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Case mix at the European Institute of Oncology: first report of the Tumour Registry, 2000–2002

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Abstract

Introduction: An institutional and centralized hospital-based tumour registry (TR) is the ideal supporting tool for the organization and management of clinical data in a comprehensive cancer centre. The purpose of this paper is to describe the development of the TR at the European Institute of Oncology (IEO), Milan, Italy, from its origin to its current applications.

Material and methods: After a series of meetings with members of administrative, clinical, research and informatics departments, the TR was activated in March 2006 with the aim of collecting data on all the individuals referred to the institute, with or at risk of developing a tumour. It was implemented on an Oracle™-based interface. A minimum dataset of variables was defined and data collection was divided into four forms, which together gather all the relevant data on patients, tumours, treatments and subsequent events.

Results: After a six-month pilot period, which involved the training of the tumour registrars, adjustments to the structure of the registry, development of a data quality control procedure and finalization of the operative protocol, since September 2006 the data collection has been fully operative. Five registrars have been chronologically entering data of all individuals who visited the IEO for the first time since 1 January 2000. As of March 2009, data on 69,637 individuals and 43,567 tumours has been reviewed, recoded and registered in the TR. Twenty-two per cent of the tumours (*n*=9578) were first invasive primaries, diagnosed and treated in the IEO; the most common sites were breast (*n*=4972), lung (*n*=627), intestines (*n*=479) and prostate (*n*=376).

Conclusion: The IEO TR has been proven functional and reliable in monitoring the activity of the hospital, allowing extraction of data from any subpopulation with characteristics of interest. The structured and centralized TR represents an important tool for our research-oriented institution.

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Introduction

The European Institute of Oncology (IEO) aims at excellence in the prevention, diagnosis and treatment of cancer through high-level clinical and scientific research. Since its opening in 1994, the number of individuals presenting for the first time to the IEO has increased year by year, reaching 38,500 in 2008. Thus, the need of a well-structured and centralized institutional database has become essential. Furthermore, to optimize the use of the great quantity of informa tion, some obstacles typical of the organization and management of hospital data had to be overcome, such as the presence of many non-standardized databases, duplication of information and absence of centralized follow-up. For these reasons, the IEO tumour registry (TR) was planned, designed and finally activated in 2006.

The purposes of a hospital-based TR are to support the administration of the hospital, back up the clinical and scientific research and, above all, serve the needs of the patient [1]. In fact a TR can provide immediate reports on the activity of the hospital, document the cancer burden borne by the hospital for specific periods of time, provide background information useful for the design of clinical studies, extract data of any subpopulation with characteristics of interest and organize a centralized follow-up of patients, avoiding duplication of information and useless contact between the hospital and the patients.

The aims of the present paper are to illustrate the development of the IEO TR, from its origin to its current applications, and to describe the case-mix of our institute. We will report data from its first three years of activity, including data on all individuals presenting to the institute between 2000 and 2002, already having or being at risk of developing a tumour.

Material and methods

Brief history

The TR project was developed in many successive phases, starting with a series of meetings and discussions on 'who' an 'what' to include. A group of experts, consisting of physicians, information technology (IT) specialists, data managers, administrative personnel and biostatisticians had regularly met for almost two years to discuss the format and the data to be collected. An important part of the planning was also dedicated to visiting and contacting other hospital-based cancer registries, in order to learn from already established realities. Thereafter, the database was designed and tested. It was decided to implement the TR using an Oracle™-based interface. The implementation, completed in February 2006, was managed in the Division of Epidemiology and Biostatistics, with the help of the IT division. The next phase involved the selection and training of dedicated data registrars. The project finally got off the ground in March 2006, and at present five dedicated persons are working full time on entering the data. Data quality control and data management are carried out by two data managers and two biostatisticians.

Eligibility criteria

We agreed to collect information on all individuals presenting at the IEO since its opening, either with a tumour or at risk of developing one. We also decided to collect information on patients with previous invasive tumours, either treated at this institute or elsewhere. In order to gain entry in the TR, patients must have: (1) the IEO unique identification number, assigned to the individual at the first visit; and (2) at least one medical report (i.e., pathological report or diagnostic examination) accessible from the institute's intranet.

Information collected

A minimum dataset of variables was defined, to establish the best compromise between synthesis and informativeness. Data collection is divided into four forms: on the first form personal data (i.e. sex, date of birth) and information on survival (i.e. date of last contact, date of last visit, vital status, cause of death) are recorded. The type of record is registered in this form. The following types of record are assigned to each individual.

1. ***Visit:*** a healthy individual comes to the IEO for either a visit or a genetic counselling.
2. ***Anamnesis****:* the patient, at the moment free of disease, reports on a tumour diagnosed in the past and already treated and cured elsewhere.
3. ***Diagnosis****:* diagnosis of tumour is made at the IEO and the patient decides to be treated and followed up elsewhere.
4. ***Second opinion****:* the patient or the patient's parents come to the IEO and ask for an opinion on a diagnosis and/or a treatment proposed elsewhere.

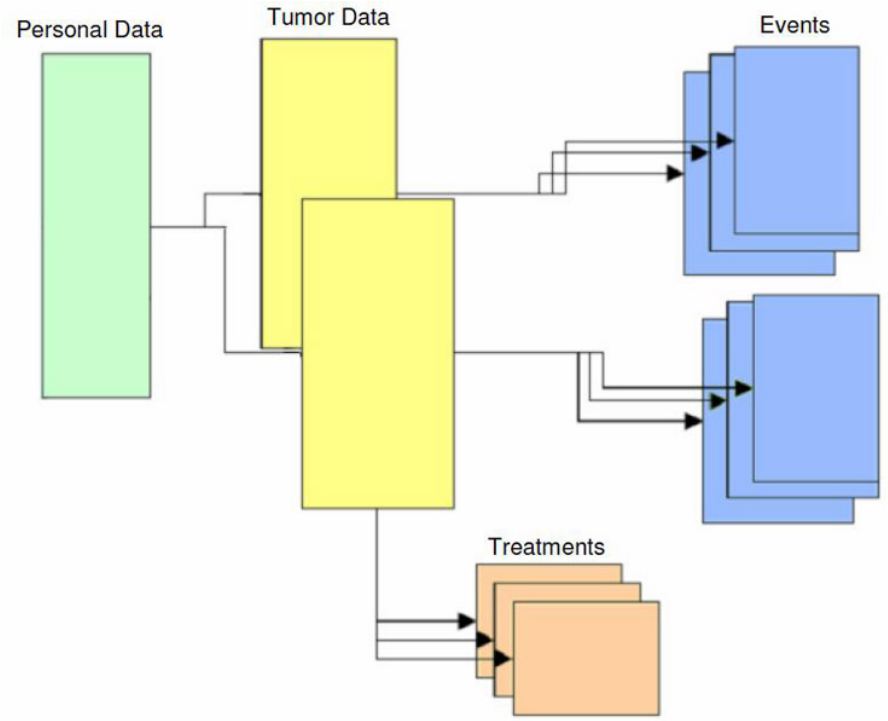

Figure 1: The structure of the IEO tumour registry

5. ***Long****:* the patient receives at least one treatment at the IEO.

Detailed information on the patient's tumour(s) (i.e. date of diagnosis, morphology, topography, TNM staging, ordinal number of the tumour for multiple tumours) is recorded on the second form, together with some epidemiological information (i.e. familiarity, height and weight at diagnosis and smoking habits). The third form is dedicated to the treatment strategy, where every therapy is classified as administered or proposed. The fourth catalogues, chronologically, all following events, tracing the whole history of the disease.

It is important to note that the amount of data collected will vary according to the type of record: the completion of all four forms only occurs for patients coded as 'Long'. For patients coded as 'Anamnesis', 'Diagnosis' or 'Second opinion' only the personal data form together with date of diagnosis, place of diagnosis, the IEO histopathological identification code (if any), topography and morphology are registered. For patients coded as 'Visit' only the personal data form is completed.

Invasive and *in situ* tumours are always collected, whereas benign tumours or negative histologies are collected only if the patient undergoes a major surgical procedure in the IEO. Examples of benign tumours/negative histologies we collect are: adenoma of the thyroid after thyroidectomy, fibroadenoma after quadrantectomy and negative histology after hysterectomy.

The structure of the TR is represented in Figure 1. The patient is the basis of the structure. Zero, one or more tumours can be linked to the patient. Zero, one or more treatments and events can be linked to each tumour.

Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) [2] is used to classify tumours according to topography and morphology except for haematopoietic tumours, for which we use the World Health Organization (WHO) ICD-10 classification [3]. Clinical and pathological staging is based on the TNM system [4], whether the fifth or the sixth edition according to the date of diagnosis. Cause of death is based on the WHO ICD-10 classification [3].

Sources of data, data entry and quality control

The IEO TR data entry is completely paperless, as all the information derives from computerized sources: the IEO patients' administrative database (personal information is automatically visible on the personal data form), medical reports

accessible on the IEO intranet, online databases (surgery, laboratory medicine, pathology, etc.) and patients' clinical dossier, which are all digitalized and accessible online.

Five data registrars work full time on data entry. Each one has specialized in a particular tumour or set of tumours in order to achieve specific knowledge and abilities. Data quality control and data management are carried out by two data managers and two biostatisticians. A data manager randomly reviews data entered by a registrar, and the two discuss potential mistakes. A field was created in which notes regarding which cases are revised by a data manager and which are not inserted. Furthermore, in order to clarify any doubt on specific cases, a medical doctor was chosen from each division as a referent to address questions to.

Results

A six-month pilot period (March to August 2006) was necessary to train the registrars, adjust the structure of the registry, develop a data quality control procedure and edit the operative protocol. Since September 2006, the data entry has been running at top speed. We started by entering individuals who presented for the first time to the IEO in the year 2000 in a sequential fashion. By March 2009, 69,637 individuals had been entered in the TR, corresponding to individuals who came for the first time to the IEO between 2000 and 2002, not necessarily presenting with a tumour. In Table 1, some characteristics of these individuals are reported. Approximately, one out of four was classified as 'Long', as he/she received at least one treatment in the IEO. Only 1.6% of individuals were 19 years old or less, as our institute does not treat paediatric tumours.

Overall, 39,480 individuals out of 69,637 had one or more tumours. Information on a total of 43,567 tumours was collected, with an average of 1.1 tumours per person. Frequencies by site, malignancy, place of diagnosis and place of surgery are reported in Table 2.

In Table 3, we reported only the first invasive primary tumours, diagnosed and treated in the IEO (n=9578), which represent the typical subgroup of tumours used for epidemiological retrospective studies. Breast was the most frequent tumour site by far (n=4972), followed by lung (n=627), intestines (n=479) and prostate (n=376). In order to show an example of the reports that can be easily obtained from the TR, we included some additional information for the most frequent tumour sites: breast (women only), colorectal, lung, non-Hodgkin lymphoma, ovary, prostate, sarcoma, skin melanoma and tongue (Appendices A–I].

Finally, we calculated that, on average, it took about ten minutes to enter a case, that is six cases per hour. The time varied depending especially on the type of record: 22 minutes for a long case, two minutes for a visit and nine minutes for other types of record. By the end of 2009, data of all individuals who referred to the IEO for the first time in the years 2000–4 will be collected, for a total of about 125,000 individuals and 80,000 tumours.

Discussion

This paper presents the first three years of activity of the IEO TR, specifically data on all individuals presenting for the first time to the institute in the years 2000–2, already having or being at risk of developing a tumour. This first analysis of the TR data demonstrated that the registry can support the administration in monitoring the hospital activity, be a supporting tool for the clinical practice as well as for epidemiological/basic research, play a key role in the production of publications on any subpopulation with characteristics of interest and, above all, improve patient management and knowledge of the disease.

Regarding information on events and survival, although patients in the TR had a theoretically adequate follow-up, with a median of six years, we preferred not to report any result, as we have not performed a detailed analysis of the quality of the follow-up yet. By now, vital status (dead/alive) and events are based on passive follow-up, with an accuracy depending on the site or other characteristics of the tumours. For example, since our institute produces many publications in breast cancer field, follow-up information on patients suffering from that tumour is updated more frequently compared to patients with other tumours. Survival analyses on different tumours might have been incomparable. By 2010, after a detailed analysis of the follow-up information collected in our institute, an active centralized follow-up will be organized and started.

Although it was decided that researchers or clinicians would not have direct access to the TR, we have established a system to collect and answer requests. Data extrapolation and analysis are managed in the Division of Epidemiology and Biostatistics.

A recent paper entitled 'Analysis of local and regional recurrences in breast cancer after conservative surgery' represents the first study conducted on the data of the TR [5]. It consisted of a multistage analysis of local, regional and distant

Table 1: Characteristics of individuals[a]

Classification	No. of Patients (%)
Gender	
Male	20,941 (30.1)
Female	48,696 (69.9)
Age	
<20 years	985 (1.6)
20-34 years	6909 (10.8)
35-49 years	19,052 (28.1)
50-64 years	24,406 (32.8)
65-79 years	16,310 (24.3)
80+ years	1975 (2.4)
Place of residence	
Northern Italy	46,940 (67.4)
Lombardy	39,207 (56.3)
Milan	14,679 (21.1)
Central Italy	12,138 (17.4)
Southern Italy	10,211 (14.7)
Foreign countries	348 (0.5)
Type of record	
Long	17,823 (25.6)
Second Opinion	19,794 (28.4)
Anamnesis	1095 (1.6)
Diagnosis	768 (1.1)
Visit	30,157 (43.3)
Total	69,637 (100.0)

[a]Individuals who presented at the IEO for the first time in years 2000-2002.

recurrences, performed on data of 2784 women treated for early breast cancer by quadrantectomy and whole breast irradiation at the IEO. The authors concluded that 'local and regional recurrences after breast-conserving surgery are rare events. They are markers of tumour aggressiveness and indicators of an increased likelihood of distant metastases'.

As shown in this paper, we can easily monitor the activity of the IEO and extrapolate data from any subpopulation with characteristics of interest. We strongly believe that a well-structured and centralized TR is a necessary tool for our, and in fact any, institution where research is a fundamental part of its activity.

Table 2: Tumours by site[a]

Tumour Site	Collected	Invasive Tumours		
	Overall[b]	Total	IEO Diagnosis	IEO Surgery
Head and neck	1294	1121	340 (30.3)	249 (22.2)
Lip	54	47	13 (27.7)	12 (25.5)
Tongue	235	224	104 (46.4)	93 (41.5)
Major salivary glands	253	135	49 (36.3)	33 (24.4)
Gum	15	13	7 (53.8)	7 (53.8)
Floor of mouth	37	34	5 (14.7)	5 (14.7)
Other and unspecified parts of mouth	210	192	66 (34.4)	53 (27.6)
Oropharynx	155	149	28 (18.8)	18 (12.1)
Nasopharynx	142	141	28 (19.9)	5 (3.5)
Hypopharynx	87	87	13 (14.9)	10 (11.5)
Other and ill defined sites	106	99	27 (27.3)	13 (13.1)
Digestive organs and peritoneum[c]	6435	6334	1215 (19.2)	693 (10.9)
Oesophagus	185	181	46 (25.4)	19 (10.5)
Stomach	1119	1109	228 (20.6)	161 (14.5)
Small intestine, including duodenum	109	105	25 (23.8)	2 (1.9)
Colon	2324	2289	418 (18.3)	277 (12.1)
Rectum, rectosigmoid junction and anus	991	977	240 (24.6)	179 (18.3)
Liver and intra-hepatic bile ducts	484	476	75 (15.8)	16 (3.4)
Gallbladder and extra-hepatic bile ducts	336	324	35 (10.8)	6 (1.9)
Pancreas	771	766	120 (15.7)	28 (3.7)
Retroperitoneum and peritoneum	56	52	19 (36.5)	4 (7.7)
Other and ill-defined sites	60	55	9 (16.4)	1 (1.8)
Respiratory and intra-thoracic organs	5068	4853	1297 (26.7)	811 (16.7)
Nasal cavities, middle ear and accessory sinuses	32	31	2 (6.5)	0 (0.0)
Larynx	622	547	188 (34.4)	167 (30.5)
Trachea, bronchus and lung	4097	3983	1014 (25.5)	610 (15.3)
Pleura	191	181	53 (29.3)	10 (5.5)
Thymus, heart and mediastinum	123	108	40 (37.0)	24 (22.2)
Other and ill-defined sites	3	3	0 (0.0)	0 (0.0)
Bone, connective tissue, skin and breast	18871	15305	7907 (51.7)	5396 (35.3)
Bone and articular cartilage	12	8	1 (12.5)	0 (0.0)
Connective and other soft tissue	954	897	383 (42.7)	156 (17.4)
Skin[d]	2280	2160	1003 (46.4)	626 (29.0)
Breast	15,625	12240	6520 (53.3)	4614 (37.7)
Genitourinary organs	8032	6694	1799 (26.9)	1192 (17.8)
Cervix uteri	1344	559	218 (39.0)	156 (27.9)
Uterine corpus	618	525	164 (31.2)	116 (22.1)
Ovary and other uterine adnexa	1222	1099	398 (36.2)	202 (18.4)
Other and unspecified female genital organs	250	176	73 (41.5)	46 (26.1)
Prostate	2378	2334	504 (21.6)	333 (14.3)
Testis	281	261	75 (28.7)	50 (19.2)
Penis and other male genital organs	44	36	11 (30.6)	11 (30.6)
Bladder	953	807	172 (21.3)	137 (17.0)
Kidney	833	801	171 (21.3)	131 (16.4)
Other and ill-defined sites	109	96	13 (13.5)	10 (10.4)
Other and unspecified sites	1631	1355	220 (16.2)	169 (12.5)
Eye	6	5	1 (20.0)	0 (0.0)
Brain	716	703	21 (3.0)	0 (0.0)
Other and unspecified parts of nervous system	16	15	0 (0.0)	0 (0.0)
Thyroid gland	825	583	190 (32.6)	164 (28.1)
Other endocrine glands and related structure	68	49	8 (16.3)	5 (10.2)
Lymphatic and haematopoietic tissue	1405	1395	554 (39.7)	28 (2.0)
Hodgkin lymphoma	238	237	96 (40.5)	3 (1.3)
Non-Hodgkin lymphoma	780	777	373 (48.0)	25 (3.2)
Multiple myeloma	171	171	46 (26.9)	0 (0.0)
Leukaemia	203	203	36 (17.7)	0 (0.0)
Other and unspecified	13	7	3 (42.9)	0 (0.0)
Non-skin melanoma	51	51	16 (31.4)	12 (23.5)
Malignant neoplasm without specification of site	780	767	206 (26.9)	23 (3.0)
Total	43,567	37,875	13,554 (35.8)	8573 (22.6)

Percentages in brackets are evaluated on total invasive tumours. [a]Among individuals who presented at the IEO for the first time in years from 2000 to 2002; [b]including all invasive and *in situ* tumours. Benign neoplasia or negative histology after radical surgery in the IEO is also collected. [c]Polyps are not collected; [d]Benign nevi are not collected.

Table 3: First invasive primaries diagnosed and treated in the IEO[a] by site, gender and age

	All	Gender		Age Distribution (years)				
		Female	Male	<35	35-49	50-64	65-79	80
Head and neck	248	82 (33.1)	166 (66.9)	28 (11.3)	35 (14.1)	101 (40.7)	74 (29.8)	10 (4.0)
Lip	10	2 (20.0)	8 (80.0)	0 (0.0)	0 (0.0)	1 (10.0)	7 (70.0)	2 (20.0)
Tongue	90	34 (37.8)	56 (62.2)	12 (13.3)	14 (15.6)	34 (37.8)	25 (27.8)	5 (5.6)
Major salivary glands	31	15 (48.4)	16 (51.6)	10 (32.3)	2 (6.5)	15 (48.4)	3 (9.7)	1 (3.2)
Gum	5	2 (40.0)	3 (60.0)	1 (20.0)	0 (0.0)	0 (0.0)	4 (80.0)	0 (0.0)
Floor of mouth	4	2 (50.0)	2 (50.0)	0 (0.0)	3 (75.0)	1 (25.0)	0 (0.0)	0 (0.0)
Other and unspecified parts of mouth	48	11 (22.9)	37 (77.1)	0 (0.0)	8 (16.7)	22 (45.8)	16 (33.3)	2 (4.2)
Oropharynx	22	6 (27.3)	16 (72.7)	2 (9.1)	2 (9.1)	10 (45.5)	8 (36.4)	0 (0.0)
Nasopharynx	13	3 (23.1)	10 (76.9)	3 (23.1)	3 (23.1)	4 (30.8)	3 (23.1)	0 (0.0)
Oropharynx Hypopharynx	10	2 (20.0)	8 (80.0)	0 (0.0)	1 (10.0)	5 (50.0)	4 (40.0)	0 (0.0)
Other and ill defined sites	15	5 (33.3)	10 (66.7)	0 (0.0)	2 (13.3)	9 (60.0)	4 (26.7)	0 (0.0)
Digestive organs and peritoneum	791	370 (46.8)	421 (53.2)	19 (2.4)	111 (14)	331 (41.8)	294 (37.2)	36 (4.6)
Oesophagus	20	9 (45.0)	11 (55.0)	0 (0.0)	4 (20.0)	10 (50.0)	5 (25.0)	1 (5.0)
Stomach	166	68 (41.0)	98 (59.0)	5 (3.0)	27 (16.3)	67 (40.4)	57 (34.3)	10 (6.0)
Small intestine, including duodenum	11	4 (36.4)	7 (63.6)	0 (0.0)	4 (36.4)	5 (45.5)	2 (18.2)	0 (0.0)
Colon	282	146 (51.8)	136 (48.2)	7 (2.5)	35 (12.4)	115 (40.8)	109 (38.7)	16 (5.7)
Rectum, rectosigmoid junction and anus	186	74 (39.8)	112 (60.2)	2 (1.1)	21 (11.3)	83 (44.6)	71 (38.2)	9 (4.8)
Liver and intra-hepatic bile ducts	31	10 (32.3)	21 (67.7)	0 (0.0)	1 (3.2)	11 (35.5)	19 (61.3)	0 (0.0)
Gallbladder and extra-hepatic bile ducts	18	7 (38.9)	11 (61.1)	0 (0.0)	7 (38.9)	6 (33.3)	5 (27.8)	0 (0.0)
Pancreas	70	47 (67.1)	23 (32.9)	3 (4.3)	10 (14.3)	31 (44.3)	26 (37.1)	0 (0.0)
Retroperitoneum and peritoneum	5	3 (60.0)	2 (40.0)	2 (40.0)	1 (20.0)	2 (40.0)	0 (0.0)	0 (0.0)
Other and ill-defined sites	2	2 (100.0)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	0 (0.0)	0 (0.0)
Respiratory and intra-thoracic organs	847	188 (22.2)	659 (77.8)	20 (2.4)	73 (8.6)	355 (41.9)	379 (44.7)	20 (2.4)
Larynx	169	12 (7.1)	157 (92.9)	1 (0.6)	11 (6.5)	75 (44.4)	76 (45.0)	6 (3.6)
Trachea, bronchus and lung	627	157 (25.0)	470 (75.0)	13 (2.1)	49 (7.8)	259 (41.3)	293 (46.7)	13 (2.1)
Pleura	20	9 (45.0)	11 (55.0)	0 (0.0)	3 (15.0)	11 (55.0)	5 (25.0)	1 (5.0)
Thymus, heart and mediastinum	31	10 (32.3)	21 (67.7)	6 (19.4)	10 (32.3)	10 (32.3)	5 (16.1)	0 (0.0)
Bone, connective tissue, skin and breast	**5837**	5370 (92)	467 (8)	320 (5.5)	2002 (34.3)	2274 (39)	1105 (18.9)	136 (2.3)
Bone and articular cartilage	1	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)
Connective and other soft tissue	180	97 (53.9)	83 (46.1)	26 (14.4)	69 (38.3)	45 (25)	38 (21.1)	2 (1.1)
Skin	684	330 (48.2)	354 (51.8)	62 (9.1)	162 (23.7)	223 (32.6)	201 (29.4)	36 (5.3)
Breast	4972	4942 (99.4)	30 (0.6)	232 (4.7)	1771 (35.6)	2006 (40.3)	865 (17.4)	98 (2.0)
Genitourinary organs	**1261**	629 (49.9)	632 (50.1)	99 (7.9)	210 (16.6)	513 (40.7)	408 (32.4)	31 (2.4)
Cervix uteri	186	186 (100.0)	0 (0.0)	26 (14.0)	81 (43.5)	59 (31.7)	19 (10.2)	1 (0.5)
Uterine corpus	99	99 (100.0)	0 (0.0)	2 (2.0)	10 (10.1)	57 (57.6)	23 (23.2)	7 (7.1)
Ovary and other uterine adnexa	243	243 (100.0)	0 (0.0)	24 (9.9)	68 (28.0)	109 (44.9)	41 (16.9)	1 (0.4)
Other and unspecified female genital organs	51	51 (100.0)	0 (0.0)	0 (0.0)	8 (15.7)	13 (25.5)	25 (49.0)	5 (9.8)
Prostate	376	0 (0.0)	376 (100.0)	0 (0.0)	1 (0.3)	172 (45.7)	198 (52.7)	5 (1.3)
Testis	60	0 (0.0)	60 (100.0)	44 (73.3)	16 (26.7)	0 (0.0)	0 (0.0)	0 (0.0)
Penis and other male genital organs	10	0 (0.0)	10 (100.0)	0 (0.0)	4 (40.0)	3 (30.0)	1 (10)	2 (20.0)
Bladder	126	19 (15.1)	107 (84.9)	1 (0.8)	8 (6.3)	50 (39.7)	62 (49.2)	5 (4.0)
Kidney	106	29 (27.4)	77 (72.6)	2 (1.9)	13 (12.3)	49 (46.2)	38 (35.8)	4 (3.8)
Other and ill-defined sites	4	1 (25.0)	3 (75.0)	0 (0.0)	0 (0.0)	2 (50.0)	2 (50.0)	0 (0.0)
Other and unspecified sites	**161**	120 (74.5)	41 (25.5)	45 (28.0)	62 (38.5)	36 (22.4)	18 (11.2)	0 (0.0)
E ye	1	0 (0.0)	1 (100.0)	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Brain	10	6 (60.0)	4 (40.0)	5 (50.0)	3 (30.0)	1 (10.0)	1 (10.0)	0 (0.0)
Thyroid gland	145	110 (75.9)	35 (24.1)	38 (26.2)	59 (40.7)	33 (22.8)	15 (10.3)	0 (0.0)
Other endocrine glands and related structure	5	4 (80.0)	1 (20.0)	1 (20.0)	0 (0.0)	2 (40.0)	2 (40.0)	0 (0.0)
Lymphatic and haematopoietic tissue	**352**	186 (52.8)	166 (47.2)	65 (18.5)	78 (22.2)	107 (30.4)	92 (26.1)	10 (2.8)
Hodgkin lymphoma	74	39 (52.7)	35 (47.3)	42 (56.8)	19 (25.7)	11 (14.9)	2 (2.7)	0 (0.0)
Non-Hodgkin lymphoma	225	126 (56.0)	99 (44.0)	21 (9.3)	52 (23.1)	72 (32.0)	72 (32.0)	8 (3.6)
Multiple myeloma	35	13 (37.1)	22 (62.9)	0 (0)	2 (5.7)	17 (48.6)	14 (40)	2 (5.7)
Leukaemia	16	8 (50.0)	8 (50.0)	2 (12.5)	3 (18.8)	7 (43.8)	4 (25.0)	0 (0.0)
Other and unspecified	2	0 (0.0)	2 (100.0)	0 (0.0)	2 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)
Non-skin melanoma	**10**	8 (80.0)	2 (20.0)	1 (10.0)	1 (10.0)	2 (20.0)	5 (50.0)	1 (10.0)
Malignant neoplasm without specification of site	**71**	32 (45.1)	39 (54.9)	4 (5.6)	12 (16.9)	38 (53.5)	17 (23.9)	0 (0.0)
Total	**9578**	6983 (72.9)	2591 (27.1)	601 (6.3)	2583 (27.0)	3756 (39.2)	2391 (25.0)	243 (2.5)

[a] 'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO).

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Appendices

Appendix A: Characteristics broken down by tumour type: breast cancer (women only)

Table A1: Characteristics at diagnosis

Classification	No.	%
Age		
<35 years	232	4.7
35-49 years	1764	35.7
50-64 years	1992	40.3
65+ years	954	19.3
Histology		
Ductal carcinoma	3773	76.3
Lobular carcinoma	465	9.4
Ductal and lobular carcinoma	179	3.6
Cribriform carcinoma	119	2.4
Carcinoma, NOS	120	2.4
Mucinous adenocarcinoma	88	1.8
Tubular adenocarcinoma	59	1.2
Papilllary carcinoma	28	0.6
Phyllodes tumour	24	0.5
Apocrine adenocarcinoma	16	0.3
Medullary carcinoma	7	0.2
Other	64	1.3
pT[b]		
PT0[c]	14	0.3
pTis[c]	18	0.4
pT1	2903	60.6
pT2	1411	29.5
pT3	202	4.2
pT4	61	1.3
pTX	180	3.8
pN[b]		
pN0	2367	48.5
pN1	1373	28.1
pN2	485	9.9
pN3	437	8.9
pNX	223	4.6
M		
M0/MX	4745	96.0
M1	197	4.0

Table A2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	HT	177	36.0
		CT	496	10.0
		HT+CT	927	18.8
		No HT/CT	153	3.1
	No RT	HT	322	6.5
		CT	145	2.9
		HT+CT	345	7.0
		No HT/CT	126	2.5
Neoadjuvant treatment + Surgery	RT	HT	147	3.0
		CT	106	2.1
		HT+CT	139	2.8
		No HT/CT	40	0.8
	No RT	HT	56	1.1
		CT	18	0.4
		HT+CT	39	0.8
		No HT/CT	13	0.3
No surgery	RT	HT	6	0.1
		CT	24	0.5
		HT+CT	17	0.3
	No RT	HT	7	0.1
		CT	20	0.4
		HT+CT	19	0.4

Figure A1: Place of surgery

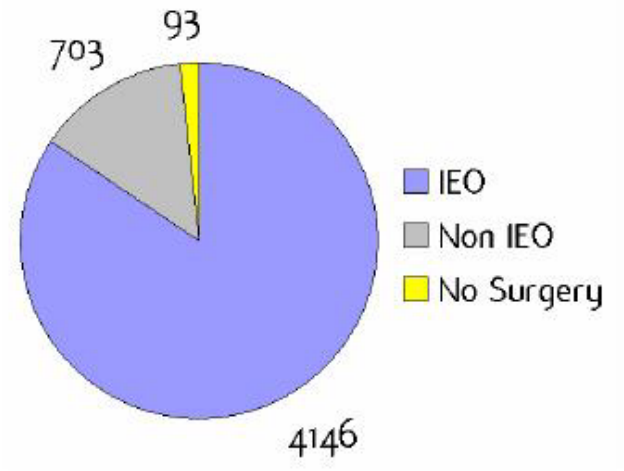
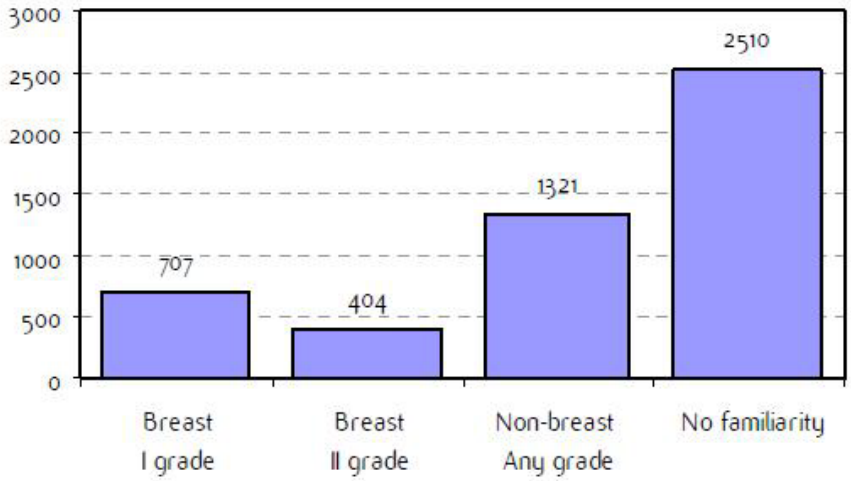


Fig A2: Familiarity for breast and non-breast cancer[b]



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]Information is missing for some patients; [c]No evidence of primary tumour after neoadjuvant treatment. RT: Radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody. NOS: not otherwise specified.

Appendix B: Characteristics broken down by tumour type: colorectal cancer (468 first invasive primaries treated and diagnosed in IEO[a])

Table B1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	248	53.0
Female	220	47.0
Age		
<50 years	65	13.9
50-59 years	117	25.0
60-69 years	153	32.7
70-79 years	108	23.1
80+ years	25	5.3
Histology		
Adenocarcinoma	419	89.5
Mucinous adenocarcinoma	31	6.6
Neuroendocrine carcinoma	5	1.1
Carcinoma, NOS	5	1.1
Squamous cell carcinoma	5	1.1
Signet ring cell adenocarcinoma	2	0.4
Small cell carcinoma	1	0.2
pT[b]		
pT0[c]	1	0.2
pT1	29	6.5
pT2	94	21.2
pT3	257	58.0
pT4	33	7.4
pTX	29	6.5
pN[b]		
pN0	205	44.7
pN1	134	29.2
pN2	79	17.2
pNX	41	8.9
M		
M0/MX	378	80.8
M1	90	19.2

Table B2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	CT	73	15.6
		No CT	7	1.5
	No RT	HT	2	0.4
		CT	195	41.7
		CT+HT	1	0.2
		No CT	129	27.6
Neoadjuvant treatment + surgery	RT	CT	10	2.1
		No CT	1	0.2
	No RT	CT	21	4.5
		No CT	10	2.1
No surgery	RT	CT	8	1.7
		No CT	3	0.6
	No RT	CT	8	1.7

Figure B1: Place of surgery

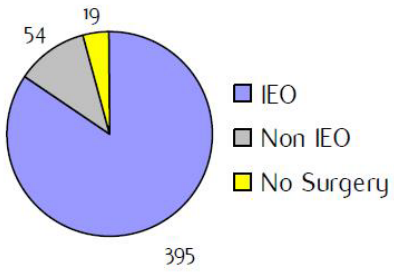
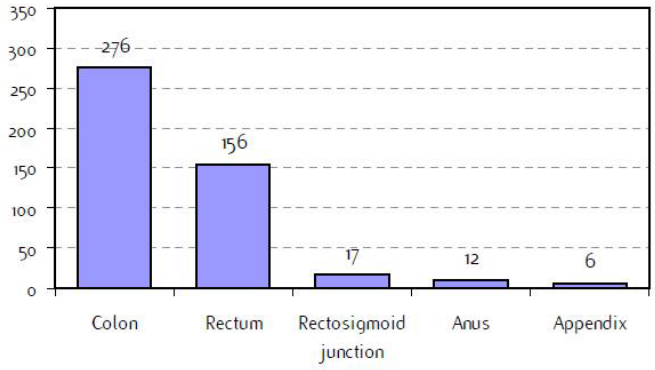


Figure B2: Specific tumour site



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]Information is missing for some patients; [c]No evidence of primary tumour after neoadjuvant treatment. RT: radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody; NOS: not otherwise specified

Appendix C: Characteristics broken down by tumour type: lung cancer (627 first invasive primaries treated and diagnosed in IEO[a])

Table C1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	470	75.0
Female	157	25.0
Age		
<35 years	13	2.1
35-49 years	49	7.8
50-64 years	259	41.3
65-79 years	293	46.7
80+ years	13	2.1
Histology		
Adenocarcinoma	297	47.4
Squamous cell carcinoma	162	25.8
Large cell carcinoma	89	14.2
Small cell carcinoma	39	6.2
Carcinoma, NOS	40	6.4
pT[b]		
pT0[c]	3	0.5
pT1	138	23.4
pT2	231	39.1
pT3	77	13.0
pT4	29	4.9
pTX	113	19.1
pN[b]		
pN0	251	50.3
pN1	113	22.7
pN2	126	25.2
pN3	9	1.8
M		
M0/MX	530	84.5
M1	97	15.5

Table C2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	HT	1	0.2
		CT	35	5.6
		HT+CT	3	0.5
		No HT/CT	45	7.2
	No RT	HT	1	0.2
		CT	25	4.0
		HT+CT	1	0.2
		No HT/CT	246	39.4
Neoadjuvant treatment + Surgery	RT	CT	20	3.2
		No CT	40	6.4
	No RT	CT	8	1.3
		No CT	79	12.6
No surgery	RT	CT	74	11.6
		No CT	7	1.1
	No RT	CT	42	6.7

Figure C1: Place of surgery

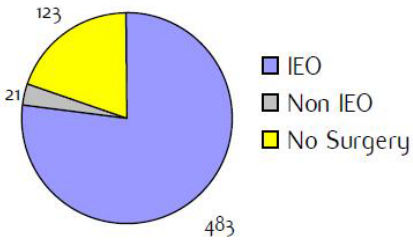
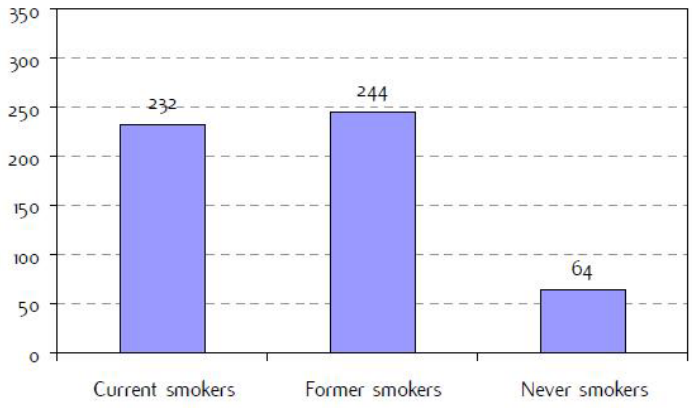


Figure C2: Smoking status at diagnosis[b]



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]information is missing for some patients; [c]No evidence of primary tumour after neoadjuvant treatment. RT: radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody.

Appendix D: Characteristics broken down by tumour type: non-Hodgkin lymphoma (225 first invasive primaries treated and diagnosed in IEO[a])

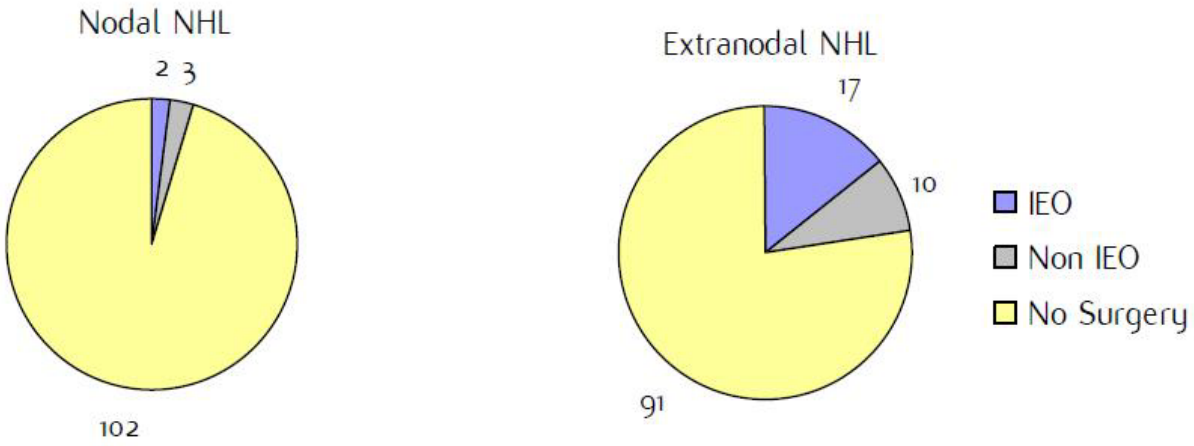
Table D1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	99	44.0
Female	126	56.0
Age		
<35 years	21	9.3
35-49 years	52	23.1
50-64 years	72	32.0
65-79 years	72	32.0
80+ years	8	3.6
Histology[a]		
Follicular NHL	46	20.4
Diffuse NHL	127	56.4
Peripheral and cutaneous T-cell L	11	4.9
Other and unspecified types	41	18.2
pS[a]		
Stage I	29	15.7
Stage II	54	29.2
Stage III	19	10.3
Stage IV	83	44.8
Extranodal extension		
Present	118	52.4
Absent	107	47.6
Extranodal site		
Stomach	18	15.3
Lip and oral cavity	11	9.3
Skin	11	9.3
Breast	10	8.5
Genitourinary sites	4	3.4
Lung	4	3.4
Major salivary glands	4	3.4
Gynecologic sites	3	2.5
Liver	3	2.5
Soft tissue	3	2.5
Other sites	11	9.3
More sites	36	30.5

Table D2: Treatment strategy

Type of Treatment		No.	%
Nodal NHL			
Surgery	RT+CT	1	0.4
	CT	4	1.8
No Surgery	RT+CT	26	11.6
	CT	76	33.8
Extra-nodal NHL			
Surgery	RT+CT	10	4.4
	RT	2	0.9
	CT	11	4.9
	No RT/CT	4	1.8
No surgery	RT+CT	32	14.2
	RT	2	0.9
	RT+CT+HT	1	0.4
	CT	56	24.9

Figure D1: Place of surgery



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]WHO classification applied; [c]Information is missing for some patients. pS: pathological stage. RT: Radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody. NHL: non-Hodgkin lymphoma; L: lymphoma.

Appendix E: Characteristics broken down by tumour type: ovarian cancer (241 first invasive primaries diagnosed and treated in IEO[a])

Table E1: Characteristics at diagnosis

Classification	No.	%
Age		
<35 years	24	10.0
35-49 years	68	28.2
50-64 years	108	44.8
65+ years	41	17.0
Histology		
Serous adenocarcinoma	98	40.7
Endometrioid adenocarcinoma	37	15.4
Borderline malignancy	34	14.1
Adenocarcinoma, NOS	22	9.1
Other type of adenocarcinoma	15	6.2
Clear cell adenocarcinoma	14	5.8
Granulosa cell adenocarcinoma	7	2.9
Mucinous adenocarcinoma	7	2.9
Germ cell tumour	5	2.1
Transitional cell adenocarcinoma	2	0.8
FIGO stage[b]		
IA	35	15.6
IB	5	2.2
IC	26	11.6
IIA	5	2.2
IIB	8	3.6
IIC	9	4.0
III	8	3.6
IIIA	3	1.3
IIIB	6	2.7
IIIC	94	41.8
IV	26	11.6

Table E2: Treatment strategy

Type of Treatment		No.	%
Surgery	HT	2	0.8
	CT	139	57.7
	CT+HT	10	4.1
	CT+MRT	4	1.7
	No	54	22.4
	HT/CT/MRT	27	11.2
Neoadjuvant treatment + surgery	CT	2	0.8
	HT+CT	1	0.4
	MRT	1	0.4
No surgery	No	1	0.4
	HT/CT/MRT	1	0.4
	CT	1	0.4

Figure E1: Place of surgery

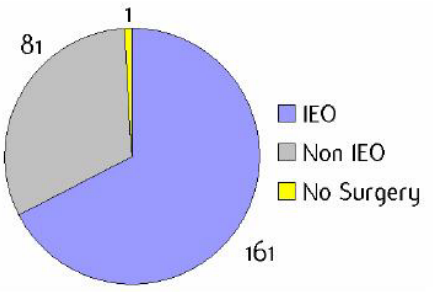
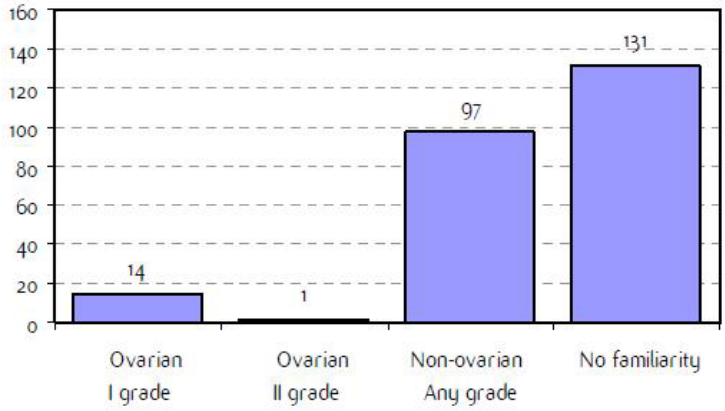


Figure E2: Familiarity for ovarian and non-ovarian cancer



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]Information is missing for some patients. HT: Hormonotherapy; CT: chemotherapy and/or monoclonal antibody; MRT: metabolic radiotherapy; NOS: not otherwise specified.

Appendix F: Characteristics broken down by tumour type: prostate (376 first invasive primaries treated and diagnosed in IEO[a])

Table F1: Characteristics at diagnosis

Classification	No.	%
Age		
<65 years	173	46.0
65-70 years	110	29.3
70-75 years	71	18.9
75-80 years	17	4.5
80+ years	5	1.3
Histology		
Acinar adenocarcinoma	372	98.9
Moucinous carcinoma	2	0.5
Adenosquamous carcinoma	1	0.3
Basaloid carcinoma	1	0.3
pT[b]		
pT2	155	43.2
pT3	112	31.2
pT4	11	3.1
pTx	81	22.6
pN[b]		
pN0	154	42.5
pN1	14	3.9
pNx	194	53.6
M		
M0/Mx	365	97.0
M1	11	3.0

Table F2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	HT	37	9.8
		CT	1	0.3
		HT+CT	4	1.1
		No HT/CT	48	12.8
	No RT	HT	31	8.2
		CT	0	0.0
		HT+CT	2	0.5
		No HT/CT	174	46.3
No surgery	RT	HT	38	10.1
		CT	0	0.0
		HT+CT	5	1.3
		No HT/CT	30	8.0
	No RT	HT	6	1.6
		CT	0	0.0
		HT+CT	0	0.0

Figure F1: Place of surgery

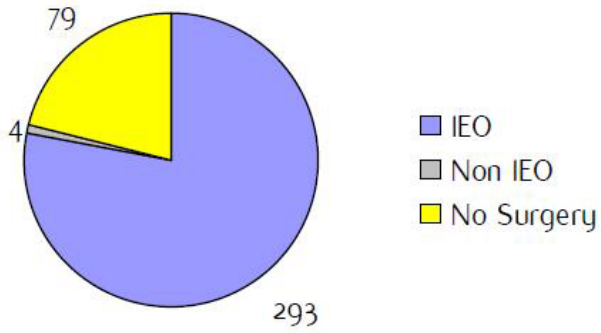
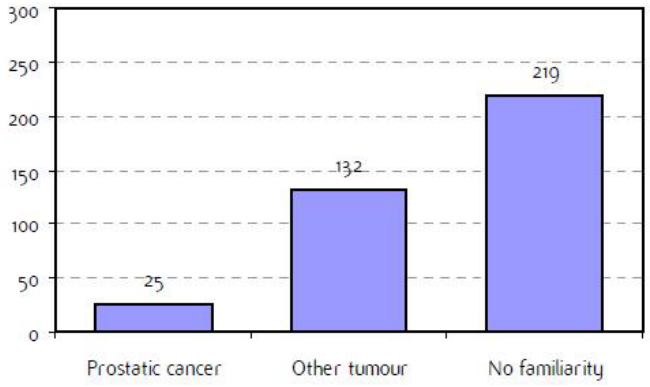


Figure F2: Familiarity for prostatic and non-prostatic cancer



[a]Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]information is missing for some patients; RT: radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody. NOS: not otherwise specified.

Appendix G: Characteristics broken down by tumour type: sarcoma (161 first invasive primaries treated and diagnosed in IEO[a])

Table G1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	76	47.2
Female	85	52.8
Age		
<35 years	16	9.9
35-49 years	50	31.1
50-64 years	42	26.1
65+ years	53	32.9
Histology		
Sarcoma, NOS	40	24.8
Leiomyosarcoma	31	19.3
Liposarcoma	25	15.5
Fibrosarcoma	18	11.2
Carcinosarcoma	11	6.8
Synovial sarcoma	8	5.0
Angiosarcoma	6	3.7
Epithelioid sarcoma	5	3.1
Kaposi sarcoma	3	1.9
Chondrosarcoma	2	1.2
Primitive neuroectodermal tumour	2	1.2
Rhabdomyosarcoma	2	1.2
Other	8	5.0
Specific site		
Viscerals organs	44	27.3
Trunk	33	20.5
Female genital organs	24	14.9
Lower extremity	24	14.9
Retroperitoneum	16	9.9
Head and neck	8	5
Upper extremity	8	5
Male genital organs	4	2.5
M		
M0/MX	152	94.4
M1	9	5.6

Table G2: Treatment strategy

Treatment Combination			No.	%
Surgery	RT	HT	2	1.2
		CT	29	18.0
	No RT	No HT/CT	36	22.4
		CT	26	16.1
		HT+CT	1	0.6
		No HT, no CT	48	29.8
Neoadjuvant treatment + surgery	RT	CT	4	2.5
		no CT	1	0.6
	No RT	no CT	3	1.9
No surgery	RT	CT	3	1.9
		HT+CT	1	0.6
	No RT	CT	7	4.3

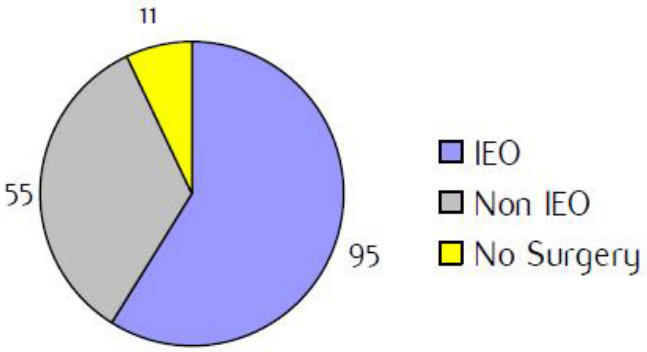


Figure G1: Place of surgery

[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]information is missing for some patients. RT: Radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody; NOS: not otherwise specified.

Appendix H: Characteristics broken down by tumour type: skin melanoma (370 first invasive primaries diagnosed and treated in IEO[a])

Table H1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	179	48.4
Female	191	51.6
Age		
<35 years	55	14.6
35-49 years	127	34.3
50-64 years	106	28.6
65+ years	82	22.2
Specific site of skin		
Skin of head and neck	26	7.0
Skin of upper extremity	44	11.9
Skin of trunk	158	42.7
Skin of lower extremity	124	33.5
Skin, NOS	18	4.9
Histology		
Superficial spreading	260	70.3
Nodular	56	15.1
Malignant, NOS	36	9.7
Acral lentiginous	9	2.4
Lentigo maligna	8	2.2
Desmoplastic	1	0.3
pT[b]		
pT1	68	18.7
pT2	71	19.5
pT3	173	47.5
pT4	33	9.1
pTX	19	5.2
pN[b]		
pN0	215	60.1
pN1	58	16.2
pN2	5	1.4
pN3	1	0.3
pNX	79	22.1
M		
M0/MX	348	94.1
M1	22	5.9

Table H2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	HT+CT	6	1.6
		No HT/CT	1	0.3
		CT	14	3.8
	No RT	HT+CT	1	0.3
		No HT/CT	270	73.0
Surgery + immunotherapy	RT	CT	9	2.4
		HT+CT	1	0.3
		No HT/CT	3	0.8
		CT	15	4.1
	No RT	HT+CT	1	0.3
		No HT/CT	49	13.2

Figure H1: Place of surgery

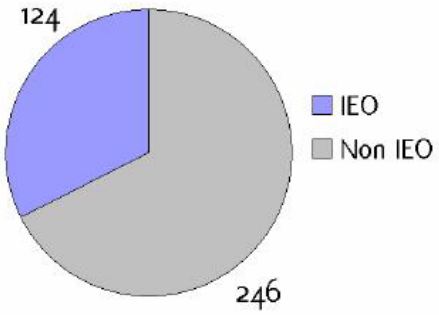
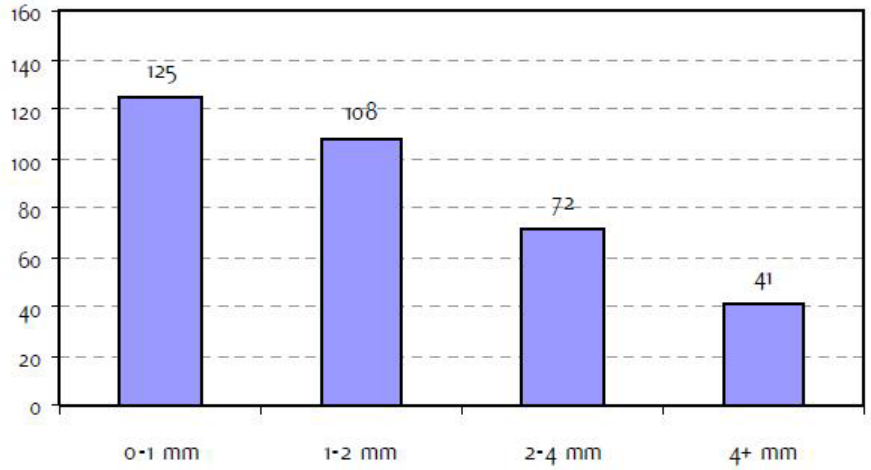


Figure H2: Breslow thickness [b]



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]information is missing for some patients. RT: Radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody. NOS: not otherwise specified.

Appendix I: Characteristics broken down by tumour type: tongue (90 first invasive primaries diagnosed and treated in IEO[a])

Table I1: Characteristics at diagnosis

Classification	No.	%
Gender		
Male	56	62.2
Female	34	37.8
Age		
<35 years	12	13.3
35-49 years	14	15.6
50-64 years	34	37.8
65+ years	30	33.3
Histology		
Squamous cell carcinoma	84	93.3
Adenocystic carcinoma	3	3.3
Mucoepidermoid carcinoma	2	2.2
Verrucous carcinoma	1	1.1
T[b]		
T1	26	29.9
T2	28	32.2
T3	8	9.2
T4	24	27.6
TX	1	1.1
N[b]		
N0	29	32.6
N1	18	20.2
N2	28	31.5
N3	2	2.2
NX	12	13.5
M		
M0/MX	89	98.9
M1	1	1.1

Table I2: Treatment strategy

Type of Treatment			No.	%
Surgery	RT	CT	11	12.2
		No CT	32	35.6
	No RT	CT	0	0.0
		No CT	37	41.1
Neoadjuvant treatment + surgery	RT	CT	1	1.1
		No CT	1	1.1
	No RT	CT	1	1.1
		No CT	2	2.2
No surgery	RT	CT	2	2.2
		No CT	3	3.3
	No RT	CT	0	0.0
		No CT	0	0.0

Figure I1: Place of surgery

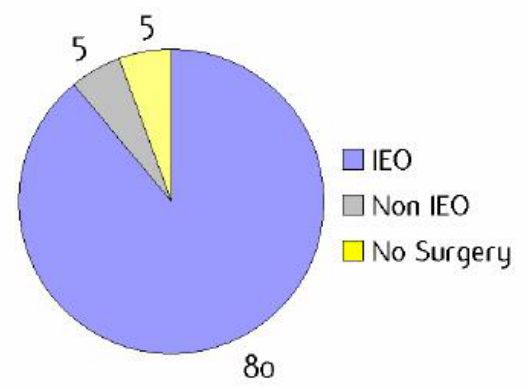
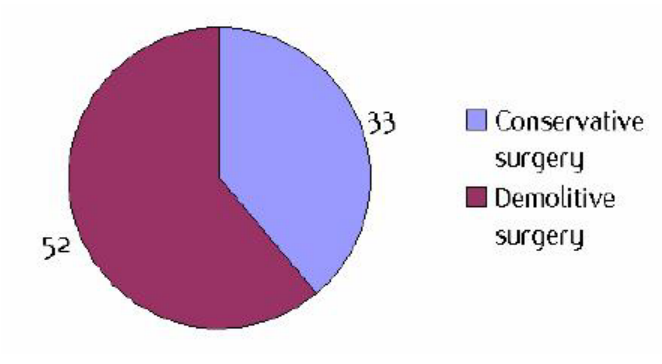


Figure I2: Type of surgery



[a]'Long' record type (at least one treatment in IEO); pathological diagnosis in IEO (at least a slide review in IEO); [b]information is missing for some patients; RT: radiotherapy; HT: hormonotherapy; CT: chemotherapy and/or monoclonal antibody.