

# European Registries for oncology

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101008548

- Population-based cancer registries
- Hospital-based/clinical cancer registries
- New approaches



# Population-based cancer registries

## European Network of Cancer Registries



International Agency for Research on Cancer **GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012**

World Health Organization

ABOUT DATA SOURCES AND METHODS FACT SHEETS ONLINE ANALYSIS HELP

QUICK LINKS

- Population Fact Sheets
- Cancer Fact Sheets
- Simple Maps
- Predictions
- FAQ

**GLOBOCAN 2012**  
ESTIMATED CANCER INCIDENCE, MORTALITY AND PREVALENCE WORLDWIDE IN 2012

**Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2)**

*Claudia Allemani, Hannah K Weir, Helena Carreira, Rhea Harewood, Devon Spika, Xiao-Si Wang, Finian Bannan, Jane V Ahn, Christopher J Johnson, Audrey Bonaventure, Rafael Marcos-Gragera, Charles Stiller, Gulnar Azevedo e Silva, Wan-Qing Chen, Olufemi J Ogunbiyi, Bernard Rachet, Matthew J Soeberg, Hui You, Tomohiro Matsuda, Magdalena Bielska-Lasota, Hans Storm, Thomas C Tucker, Michel P Coleman, and the CONCORD Working Group\**



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# Burden and centralised treatment of rare tumors: results of RARECAREnet – a population-based study

	Belgium (10.5*)			Bulgaria (7.7*)			Finland (5.3*)			Ireland (4.2*)			Netherlands (16.3*)		
	Cases	H75	Treat	Cases	H75	Treat	Cases	H75	Treat	Cases	H75	Treat	Cases	H75	Treat
Head and neck	2098	29	105.6	1180	10	145.1	439	6	82.2	368	7	63.0	2439	12	201.4
Epithelial ovary	760	50	19.5	627	16	52.3	370	10	44.5	261	15	21.0	1118	47	30.2
Oesophagus	689	31	29.3	77	14	5.2	163	8	21.6	289	9	37.1	1422	31	42.0
CNS	623	20	48.4	412	13	41.7	57	4	19.1	229	3	106.3	912	14	84.0
Soft tissue sarcoma	500	35	16.6	372	21	18.4	165	7	25.6	157	17	10.6	802	33	26.4
Thyroid	576	34	14.2	220	12	20.4	286	12	22.8	98	11	9.6	418	31	17.1
Testis	244	40	8.4	180	19	12.4	101	9	14.3	144	12	15.6	609	42	18.4
Biliary tract	214	44	4.9	183	23	6.5	147	13	11.3	122	14	7.7	582	38	12.2
Gastroenteric-pancreatic neuroendocrine tumour	287	46	5.6	30	21	1.3	148	13	9.3	61	20	2.7	355	44	6.9
Liver	250	22	11.0	107	12	7.6	165	11	12.8	68	12	4.6	236	36	5.2
Urinary tract	292	48	6.7	67	17	4.1	48	12	3.9	24	10	2.3	419	46	7.7
Mesothelioma	184	25	8.7	34	10	3.7	64	9	6.8	25	11	2.0	481	43	9.8
Vagina	172	35	5.8	120	9	14.0	70	5	14.8	40	9	4.7	296	14	21.8
Bone sarcoma	81	10	10.2	55	13	4.6	28	3	9.6	30	7	5.2	195	5	43.3
Anal canal	95	27	5.3	39	12	4.1	24	7	4.6	30	9	4.4	135	22	7.2
Melanoma of uvea	43	2	21.9	17	7	2.7	6	1	5.5	29	4	5.7	156	2	80.2
Penis	63	43	1.4	39	17	2.4	21	10	2.1	20	15	1.2	109	26	3.7
Small intestine	62	37	1.9	15	13	1.1	26	13	2.1	27	20	1.3	120	38	2.6
Neuroendocrine carcinoma of skin	46	32	1.9	1	3	0.4	0			15	18	0.8	77	37	2.3
Non-epithelial ovary	20	19	1.3	43	17	3.2	8	9	1.1	8	15	0.6	32	24	1.4
Endocrine carcinoma of thyroid	31	22	1.4	10	9	1.2	8	8	1.2	5	10	0.5	32	13	2.7
Thymus	22	20	1.4	7	8	1.3	4	5	1.1	5	5	1.3	36	15	2.8
Nephroblastoma	18	4	7.4	6	3	2.8	8	3	4.7	7	1	13.4	30	4	16.9
Melanoma of mucosa	14	24	0.8	2	5	0.8	10	7	1.7	6	11	0.6	34	13	3.0
Adrenal cortex	13	14	1.1	13	10	1.3	6	7	0.9	5	11	0.4	25	15	1.5
Embryonal CNS	21	9	4.2	14	9	2.5	6	3	3.1	9	3	6.3	0		
Neuroblastoma	15	4	5.7	8	5	1.7	1	1	2.1	7	2	5.4	12	4	6.2
Retinoblastoma	10	1	14.0	3	5	0.5	3	2	1.5	3	2	1.8	22	1	30.7
Trachea	10	18	0.9	5	4	1.1	4	5	0.9	2	4	0.4	11	11	1.1

doi: 10.1016/S1470-2045(17)30445-X



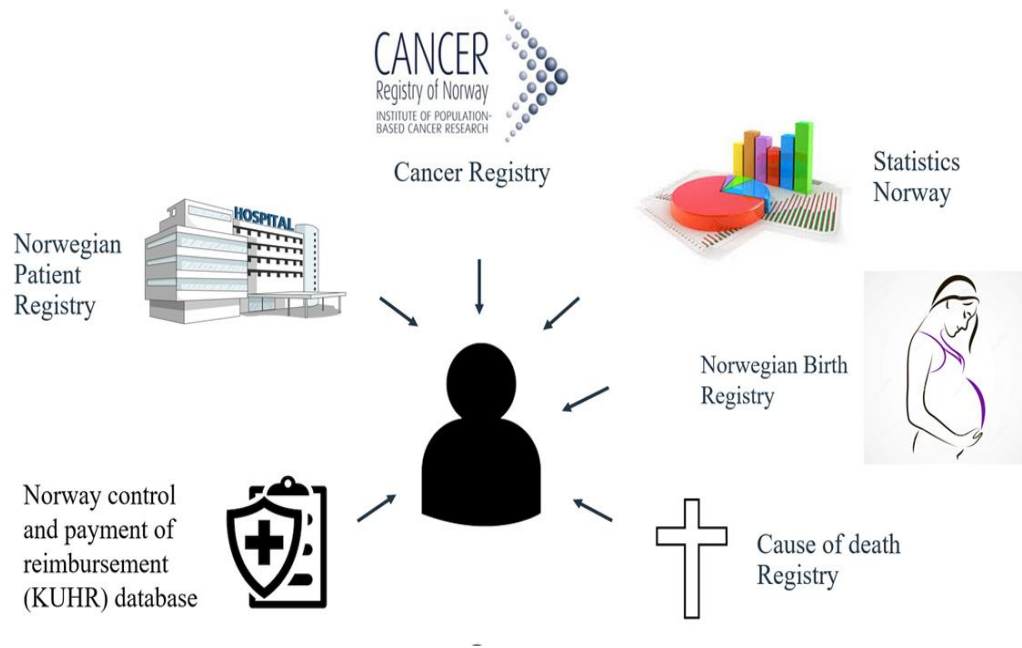
# Quality of care for head and neck cancers

## Quality of Care Indicators for Head and Neck Cancers: The Experience of the European Project RARECAREnet

Annalisa Trama<sup>1\*</sup>, Laura Botta<sup>1</sup>, Roberto Foschi<sup>1</sup>, Otto Visser<sup>2</sup>, Josep Maria Borrás<sup>3</sup>, Tina Zagar<sup>4</sup>, Maja Primic-Zakelj<sup>5</sup>, Francesca Belli<sup>6</sup>, Nadya Dimitrova<sup>7</sup>, Gemma Gatta<sup>8</sup> and Lisa Lictra<sup>9</sup> on behalf of the RARECAREnet High Resolution Working Group

Country	Indicator 2. Time to start RT or surgery	Indicator 3. Time in starting adjuvant therapy	Indicator 4% of patients with L disease stage treated with surgery or RT	Indicator 5% of patients with A disease stage treated with multi therapy
	% starting surgery or RT < 1 month from diagnosis	% starting adjuvant therapy < 8 weeks from the surgery	% treated with surgery alone or RT alone	% treated with multi therapy
Ireland	41	33	72	43
Italy	61	52	75	19
Netherlands	39	79	79	21
Slovenia	41	57	72	44

# Population-based registries... enrichments



## Pros

- Unbiased
- High number of cases
- Rare events
- Long-term follow-up

## Cons

- Diagnostic uncertainty
- Missing clinical details
- Heterogeneity in measurements of treatment outcomes

# Clinical cancer registry

*“an organized system that uses **observational study methods** to collect uniform data (clinical and other) for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes”*

*Gliklich RE, Dreyer NA. Registries for Evaluating Patient Outcomes: A User's Guide (2nd ed.). Rockville, MD: Agency for Healthcare Research and Quality, 2010.*

# EURACAN registry



1. **Head & neck cancers**
2. **Sarcomas**
3. Digestive rare cancers
4. Neuroendocrine tumours
5. Rare thoracic cancers
6. Endocrine gland tumours
7. Central nervous system tumours
8. Rare female genital cancers
9. Rare urological and male genital tumours
10. Rare skin cancers & non-cutaneous melanoma





# Registry objectives

ClinicalTrials.gov Identifier: NCT05483374

to help describe the natural history of rare head and neck cancers;

to evaluate factors that influence prognosis (e.g. mortality, survival, progression free survival and treatment response);

to assess treatments effectiveness (systemic, radiotherapy, surgery, target therapy, immunotherapy and possible combinations);

to measure indicators of quality of care (diagnostic and staging procedures, treatment strategies, follow-up etc.).

Virtual bio and imaging bank



# Inclusion criteria

**Patients with epithelial tumours of the rare head and neck cancers (sinonasal, NPC, salivary gland, middle ear)**

- Squamous; **Adenocarcinoma; Neuroendocrine**; adenosquamous carcinoma, teratocarcinosarcoma, NUT carcinoma (NO sarcoma, melanoma or other histologies)

**Adult rare head and neck cancer patients; age  $\geq 18$  years old** (EURACAN vs PaedCan)

**Patients with a diagnosis done and/or confirmed by the expert centre contributing data to the registry**

Patients entering the hospital for **any clinical phase** of the disease (diagnosis, treatment of primary localised, of primary local advanced, of primary metastatic, treatment of recurrence). **The hospital will collect information on the entire disease regardless of when it started to manage the patient.**

**Prospective registry**



## Information available

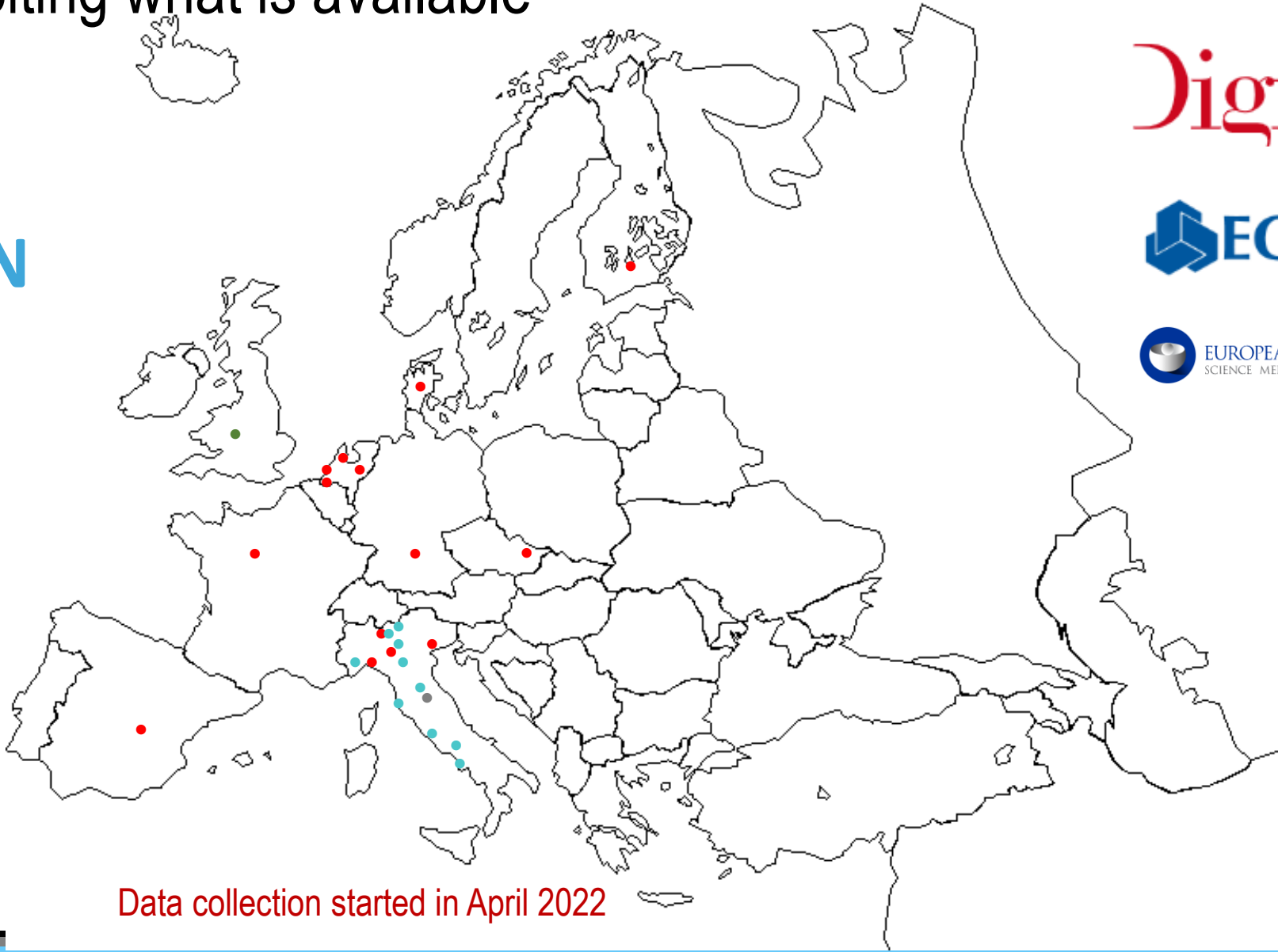
- Demographic and lifestyle (eg, age, sex, education, alcohol, smoking, comorbidities)
- Previous cancer and genetic syndrome
- Primary cancer (site, histology, EBV, HPV status)
- Staging (procedures, cTNM, pTNM)
- Treatment (surgery, **radiotherapy**, systemic: intent, setting, regimen...)
- Progression/relapse (local, regional, metastatic + treatment)
- Adverse events
- Life status





# Exploiting what is available

## • EURACAN

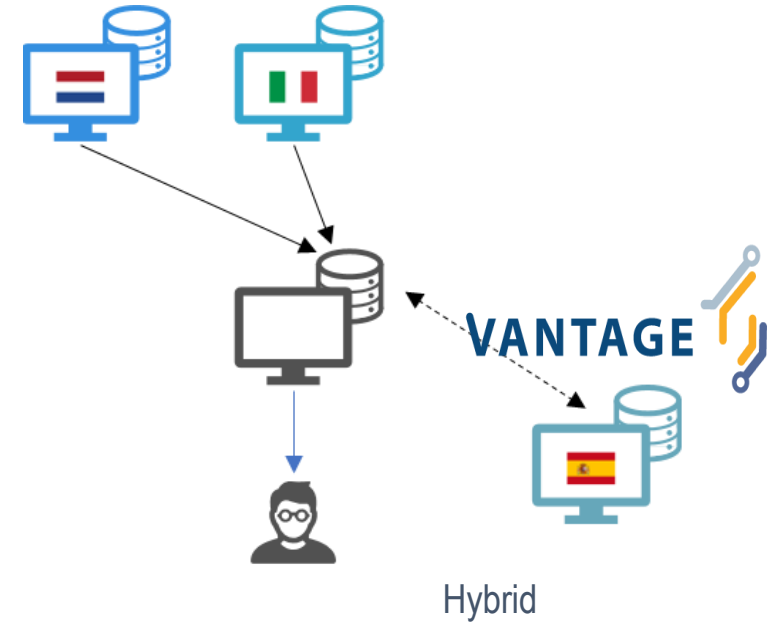
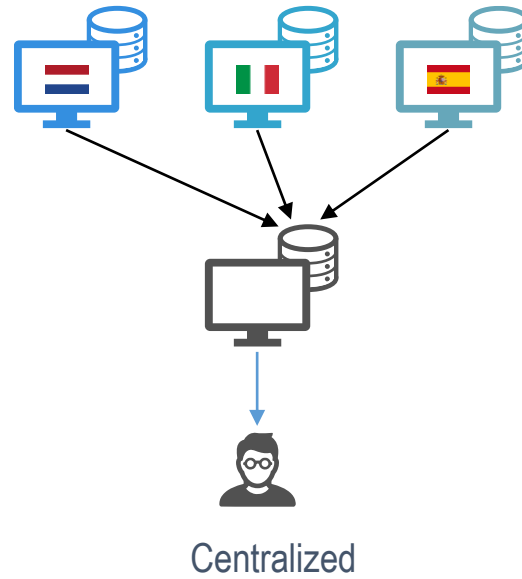
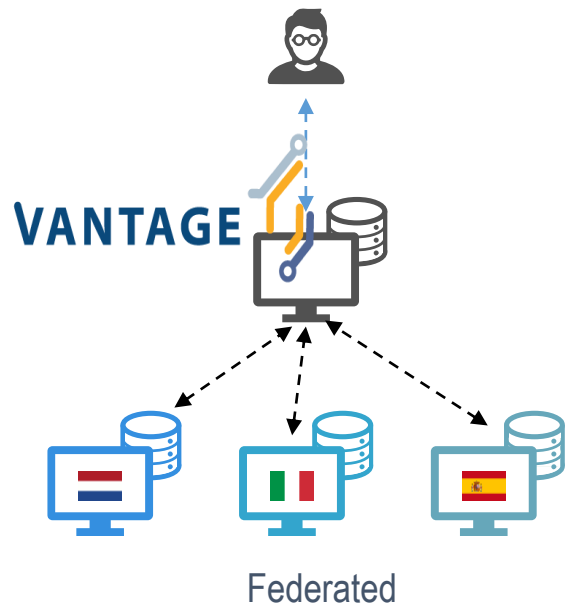


Data collection started in April 2022



om the European Union's Horizon 2020 e under grant agreement No 101008548

# IT infrastructure vs legal framework





# Soft tissue sarcoma registry

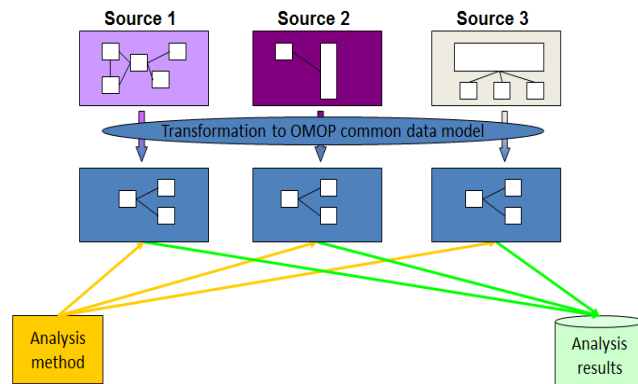
Common sarcomas

Core data set

Data integration from already available DBs

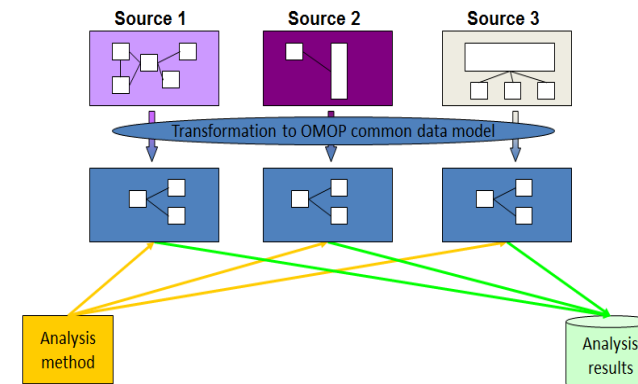
The Observational Medical Outcomes Partnership (OMOP) Common Data Model

OMOP Common Data Model



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# Registry quality assurance

## Health care provider level

- Automated data quality checks are in place at data entry
- Data quality checks can be run by users
- Training
- Guidelines

## Central level

- Centralised data manager monitoring (data quality reports issued, contact with data providers)
- Routine meetings discussing data quality (including data retrieval and data sources)
- Bench mark
- Data checked and accessible for the analyses yearly

# Data access rules

Data remain the property of the contributing HCPs or registries

**Each HCP or national registry is free to access and use its own data for research purposes**

## **Who can use the registry data (upon the presentation of a study protocol)**

each HCP or national registry including data in the EURACAN Registry

**third parties** (e.g., pharmaceutical companies, patient organisations, competent authorities etc.)

**commercial companies, depending on the study, may be asked to contribute funding. Data do not move from the HCPs or national registries and the commercial companies will not access the EURACAN registry federated database.**

## **Review of the study protocol**

domain registry working group (RWG), made up of 3 to 5 members including an ePAG, to review the study protocols presented for the domain. Additional expertise may be brought in as required.

## **HCP/registries agreement**



# Legal basis: country specific

## General Data Protection Regulation

Under Article 9(2) of the GDPR, lawful processing of personal data for scientific research entails:

- the consent of data subjects,
- the pursuing of a substantial public interest,
- the pursuing of a scientific research purpose.

Institutional consent already collecting the consent of the patients for using their data for future research can be used

Ad hoc registry consent (**template available in english**)



gear icon harmonization software + AI icon NLP to process texts

according to the IDEA4RC data model



head and neck cancers + sarcoma database

