelihood $= -3762.2065$ LR chi$^2(6) = 47.26$				
Male		1.245467	0.090686	0.003
Age >49		1.333289	0.104200	0.000
Resident of southern regions		1.313561	0.118063	0.002
Own experience of cancer (Q17)		1.155135	0.090001	0.064
Experience of cancer in the family (Q16)		1.137620	0.220123	0.505
Aware of cancer registry (Q2)		1.346390	0.245652	0.103
	Cut-off point 1	−1.566630	0.080296	
	Cut-off point 2	−0.257750	0.069048	
	Cut-off point 3	0.678866	0.070283	
	Cut-off point 4	2.124766	0.083575	

their treating doctors. Cancer registration requires information about sensitive medical records in addition to personal identifiers. This may increase feelings of resistance. Moreover, cancer screening brings people a direct advantage; however, cancer registration seems not to provide any immediate merit.

The logit modeling showed us that only general background factors (age, sex, and residence region) affected opinions on the cancer registration. Cancer experience slightly increased respondents' knowledge of the cancer registry system, but it had no significant effect on their opinion of it. Such differences of opinion concerning privacy probably result from age and sex differences, rather than from the tendency for young women to be more concerned about conditions such as breast, ovarian or cervical cancer. For example, the "Public opinion poll concerning protection of individual information" in September 2006 showed more uneasiness regarding information leakage among female respondents [10]. In that poll, young respondents and city residents felt uneasiness regarding the misuse of personally identifiable information. We consider that the results of our study do not reflect a specific tendency about "cancer" or "cancer registration".

4.2. Research limitations

The research subjects were recruited from those designated "research monitors" by Nikkei Research Ltd. Strictly speaking, this may introduce bias if we consider them to represent the general population, since the monitors are willing to be registered in Nikkei Research Ltd., and this motivation might lead to such people having similar characteristics. However, nowadays in Japan, it is not at all feasible to achieve a high response rate in social science research by selecting subjects from the telephone directory or electoral roll, although such methods were satisfactory a few decades ago. Research with low response rates, for example 30%, is much less reliable than the present survey. We believe strongly that using a database of a research and marketing company was the most efficient way to obtain answers as close as possible to the "real" opinion of the general population.

The difference in methodology between the two studies, i.e., telephone interview in the British study versus mailed questionnaires in the present study, might impede comparability. However, it is extremely difficult to maintain a high response rate with the telephone investigation method in Japan. We considered it more important to have a high response rate than to achieve methodological commonality between the two studies.

4.3. The future of cancer registration in Japan

A decade ago, researchers were encouraged to achieve social recognition for cancer registration throughout the world. At that time, there remained criticism against the epidemiological research based on cancer registration without individual consent of the patients, based on the principles of the Helsinki Declaration [11,12]. Times have changed, in particular after the enactment of the European Commission directive in 1995, and we now have consensus that cancer registration is exempt from the basis of individual informed consent because it can only benefit society. The alternative of making the data anonymous by replacing all the identifiers with codes would impede cancer surveillance [13] and is not realistic. The unfortunate example in Estonia warns against the overzealous implementation of data protection, even under a favorable situation [14]. What we need is to achieve a proper balance between protection of patient privacy and public health interests by setting appropriate policies, regulations, and use of technology [15], while avoiding overly restrictive policies and an exaggerated reaction [16].

As for the anxiety regarding the treatment of personal information in Japan, we think that feelings will soften if transparency in data processing is improved, specifically regarding what information is accumulated by which route, and what it is used for. The public are then more likely to feel, "we are taking advantage of our predecessors' contributions now, and are proud to do the same for the following generation's health", which seems to be the prevailing sentiment in the UK. We also have to enhance the opinion of cancer registration in the general population by describing the rigor of the registries' safety management measures, which treat personal information according to strict international standards [17].

It is worth noting that the Japanese public thought that they would be disadvantaged if their region had no cancer registry system (Q7). Unlike countries with a national registry (e.g., Nordic countries) or those where the cancer registries have no plan to cover the whole country (e.g., England, France, Italy), the Japanese cancer registry system aims to create independent regional cancer registries to cover the whole country. Considering the National Cancer Control Act in 2006, pertaining to the standardization and the equalization of cancer information based on cancer registration, the results of the present study support the continuation of our project [16].

In the "Administrative divisions cancer measures" questionnaire which the Nikkei Newspaper sent to the cancer registries, the registries answered that legislation and financial support were of course important, and "understanding of society" was one of the most important factor considered to enhance the position of cancer registration. We need a long-term strategy to ensure that the public is well informed on cancer registration [18]. In the USA, 64.3% of registries had educational materials to explain the system and to describe the possibility that researchers may contact patients about participating in a study [16]. Japanese cancer registries should emulate the American example, and promote passive educational approaches (web sites, pamphlets, brochures, etc.).

After 50 years of cancer registration in Japan, we are at a crossroads. Compared with other developed countries, we have not yet completed a system that can provide sufficient cancer registry data for means of cancer control or to evaluate cancer screening. Nor have we been able to use cancer registry data in a large-scale cohort study. To obtain the "understanding of society," we need to actively utilize information from the cancer registry and to educate the public about examples of actual use that have wide appeal. The future of cancer control therefore depends on our efforts and on public cooperation.

Conflict of interest statement

There is no conflict of interest concerning this study.

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ORIGINAL PAPER

Recent trends and patterns in breast cancer incidence among Eastern and Southeastern Asian women

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Abstract

Background Incidence of breast cancer is rising in Asian countries, and breast cancer is the most common cancer among Asian women. However, there are few recent descriptive reports on the epidemiology of breast cancer among Eastern and Southeastern Asian populations.

Methods We examined incidence trends for invasive breast cancer in women aged ≥ 20 years from 15 registries in Eastern (China, Japan, the Republic of Korea, Taiwan) and Southeastern Asia (the Philippines, Singapore, Thailand) for the period 1993–2002 mainly using data from *Cancer Incidence in Five Continents,* Volumes VIII and IX. We compared trends in annual incidence rates and age-specific incidence curves over a 10-year period. We also compared the incidence rates of Asian-Americans with the rates of their Asian counterparts.

Results Breast cancer incidence rates increased gradually over time in all study populations. Rates were relatively high in Southeastern Asia and became progressively lower along a south-to-north gradient, with a fourfold geographic variation within the study populations. Age-specific incidence curves showed patterns that gradually changed according to incidence rates. Breast cancer incidence among Asian women living in the

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