

**CONSENSUS MEETING AND CONFERENCE
IMPROVING THE METHODOLOGY OF CLINICAL RESEARCH ON RARE CANCERS
BRUSSELS, 10 FEBRUARY 2012**

The epidemiology of rare cancers in Europe

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Rare cancers are not so rare: The rare cancer burden in Europe

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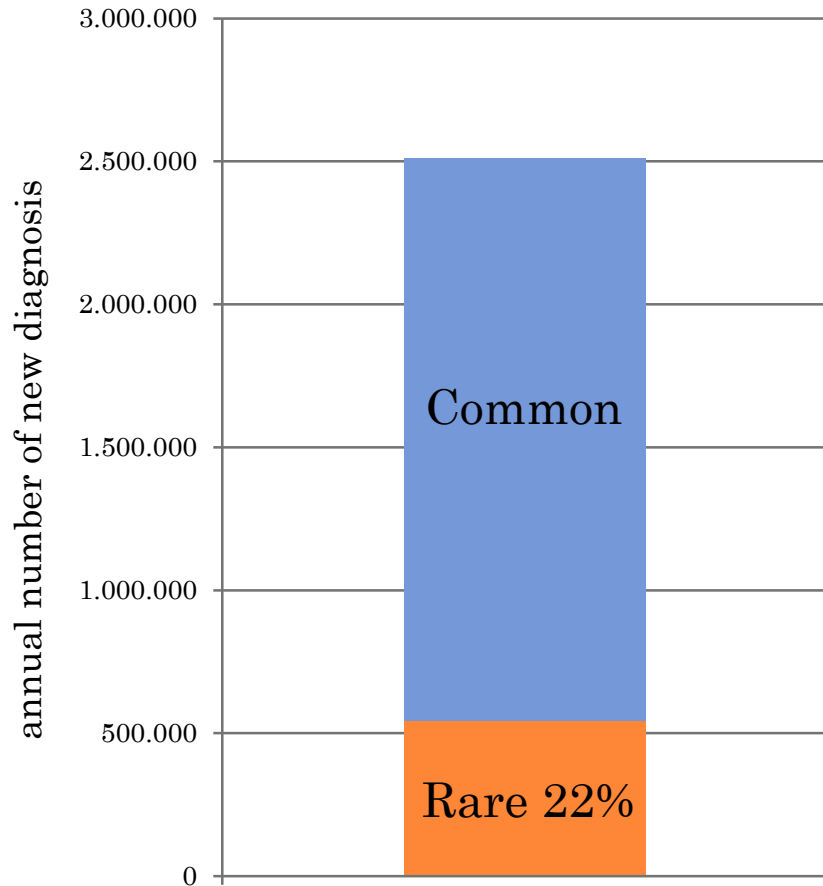
Numbers in Europe



Surveillance of Rare Cancers in Europe



RARE CANCERS: INCIDENCE



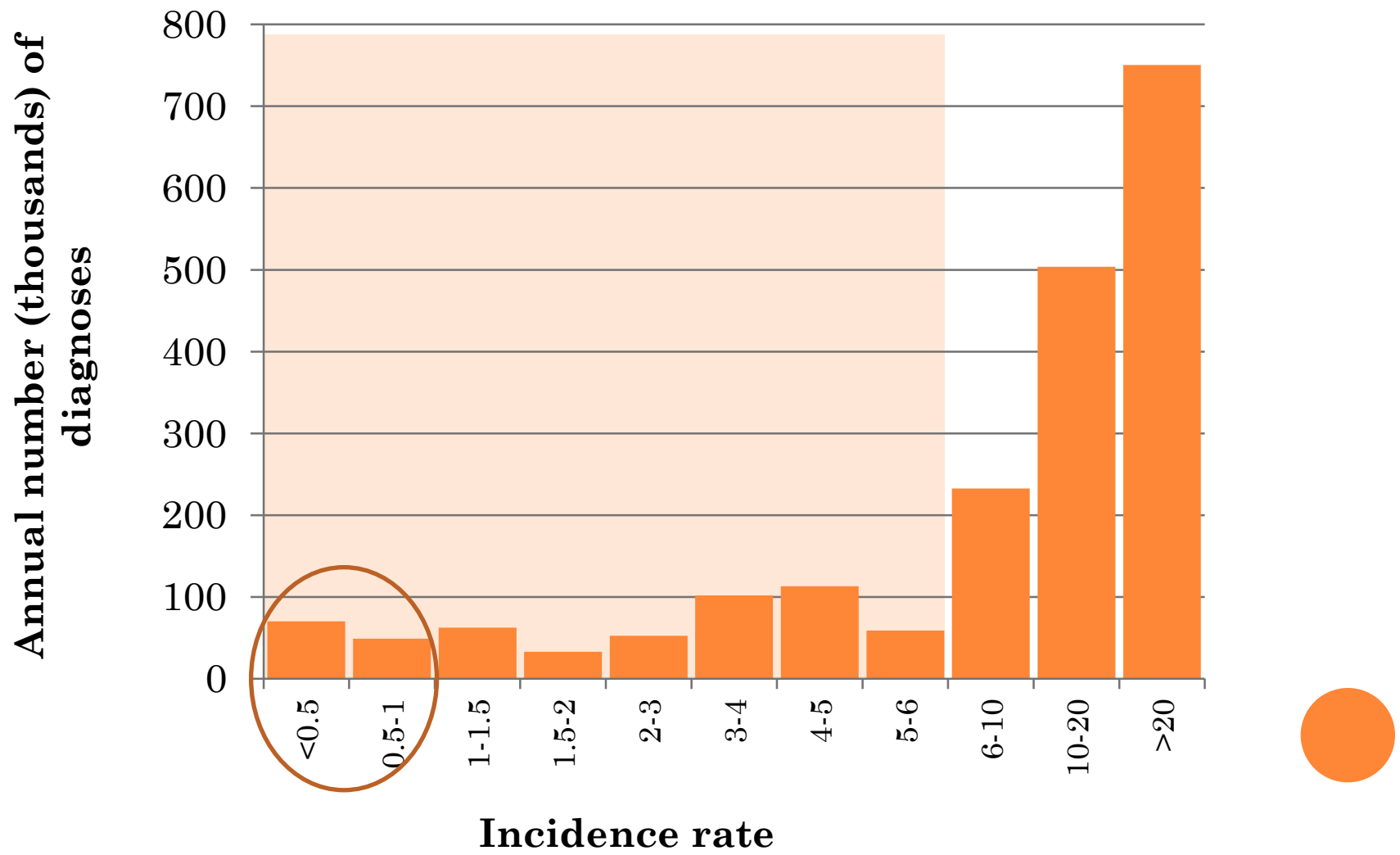
186 rare cancers

About 500,000 new cases/year in EU27

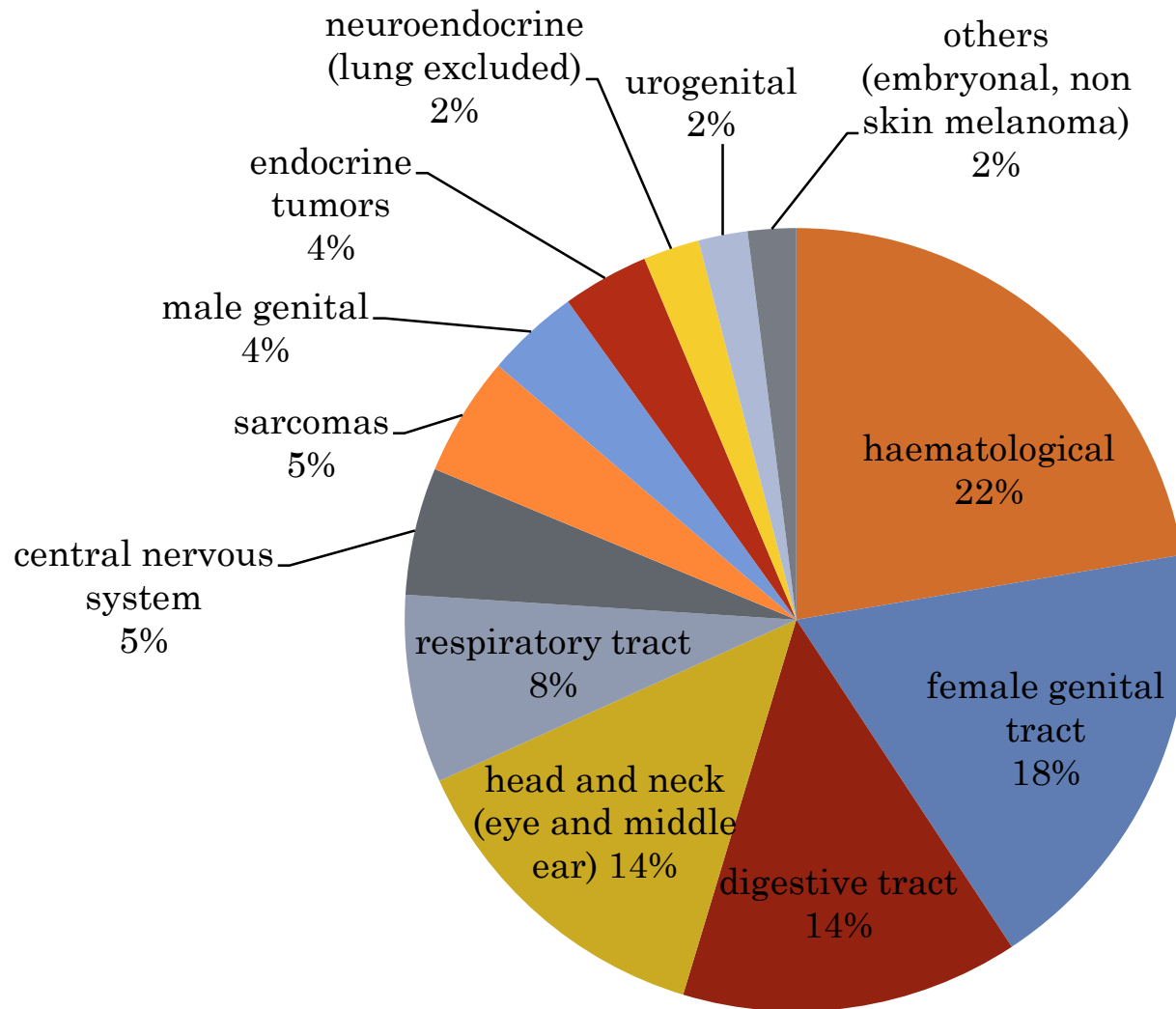
22% of all cancer diagnosed/year



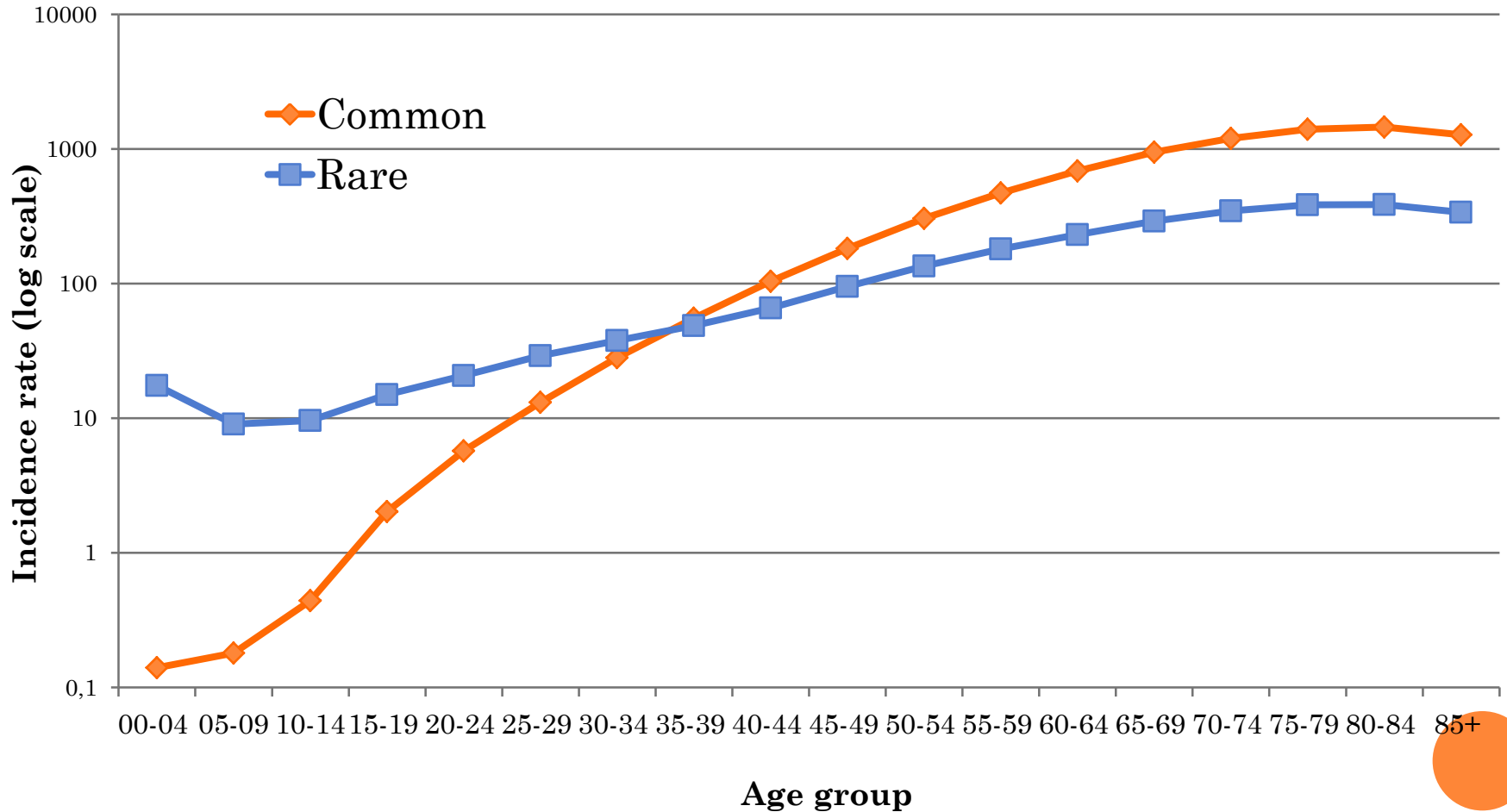
DISTRIBUTION OF ANNUAL NUMBER OF DIAGNOSES IN EU27 ACCORDING TO CATEGORIES OF INCIDENCE RATE



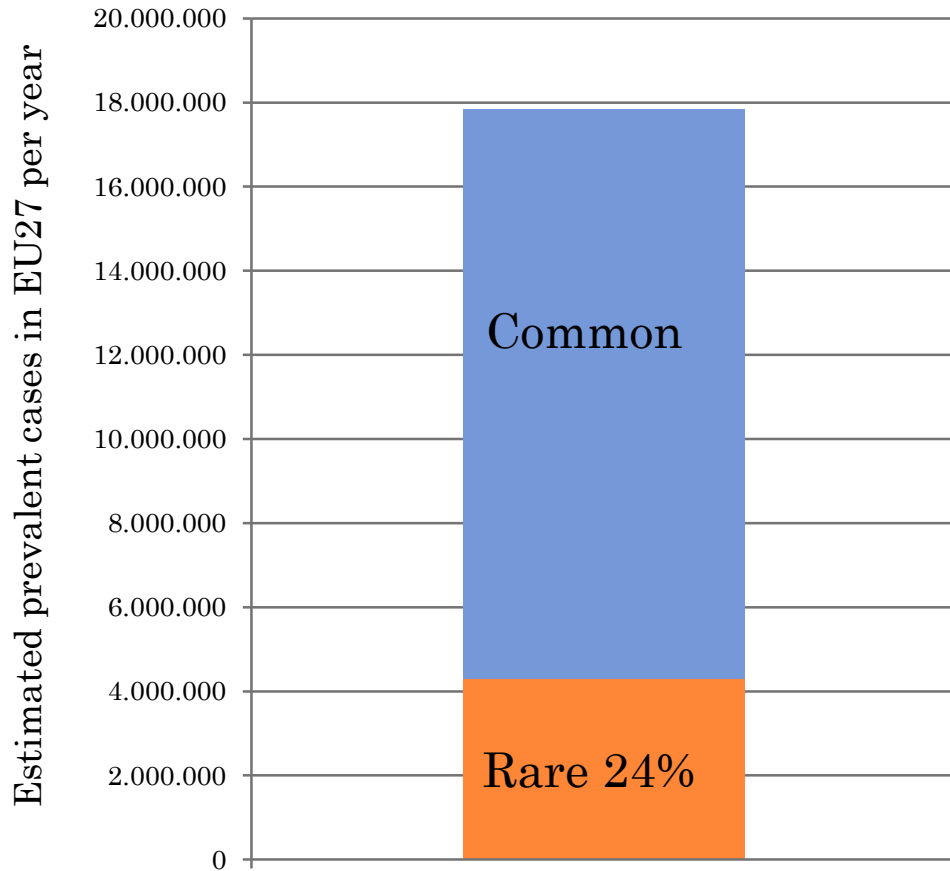
DISTRIBUTION OF MAJOR FAMILIES OF RARE TUMORS WITHIN ALL RARE CANCERS



AGE-SPECIFIC INCIDENCE RATES FOR RARE AND COMMON CANCERS IN EU 27



RARE CANCERS: PREVALENCE



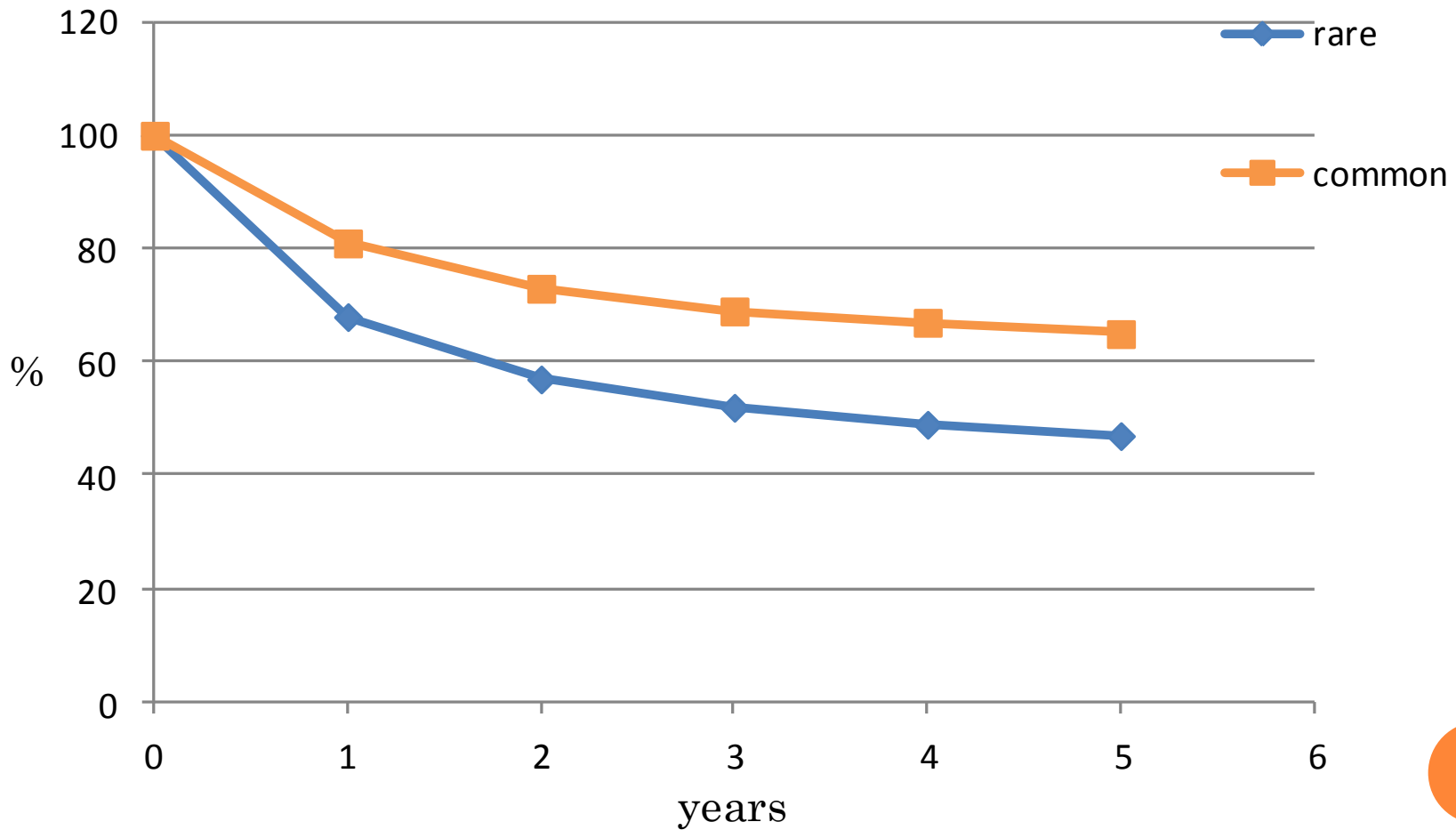
186 rare cancers

4,300,000 people alive in the EU27 with a previous diagnosis of a rare cancer

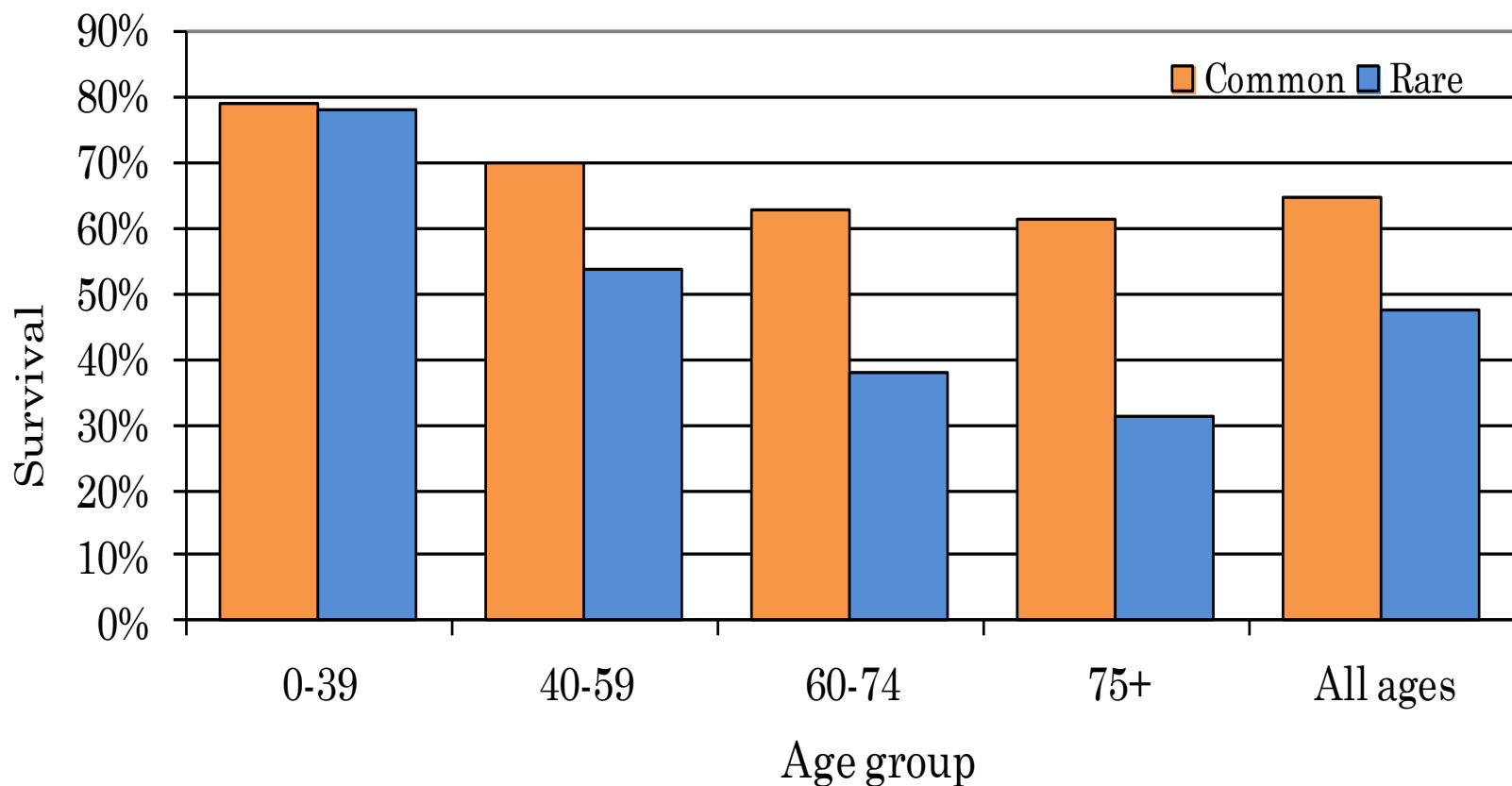
24% of the total cancer prevalence



RARE CANCERS: 5 YEAR RELATIVE SURVIVAL



5 YEAR RELATIVE SURVIVAL FOR RARE AND COMMON CANCERS IN EU27 BY AGE GROUP



RARECARE – WHAT'S ADDED

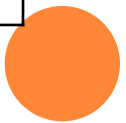
- Put numbers to a problem long known to exist
- Confirmed low outcome of rare cancers
- Made prevalence available for rare cancers
- Identified a new priority for population-based cancer registries



RARE CANCER DEFINITION

- Incidence is the best indicator to define rare cancers

	Crude incidence per 100,000/ year	Relative 5-year survival (%)	Complete prevalence per 100,000
Squamous cell carcinoma with variants of lung	13	13	25
Adenocarcinoma with variants of lung	10	14	22
Adenocarcinoma with variants of stomach	15	23	46



NOT JUST DESCRIPTIVE EPIDEMIOLOGY

RARECARENET



AIMS

- To describe the **health care pathways** for rare cancers and update **epidemiological** indicators.
- To **identify** and disseminate information on **centers of expertise** for rare cancers.
- To produce and disseminate **information on diagnosis and management** of rare cancers.
- To develop and **disseminate information for patients and patients' associations** dedicated to rare cancers.



RESEARCH COMMUNITY

Don't forget to include those who studies the disease in the Community



Thank you for your attention!!

www.rarecare.eu

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THE RARE CANCER BURDEN IN EUROPE

- **22% of all new malignancies**
 - About 30% of Europeans have one of the particularly rare forms that affect <1/100,000
- **24% of the total cancer prevalence** (4 millions people living with a diagnosis of rare cancers in EU27)
- **Rare cancer survival is worse than common cancer** 47% vs 65%





- uterine cervix and thyroid carcinoma are rare according to the incidence (RARECARE) criterion and 'common' according to the prevalence criterion.
- Six cancers are common according to the incidence criterion and rare according to the prevalence criterion:
 1. stomach adenocarcinoma,
 2. pancreatic adenocarcinoma,
 3. Lung adenocarcinoma,
 4. lung squamous cell carcinoma,
 5. poorly differentiated endocrine carcinomas of lung and
 6. the group other non-Hodgkin mature B cell lymphomas.



ESTIMATES OF PREVALENCE FOR RARE AND COMMON CANCERS BY SITE IN EU27

		Prevalence per 100,000	Estimated prevalent cases in EU27 per year	Prevalence distribution (%)
Rare	Haematopoietic system	90	450,444	70
Common	Haematopoietic system	32	161,618	25
All	Haematopoietic system	130	647,596	100
Rare	Female genital tract	176	880,922	53
Common	Female genital tract	127	633,280	38
All	Female genital tract	332	1,658,891	100
Rare	Respiratory tract	60	300,193	46
Common	Respiratory tract	56	279,942	43
All	Respiratory tract	130	648,321	100
Rare	Male genital tract	93	465,363	23
Common	Male genital tract	279	1,396,883	70
All	Male genital tract	400	1,997,563	100
Rare	Digestive tract	51	254,473	11
Common	Digestive tract	399	1,996,625	84
All	Digestive tract	476	2,380,246	100
Rare	Breast	60	300,759	9
Common	Breast	520	2,599,432	74
All	Breast	700	3,500,906	100
Rare	Urinary system	18	91,683	8
Common	Urinary system	202	1,010,735	85
All	Urinary system	238	1,188,660	100

