



WP 7 - Task 6

Promoting the use of comprehensive cancer prevalence indicators in Europe

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TASK 6: MAIN OBJECTIVE & RATIONALE

Aim

promote the use of **current registries datasets** to derive **population-based indicators** on **cancer prevalence** at Country level in Europe

Why?

prevalence indicators only sparsely available despite their **informative potential**, especially in the context of a dramatic increase of cancer survivors

CANCER PREVALENCE: CURRENTLY AVAILABLE INFORMATION

GLOBOCAN provides
5-y prevalence by
cancer site, sex and
geographical area

Long-term observed
prevalence available from
historical registries (30y or
more), e.g. **NORDCAN** for
Nordic European countries

International Agency for Research on Cancer



GLOBOCAN 2012: Estimated Cancer Incidence,
Mortality and Prevalence Worldwide in 2012



ABOUT

DATA SOURCES AND METHODS

FACT SHEETS

ONLINE ANALYSIS

HELP

You are here: Home / Fact Sheets / Cancer Fact Sheets

All cancers excl. non-me...

Incidence: [men](#)

Mortality: [men](#)

Incidence: [women](#)

Mortality: [women](#)






All Cancers (excluding non-melanoma skin cancer)

Estimated Incidence, Mortality and Prevalence Worldwide in 2012

Estimated numbers (thousands)	Men			Women			Both sexes		
	Cases	Deaths	5-year prev	Cases	Deaths	5-year prev	Cases	Deaths	5-year prev
World	7410	4653	15296	6658	3548	17159	14068	8202	32455
More developed regions	3227	1592	8550	2827	1287	8274	6054	2878	16823
Less developed regions	4184	3062	6747	3831	2261	8885	8014	5323	15632
WHO Africa region (AFRO)	265	205	468	381	250	895	645	456	1363
WHO Americas region (PAHO)	1454	677	3843	1429	618	4115	2882	1295	7958
WHO East Mediterranean region (EMRO)	263	191	461	293	176	733	555	367	1194
WHO Europe region (EURO)	1970	1081	4791	1744	852	4910	3715	1933	9701
WHO South-East Asia region (SEARO)	816	616	1237	908	555	2041	1724	1171	3278
WHO Western Pacific region (WPRO)	2642	1882	4493	1902	1096	4464	4543	2978	8956
IARC membership (24 countries)	3689	1900	9193	3349	1570	9402	7038	3470	18595
United States of America	825	324	2402	779	293	2373	1604	617	4775
China	1823	1429	2496	1243	776	2549	3065	2206	5045
India	477	357	665	537	326	1126	1015	683	1790
European Union (EU-28)	1430	716	3693	1206	561	3464	2635	1276	7157



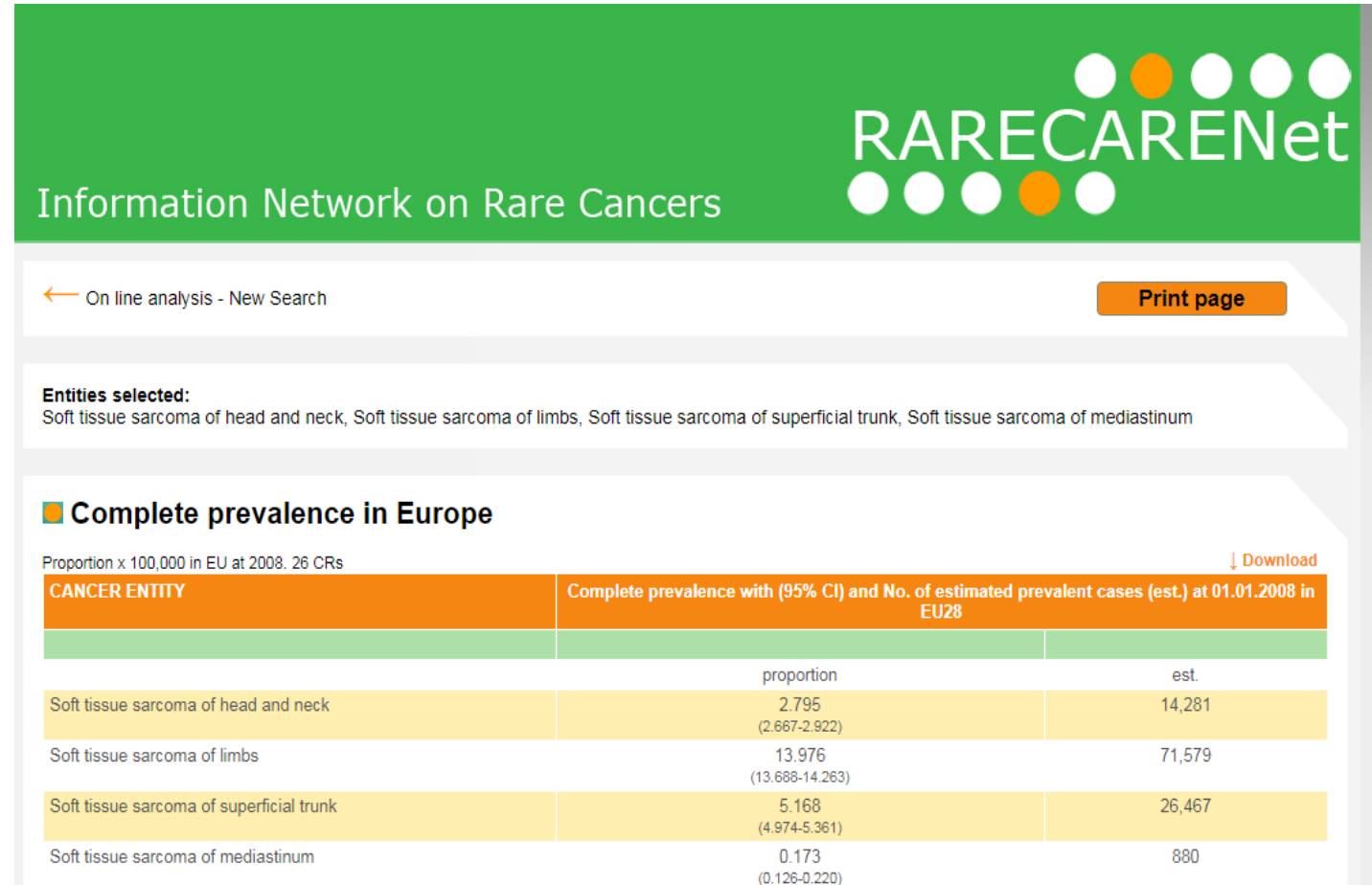
All sites but non-melanoma skin cancer, Female
Prevalence (end of 2016), age 0-85+

Country	Numbers (Proportion per 100,000)						
	1-year	3-year	5-year	10-year	Total		
Nordic countries	55309 (410.4)	150495 (1116.8)	229552 (1703.5)	387356 (2874.5)	707206 (5248.1)		
 Denmark	13725 (475.7)	37114 (1286.4)	56342 (1952.9)	95514 (3310.6)	164598 (5705.1)		
 Finland	11437 (411.9)	30589 (1101.8)	46755 (1684.1)	79133 (2850.3)	147931 (5328.3)		
 Iceland	542 (323.9)	1464 (875.0)	2273 (1358.5)	3958 (2365.6)	7459 (4458.0)		
 Norway	10506 (402.7)	28465 (1091.0)	42975 (1647.1)	71679 (2747.2)	130739 (5010.7)		
 Sweden	19099 (379.1)	52863 (1049.4)	81207 (1612.0)	137072 (2721.0)	256479 (5091.3)		

Proportions per 100,000

COMPLETE PREVALENCE: RARE CANCERS IN EUROPE

- Complete prevalence for **rare cancers** in Europe
- **RARECARE** project
Eur J Cancer 2011
- **RARECARE-net** project
Lancet Oncol 2017



<http://www.rarecarenet.eu>

COMPREHENSIVE PREVALENCE INDICATORS IN ITALY

AIRTUM Monographs 2011, 2015

- Systematic estimates of prevalence in Italy
- complete and by disease duration
- Indicators on cured survivors, time to cure and cure fraction

CURE FRACTION AND TIME TO CURE BY AGE AT DIAGNOSIS AND SEX FOR CANCER PATIENTS DIAGNOSED IN ITALY IN 1985-2009

AGE AT DIAGNOSIS	CURE FRACTION %	
	MALE	FEMALE
0 - 44	43%	45%
45 - 59	30%	29%
60 - 74	18%	14%
75+	12%	9%

AGE AT DIAGNOSIS	TIME TO CURE YEARS	
	MALE	FEMALE
0 - 44	21	25
45 - 59	>25	>25
60 - 74	>25	>25
75+	>25	>25

<https://www.registri-tumori.it/cms/pubblicazioni/i-tumori-italia-rapporto-2014-prevalenza-e-guarigione-da-tumore-italia>



Pool of Italian Cancer Registries - 1 January 2010

LINFOMA NON-HODGKIN NON-HODGKIN LYMPHOMA

(ICD-10 C82-85,96)

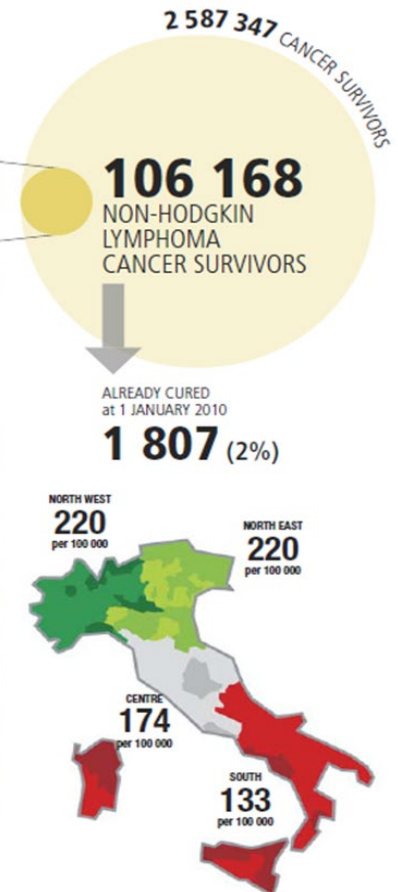
COMPLETE PREVALENCE BY YEARS SINCE DIAGNOSIS

YEARS →	≤ 2	(2 - 5]	(5 - 10]	(10 - 15]	(15 - 20]	> 20
No. →	18 577	23 331	25 656	16 826	9 333	12 444
% →	17%	22%	24%	16%	9%	12%
PROPORTION PER 100 000	33	41	46	30	17	22
	MALE 51%			FEMALE 49%		

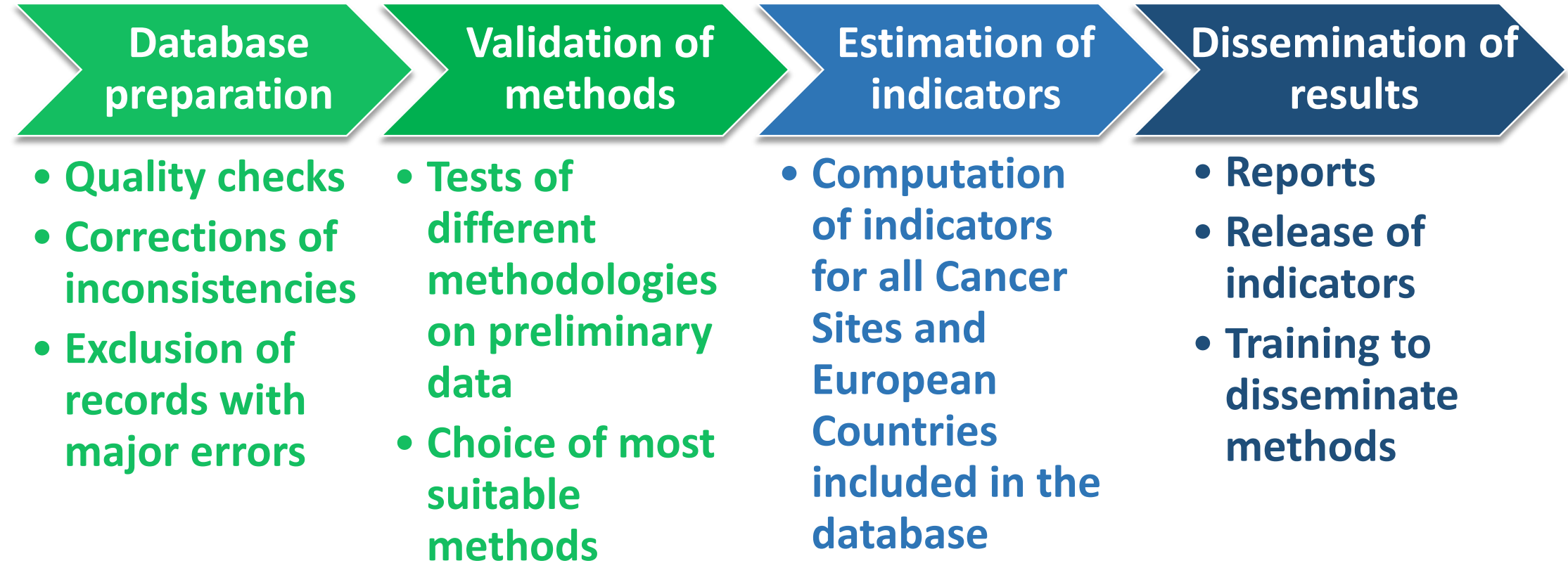
COMPLETE PREVALENCE BY SEX, MACRO-AREA, AND AGE (PROPORTION PER 100 000)

AGE CLASS →	0-44	45-59	60-74	75+	ALL AGES
MALE					
NORTH WEST	59	240	499	672	228
NORTH EAST	53	253	521	775	232
CENTRE	48	222	356	550	178
SOUTH	53	182	344	395	145
POOL	54	225	451	619	199
FEMALE					
NORTH WEST	40	191	441	499	212
NORTH EAST	43	195	431	540	208
CENTRE	40	185	349	423	170
SOUTH	34	153	278	292	122
POOL	39	180	384	453	178
BOTH SEXES					
NORTH WEST	49	215	468	561	220
NORTH EAST	48	224	474	625	220
CENTRE	44	203	352	472	174
SOUTH	43	167	309	333	133
POOL	47	202	416	515	188

**AIRTUM- Report 2014,
Epid&Prev 2015**



TASK 7.6: GENERAL WORK PLAN



TASK 7.6: DATABASE

- Task 7.6 activity relies on the [EUROCARE-6 project](#), the widest collaborative study on cancer survival and prevalence in Europe
- **Unique** data collection protocol, quality checks procedures, statistical methods for all countries/CRs
- Data collection protocol and quality checks **agreed and harmonised with ENCR-JRC** call for data 2015-2016



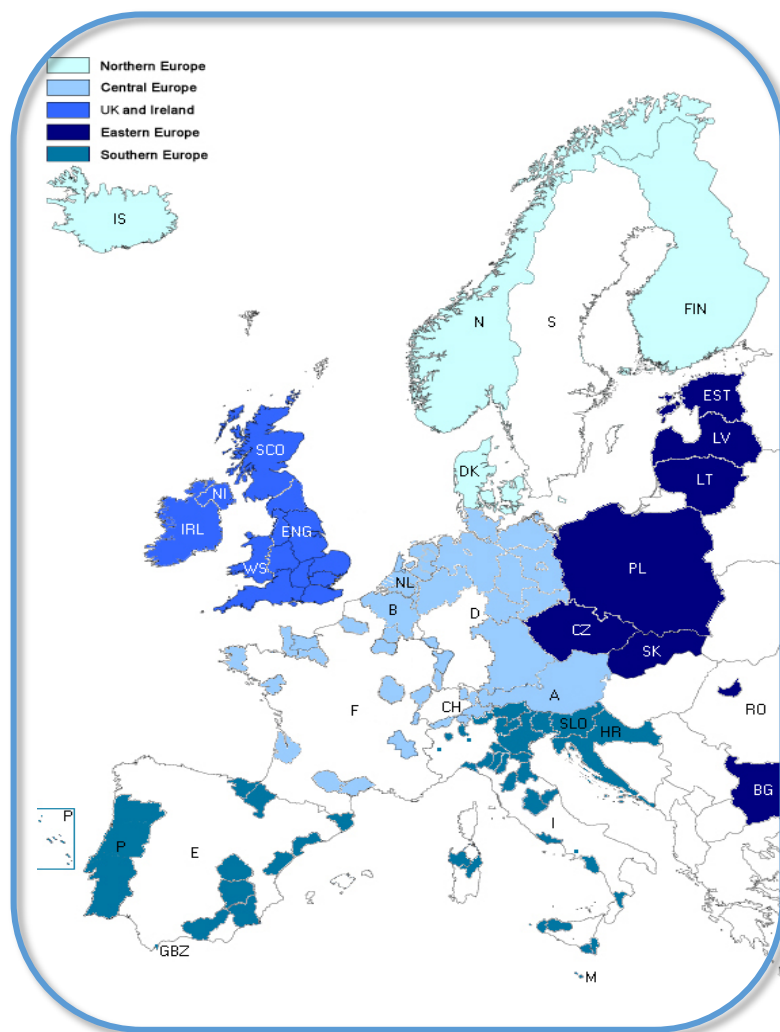
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Call for data

The ENCR and the JRC have organised the 2015 ENCR-JRC Call for Data intended for all the European Cancer Registries in order to build a unique anonymised database of cancer data. It is the wish of the ENCR to reduce the number of data calls due to the heavy workload on Cancer Registries responsible for submitting cleaned data to various European

EUROCare-6 DATA FROM 134 CANCER REGISTRIES



**102
Eligible
Cancer
Registries**

29 Countries
23 National Registries +
6 with partial coverage

**6 countries with local
registries (79 CRs):**
France (16), Germany (7), Italy
(39), Portugal (3), Spain (9),
Switzerland (5)



29 PARTICIPATING COUNTRIES POPULATION AND TIME COVERAGE

	Countries	Time period																Max duration	Prevalence Index Date 1 Jan yyyy																					
		78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93			94	95	96	97	98	99	00	01	02	03	04	05	06	07	08	09	10	11	12	13	14
23 National CRs	DENMARK																																						37	2015
	FINLAND																																						36	2014
	ICELAND																																						37	2015
	NORWAY																																						38	2016
	IRELAND																																						19	2013
	UK-ENGLAND																																						19	2014
	UK-NORTHERN IRELAND																																						21	2012
	UK-SCOTLAND																																						36	2012
	UK-WALES																																						22	2013
	AUSTRIA																																						30	2013
	BELGIUM																																						10	2014
	THE NETHERLANDS																																						25	2014
	BULGARIA																																						21	2014
	CZECH REPUBLIC																																						20	2012
	ESTONIA																																						35	2013
	LATVIA																																						14	2014
	LITHUANIA																																						20	2013
	POLAND																																						13	2012
	SLOVAKIA																																						33	2011
	CROATIA																																						13	2011
	CYPRUS																																						11	2013
	MALTA																																						21	2014
	SLOVENIA																																						30	2013
79 Local CRs																																								
	France (16)	2		1									7		1			1	1						2				1										6-35	2012
	Germany (7)																1					1		1	1	1	1	1										8-20	2011-2014	
	Italy (39)	2			1				1	2	1	1		1	1	1		1	4	4		1	3			1	6		1	5	2							6-37	2011-2014	
	Portugal (3)																							2							1							4-13	2011-2013	
	Spain (9)	1				1			1	1		1		1				1		1								1										9-33	2013-2015	
	Switzerland (5)	1			1							1												1						1								8-36	2013-2014	

Diagnosis

Follow up

Diagnosis & Follow-up

 Diagnosis
 Follow up
 Diagnosis & Follow-up

TASK 7.6: TARGET INDICATORS

1. Complete and limited-duration prevalence

- time projections
- phase of care (initial, terminal, intermediate)

2. Prevalence of cured patients, cure fraction and time to cure (*mixture cure models*)

3. Life expectancy of cancer survivors



Validation of methods and estimates on the of **prevalence** for **3 iPAAC index tumors: colon, pancreas and skin melanoma**

Evaluation of methods for the **projection** of prevalence estimates to **1st January 2021** (in progress)

- **Complete prevalence**

- **Proportion (number)** of people alive at a given date (*index date*) who had a cancer diagnosis, regardless of how long ago the diagnosis was made

- **Limited-duration prevalence**

- Proportion (number) of people alive at the index date who had a diagnosis **n years before**. e.g. 1, 2, 5, 10, 20, ... y

- **Observed prevalence**

- Observed by CRs following up life status of incident cases over time
- Maximum observed duration is limited by time length of cancer registration
- Only historical CRs (activity >40,50 years) can measure complete prevalence, all others CRs measure limited-duration prevalence

OBSERVED PREVALENCE:

- **Counting method**

- Incident cases alive at the index date are simply 'counted'
- Alive patients among those lost to follow up are estimated using patients' survival

Problem

prevalence can be highly underestimated if the registry has a short registration period

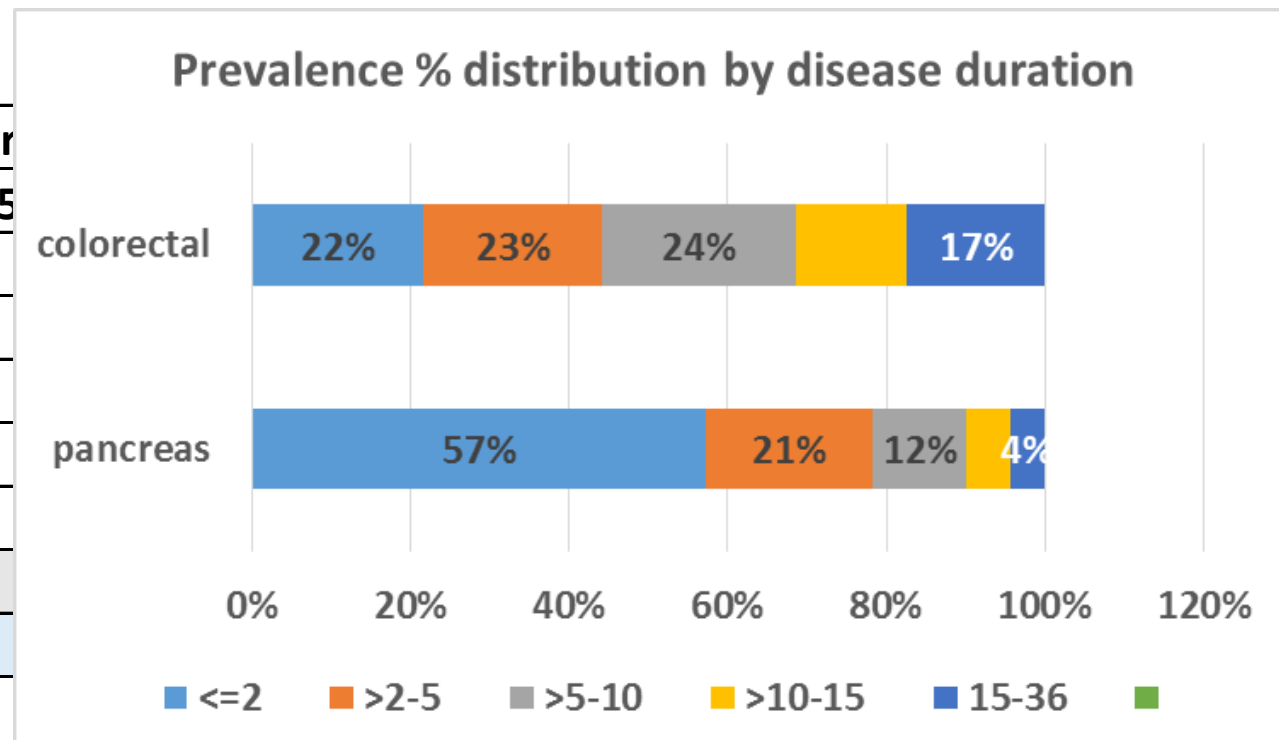
**COLORECTAL CANCER Prevalence at 1/1/2014 in Belgium
(EUROCARE-6 results)**

Disease Duration	Estimated Prevalence Prop. X 100,000	Estimated Prevalence Count	Known Alive	Lost	Lost Estimated Alive	Dead Prior to Prevalence Date
<=1 Year	66	7,413	7,392	23	21	944
>1-2 Years	57	6,333	6,299	42	34	1,989
>2-3 Years	49	5,480	5,444	47	36	2,796
>3-4 Years	43	4,857	4,832	36	25	3,234
>4-5 Years	40	4,495	4,469	38	26	3,542
>5-6 Years	37	4,089	4,066	33	23	3,951
>6-7 Years	31	3,498	3,467	55	31	4,238
>7-8 Years	29	3,220	3,184	57	36	4,436
>8-9 Years	26	2,900	2,866	66	34	4,558
>9-10 Years	25	2,751	2,708	90	43	4,749
>10-11 Years	0	0	0	0	0	0
>11-12 Years	0	0	0	0	0	0
>12-13 Years	0	0	0	0	0	0
>13-14 Years	0	0	0	0	0	0
>14-15 Years	0	0	0	0	0	0
>15-36 Years	0	0	0	0	0	0
<=36 Years	403	45,037	44,727	487	310	34,437

UNOBSERVED PREVALENCE

- CRs miss patients surviving **longer than the registration period length**
- The impact of a limited observation time on complete prevalence estimation depends on cancer **PROGNOSIS** and **AGE**

COLORECTAL	Observed	
Duration	00-49	50-99
<=2	389	
>2-5	309	
>5-10	235	
>10-15	76	
15-36	39	
TOTAL	1,048	
% 15-36	4%	



COMPLETENESS OF OBSERVED PREVALENCE IN EUROCARE-6

- **16 CRs** (10 Regional + 6 National)
with registration periods **> 30 years**

⇒ Observed **prevalence** virtually
complete

- **59 CRs** (47 Regional + 12 National)
with registration periods **< 20 years**

⇒ Observed **Prevalence** is **far from complete for many cancer sites**

Observation Length (years)	National CRs	Regional CRs	All CRs
5-10	1	22	23
10-15	4	13	17
15-20	4	13	17
20-30	7	21	28
30-37	7	10	17
All	23	79	102



Data from registries with long durations can be used to **estimate correction factors** needed to obtain **complete prevalence**

COMPLETE PREVALENCE: ESTIMATION

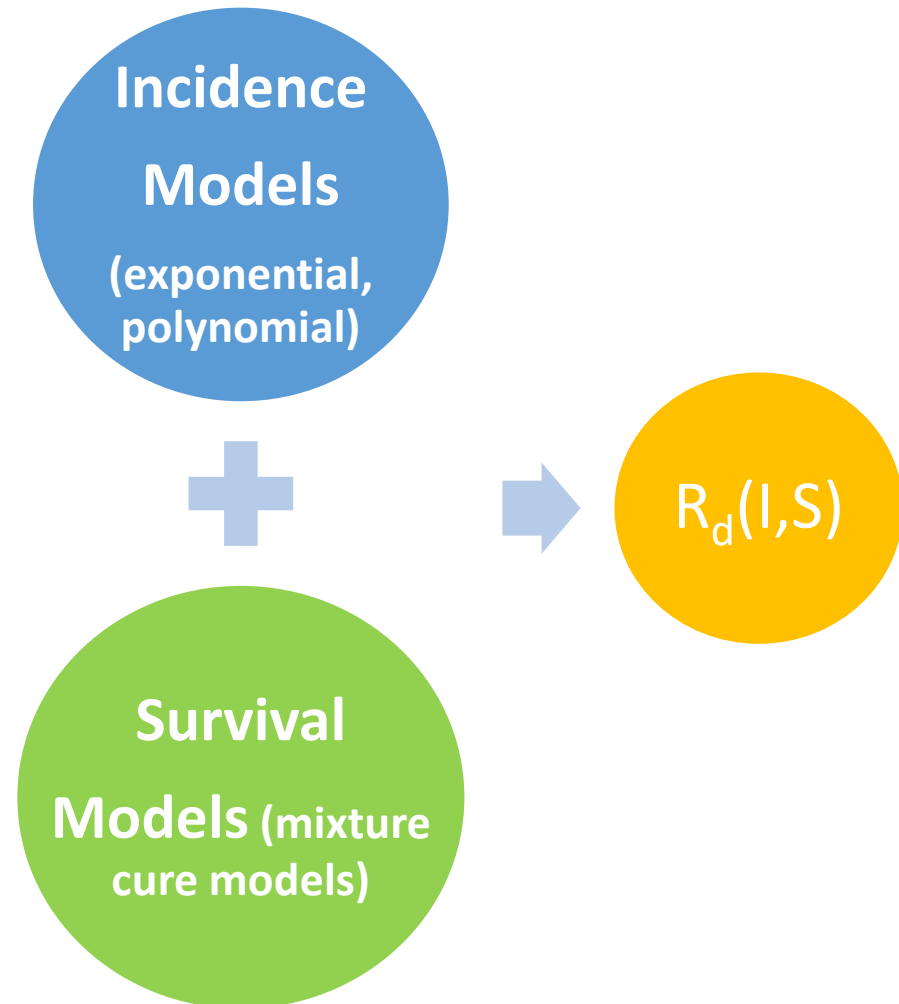
- **Completeness index** method¹

$$P'_{\text{complete}} = P_d / R_d$$

where d=disease duration

- **R_d** expresses completeness (%) of limited-duration P_d and is **estimated by modelling cancer incidence and survival**

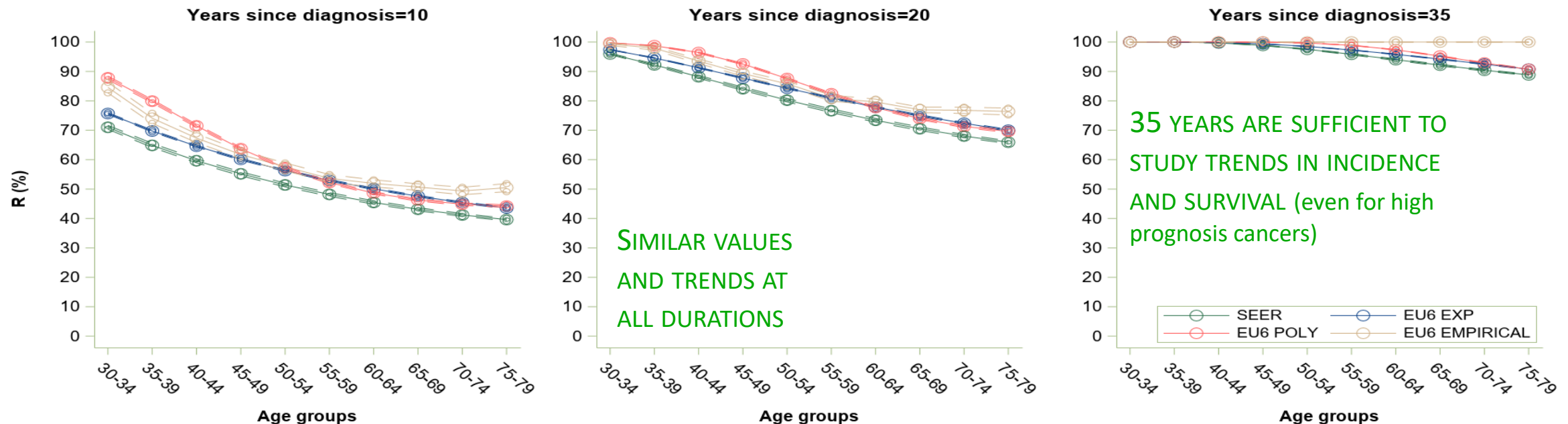
¹ Capocaccia and De Angelis, Stat Med 1997



VALIDATION OF COMPLETENESS INDEXES

Comparison between model-based (EUROCARE-6 and SEER) and empirical indexes

Example: females, Skin Melanoma, completeness indexes by age and years since diagnosis



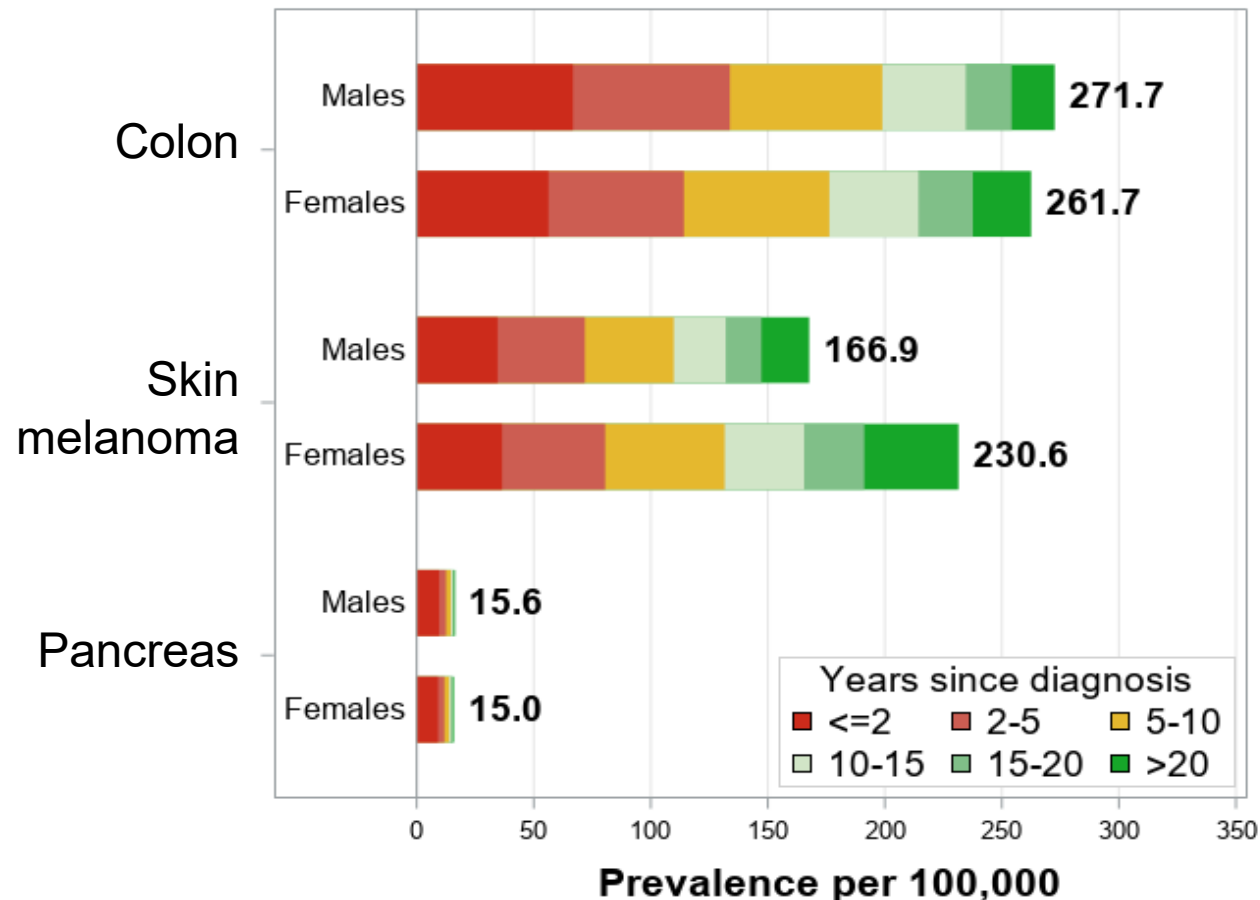
TARGET INDICATORS: 1

LIMITED DURATION & COMPLETE PREVALENCE

- Index tumours
- Europe
 - Pool of EUROCare-6 registries
- 1st January 2013

Estimates provided by:

- sex
- age at prevalence
- country



COMPLETE PREVALENCE BY COUNTRY: COLON CANCER, ALL AGES

Males

Females

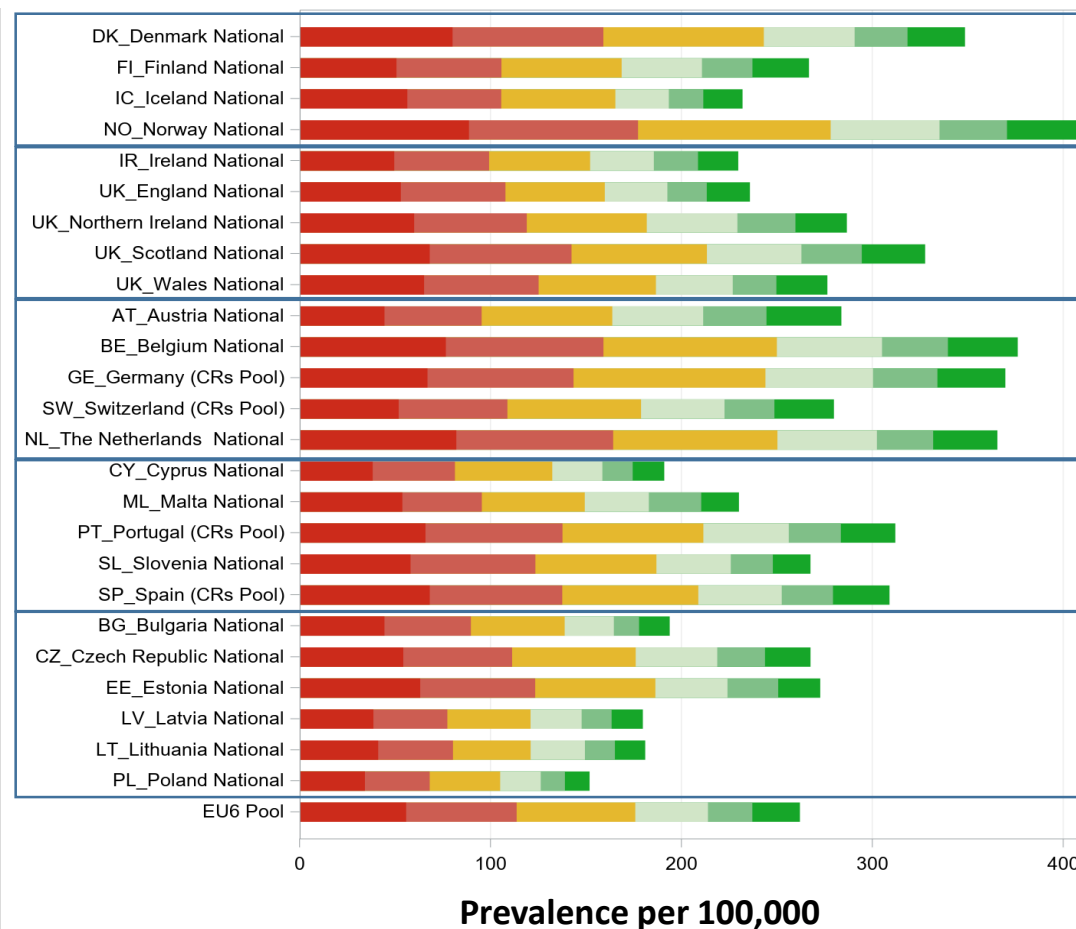
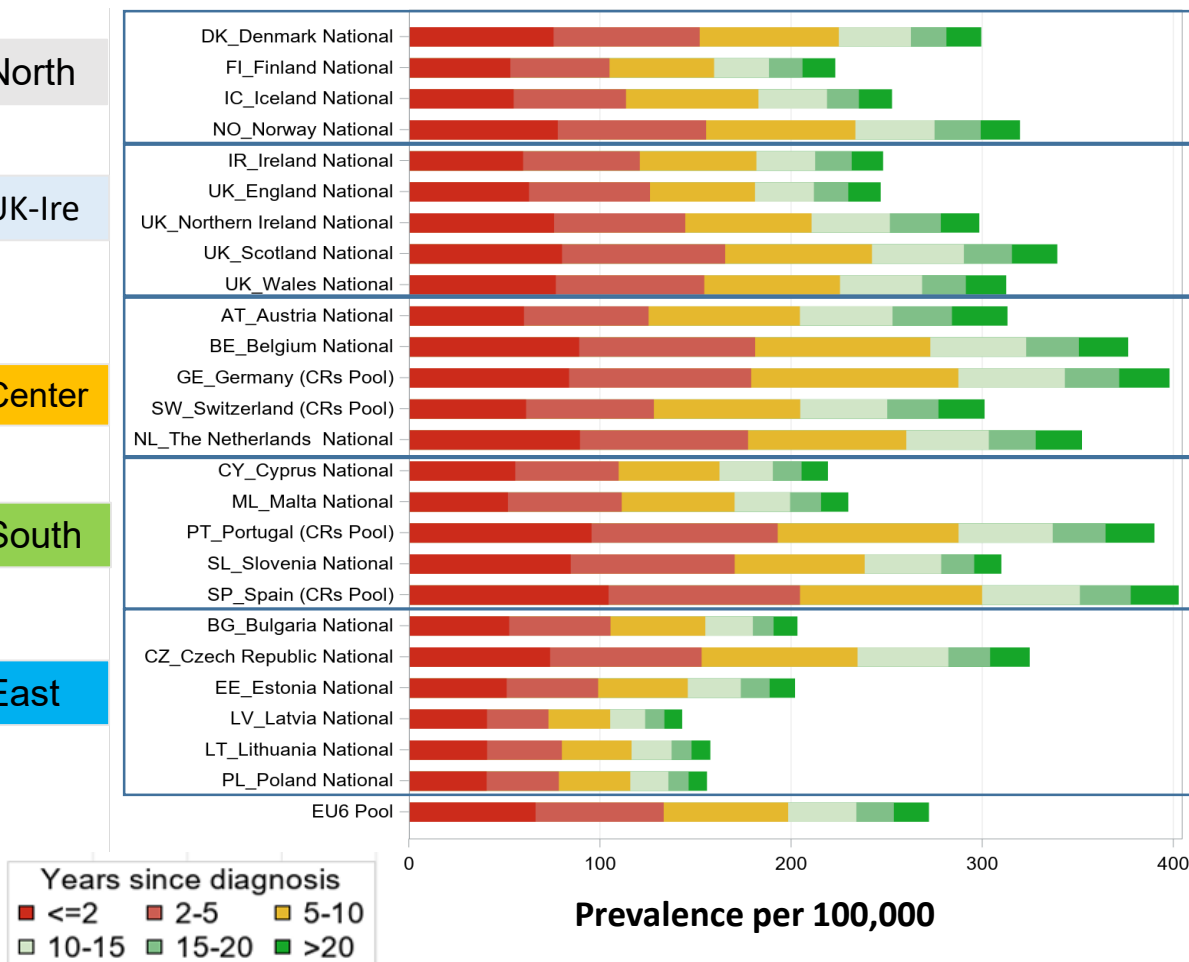
North

UK-Ire

Center

South

East



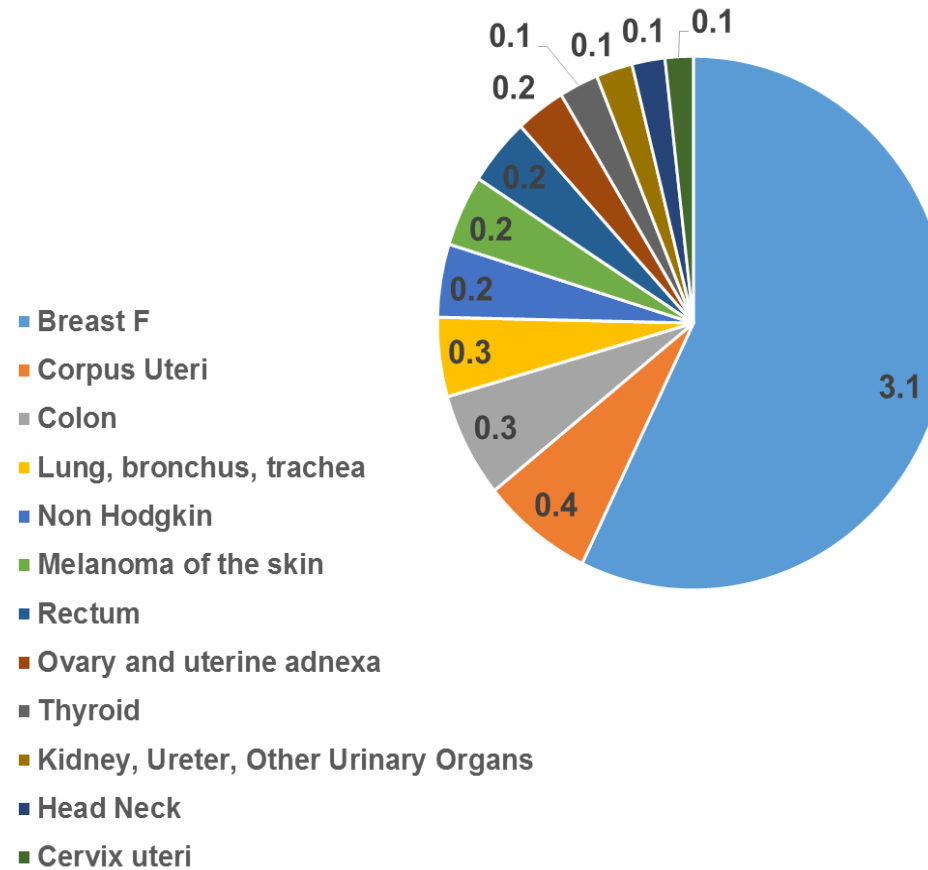
TARGET INDICATORS: 1

COMPLETE PREVALENCE - SITE RANKING

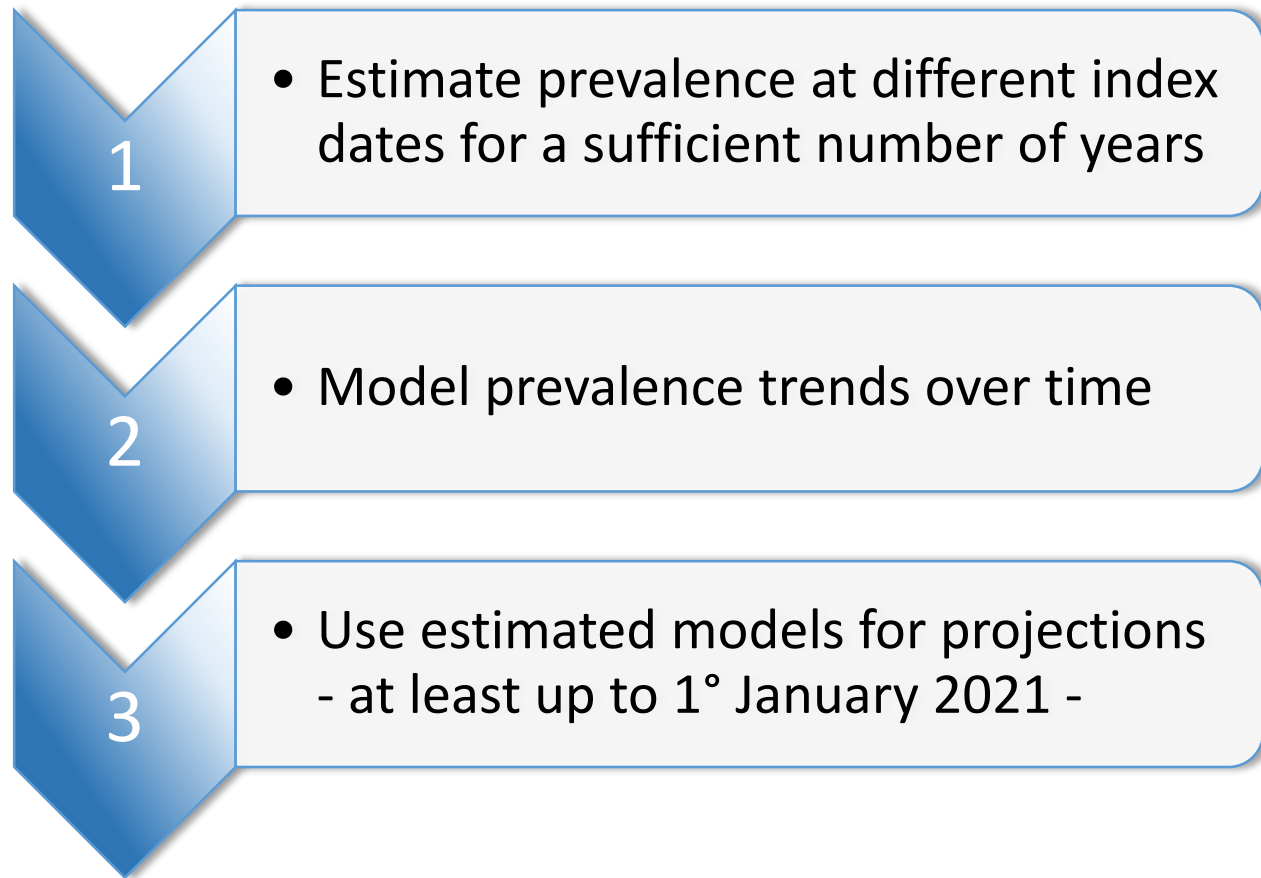
- **Belgium**
- **60-64 years of age**
- **1st January 2013**

1. Breast
2. Colon – Rectum
3. Corpus uteri
4. Lung
5. Non Hodgkin

BELGIUM, COMPLETE PREVALENCE 2013 (%) WOMEN, AGE 60-64



IN PROGRESS: TIME PROJECTIONS

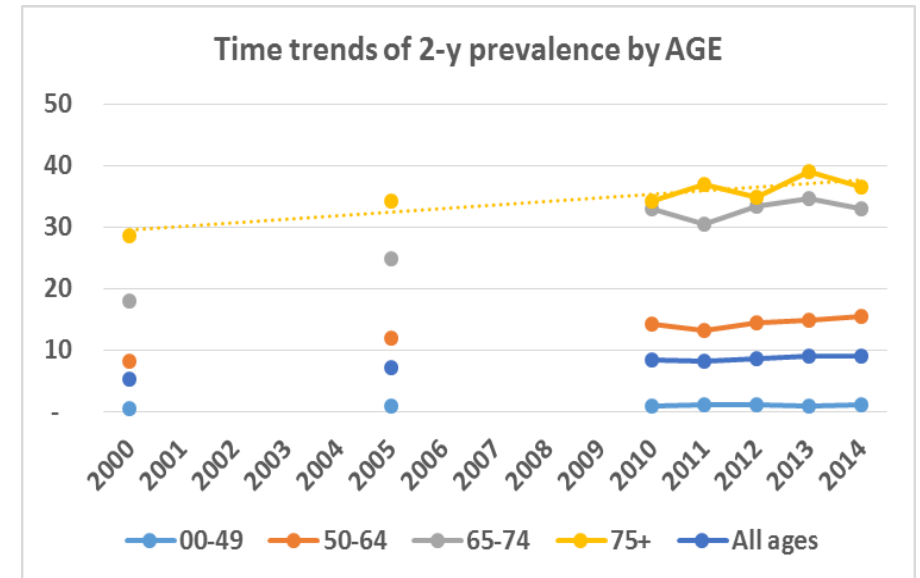


Example:

Norway, **pancreatic cancer**

Incidence data 1978-2014

Follow up to 2015



FURTHER STEPS: CURE OF CANCER

Questions:

- *How many patients can expect to be cured from cancer?*
- *How long does it take for a patient to be cured from cancer?*
- *How long can a cancer patient expect to live after diagnosis?*

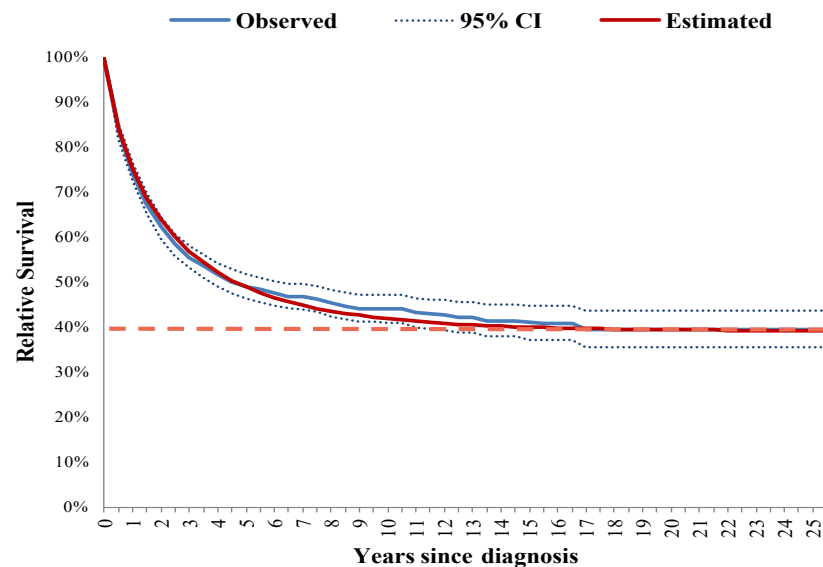
PREVIOUS WORK ON EURO CARE-5 DATA:

- ⇒ *Interesting information for patients and physicians*
- ⇒ *Base for public health decisions (need and costs of care)*

- Dal Maso L., et al. Ann Oncol. 2014; 25:2251-60. doi:10.1093/annonc/mdu383
- AIRTUM Working Group. Epidemiol Prev. 2014; 38(6 Sup1):1-122. www.registri-tumori.it/cms/it/Rapp2014
- Dal Maso L., et al. Submitted 2019.

PREVALENCE OF CURED PATIENTS: CURE FRACTION

- **Cure fraction:** proportion of patients who have reached the *same mortality probability of the general population* of the same sex and age



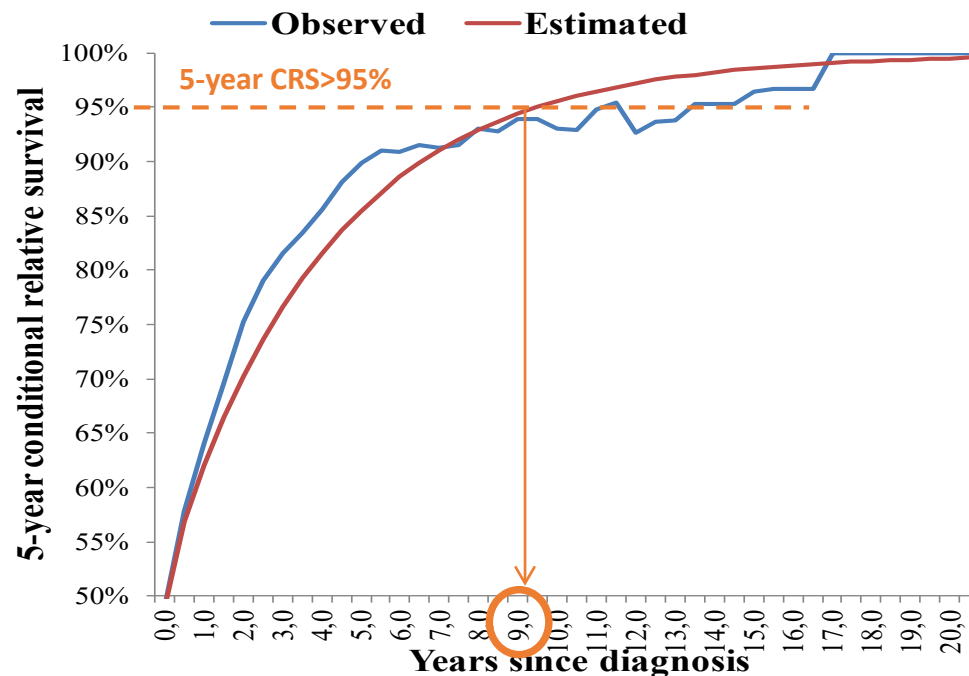
EXAMPLE: Cancer patients diagnosed in Italy (1988-1990) with **colorectal cancer** at age 65-74 years

Cure fraction = 40%

We expect 40% of patients diagnosed between 65 and 74 years of age to be cured from colorectal cancer in Italy

PREVALENCE OF CURED PATIENTS: TIME TO CURE

- **Time to cure:** time after diagnosis needed for cancer patients to reach the same mortality probability as the general population



EXAMPLE: Cancer patients diagnosed in Italy (1988-1990) with **colorectal cancer** at age 65-74 years

Time to cure = 9 years

We expect colorectal cancer patients diagnosed between 65 and 74 years to be cured 9 years after diagnosis

TASK 7.6: IMPACT AND EUROPEAN ADDED VALUE

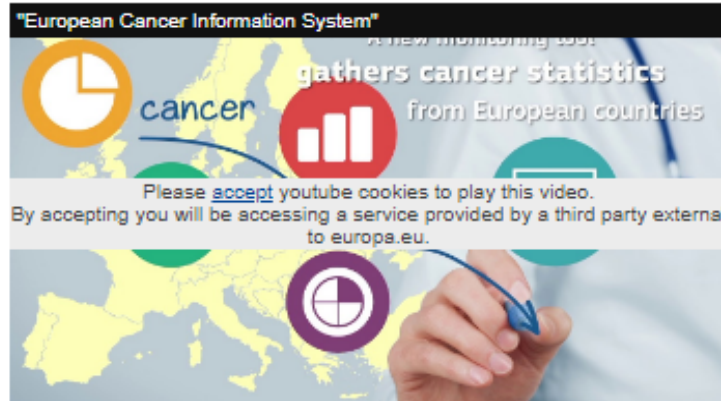


1. **Capacity building at EU MS level:** promoting the use of prevalence indicators will help to address information needs of relevant stakeholders (health professionals, patients, decision makers and research community)
2. **Integrating the European Cancer Information System (ECIS)** Comprehensive and comparable indicators on cancer survivors in EU by country will feed the EC **web-site** managed by the **ENCR-JRC**



ECIS - European Cancer Information System

Measuring cancer burden and its time trends across Europe



ECIS provides the latest information on indicators that quantify cancer burden across Europe. It permits the exploration of geographical patterns and temporal trends of incidence, mortality and survival data across Europe for the major cancer entities.

The purpose of the web-application is to **support research** as well as public-health decision-making in the field of cancer and to serve as a point of reference and information for **European citizens**.

Prevalence ?

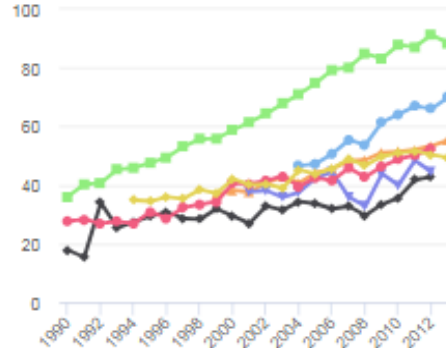
Estimated indicators
on cancer survivors by
cancer type, sex, age,
and European country

Information on
disease duration, cure,
phase of care, life
expectancy



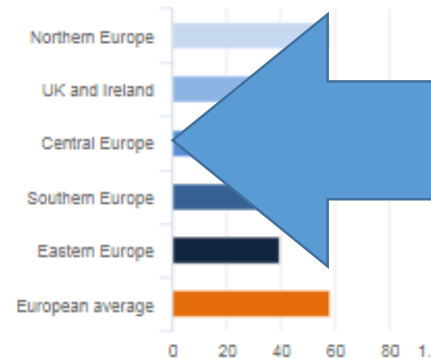
Incidence and mortality estimates 2018

National estimates of cancer incidence and mortality in 2018, for the major cancer sites in 40 European countries.



Incidence and mortality historical data

Incidence and mortality statistics over time by cancer site and demographic variables, in European cancer registration areas.



Survival estimates

Estimated indicators of survival, by cancer sites and sex, across European countries and regions.

TASK-6 PARTNERSHIP

Task leader: ISS, Italy

9 iPAAC Partners/Countries

- INT, CRO-Aviano, ISPRO, MoH, Italy
- WIV-ISP, National CR*, Belgium
- NCPHA, Bulgaria
- HZJZ, National CR, Croatia
- RIVM, National CR*, Netherlands
- CRN (OUS), National CR, Norway
- NIPH – NIH, National CR*, Poland
- INSP, Romania
- ICO, Local CR* Spain

***Cancer Registries affiliated to the national iPAAC Competent Authority (CA)**

COLLABORATING PARTNERS AND STAKEHOLDERS



- **Cancer registries**
 - ENCR – European Network of Cancer Registries
 - National Associations of Cancer Registries (Italy, Spain)
 - Single European registries affiliated to national CA in iPAAC
- **JRC - Joint Research Center** in Ispra (IT)
- **Sub-contracts**
 - **ECPC** – European Cancer Patients Coalition
 - **AIRTUM** – Italian Association of Cancer Registries
- **Experts**
 - Research groups from European registries/countries with experience in Task 6 topics



THANK YOU
for your attention!