

RARECAREnet: mapping rare cancers

Annalisa Trama

Fondazione IRCCS Istituto Nazionale dei Tumori, Milano

Disclosure slide

- I have nothing to declare



ELSEVIER

Available at www.sciencedirect.com

SciVerse ScienceDirect

journal homepage: www.ejconline.com



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

Gemma Gatta ^{a,*}, Jan Maarten van der Zwan ^b, Paolo G. Casali ^c, Sabine Siesling ^b, Angelo Paolo Dei Tos ^d, Ian Kunkler ^e, Renée Otter ^b, Lisa Licitra ^f, Sandra Mallone ^g, Andrea Tavilla ^g, Annalisa Trama ^a, Riccardo Capocaccia ^g, The RARECARE working group

^a Department of Preventive and Predictive Medicine, Fondazione IRCSS, Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milan, Italy

^b North East Netherlands Cancer Registry, Comprehensive Cancer Centre North East, P.O. Box 330, 9700 AH Groningen, The Netherlands

^c Department of Cancer Medicine, Fondazione IRCSS, Istituto Nazionale dei Tumori, Via Venezian 1, 20133 Milan, Italy

^d Department of Pathology, General Hospital of Treviso, Via Borgo Cavalli 42, 31100 Treviso, Italy

22% of new cancers diagnosis in EU are rare cancers

RARECARE – what's added

- Provided a definition of rare cancers based on frequency (incidence < 6/100,000/year in EU)
- Provided a list of rare cancers (www.rarecarenets.eu)
 - 186 rare cancers vs 17 common cancers
- Put numbers to a problem long known to exist
 - 540,000 new cases (22% of new cancers)
 - 4,300,000 patients living with a rare cancers (24% prevalent cases)
 - low outcome of rare cancers

RARECAREnet – what's new

- 1 to collect and disseminate information on **updated epidemiological indicators** on the basis of 83 population-based Cancer Registries from 24 countries in Europe.
- 2 to describe the **healthcare pathways** for rare cancers.
- 3 to develop a **clinical database on a sub-group of rare cancers**.
- 4 to propose quality criteria for **centres of expertise** for rare cancers.
- 5 to list **centres of treatment** for rare cancers in Europe.
- 6 to support the identification of **European Reference Networks**
- 7 to develop and disseminate **current clinical approaches** to rare cancers.
- 8 to increase **awareness** among general practitioners and pathologists about rare cancers.
- 9 to **disseminate information** tailored to the needs of patients and of all concerned stakeholders.
- 10 to **support patients' associations empowerment**.

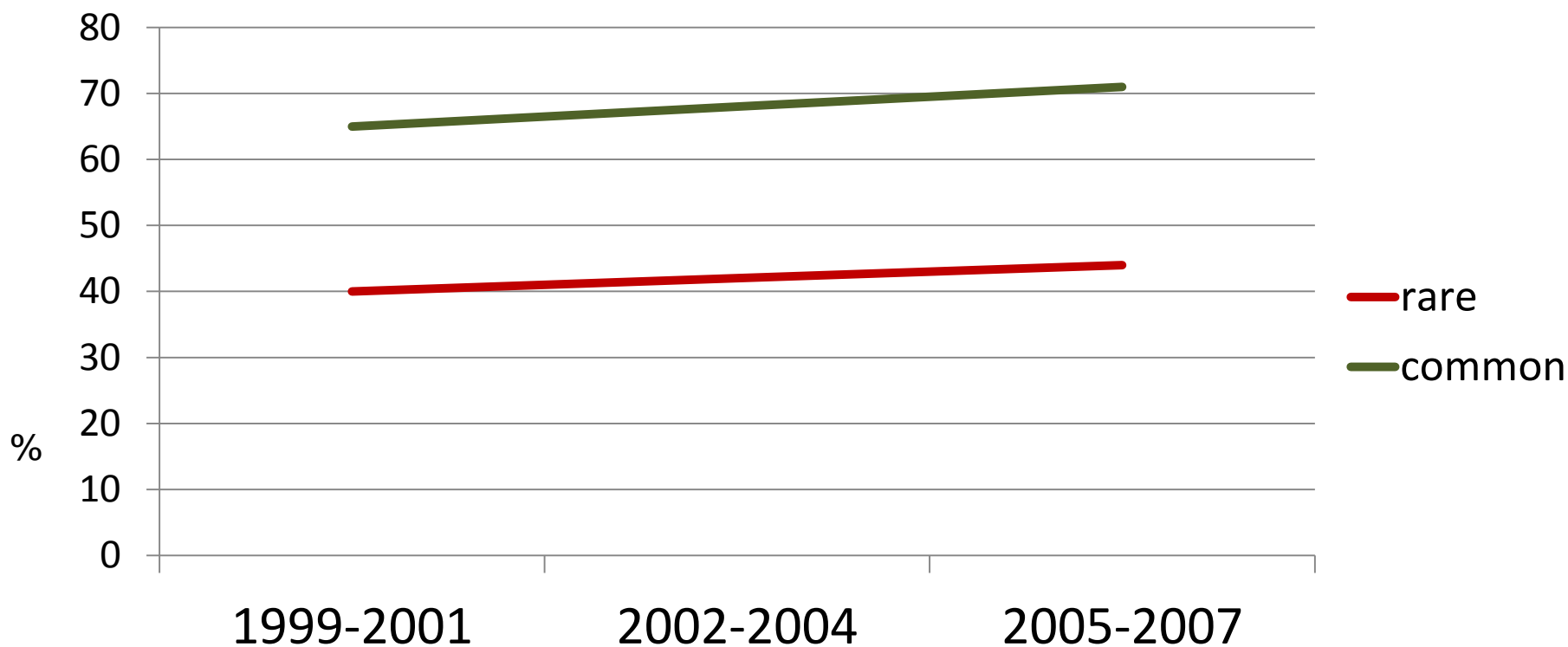
RARECAREnet new data

The burden of rare cancers in EU countries

	New rare cases/year	% rare cancers on new diagnosis
European Union (28)	582,113	22
Germany	94,142	22
France	75,270	28
United Kingdom	73,339	20
Italy	68,506	20
Spain	53,634	26
Poland	44,228	21
Netherlands	19,259	25
Belgium	12,811	23
Portugal	12,037	25
Austria	9,701	22
Bulgaria	8,361	21
Finland	6,229	19
Slovakia	6,210	25
Ireland	5,270	17
Croatia	4,892	21
Lithuania	3,411	22
Slovenia	2,363	23
Latvia	2,323	22
Estonia	1,515	28
Malta	484	25

Source: unpublished data
RARECAREnet

Time variation in 5 year relative survival 1999-2007 (age standardised)



Source: unpublished data RARECAREnet

What kind of health care organisation?

Country	Population	Incidence rate		
		0.5/100,000	1/100,000	6/100,000
France	65,578,819	328	656	3,935
Italy	59,685,227	298	597	3,581
Poland	38,533,299	193	385	2,312
Netherlands	16,779,575	84	168	1,007
Belgium	11,161,642	56	112	670
Portugal	10,487,289	52	105	629
Bulgaria	7,284,552	36	73	437
Finland	5,426,674	27	54	326
Slovakia	5,410,836	27	54	325
Slovenia	2,058,821	10	21	124
Estonia	1,320,174	7	13	79

Source: unpublished RARECAREnet analyses

Centralisation?

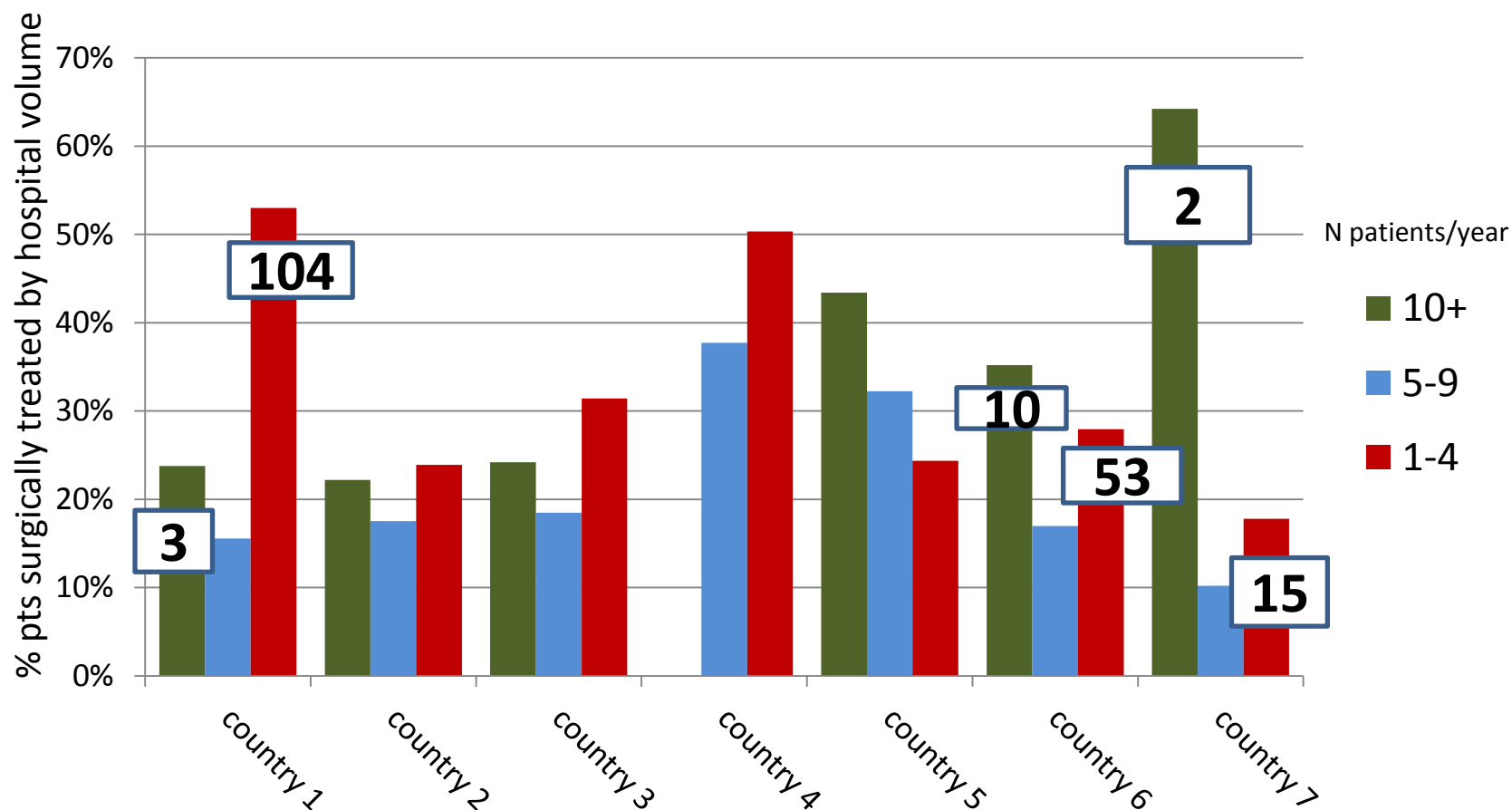
Centres of expertise?

European reference networks?

Centralisation of surgery in soft tissue sarcomas

- **RARECAREnet pilot study on hospital volume**
- Preliminary results, based on 7 countries
- (≈ 9000 soft tissue sarcoma patients surgically treated, diagnosed 2000-2007)

Surgery hospital volume for soft tissue sarcoma in 7 EU countries

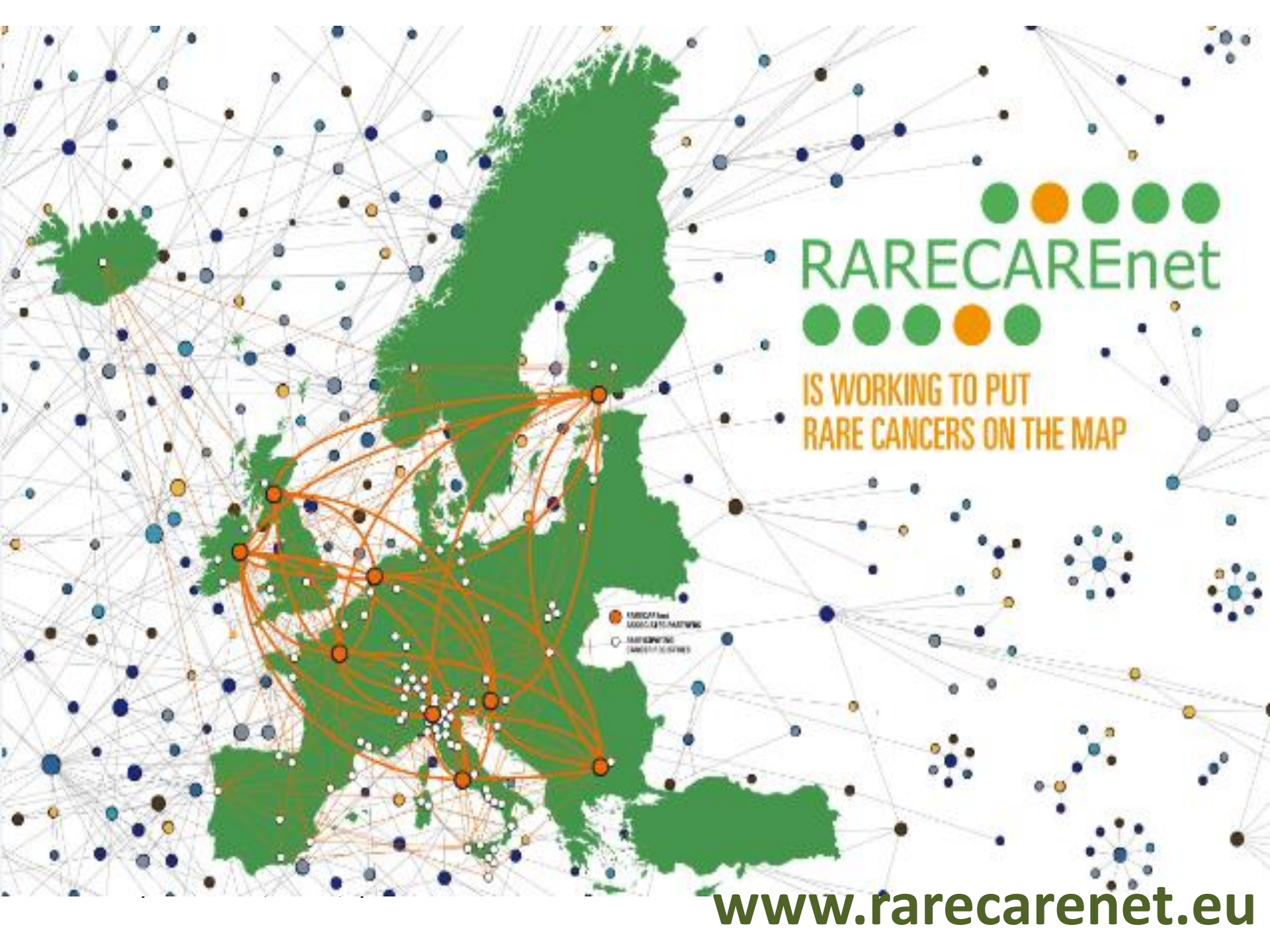


Source: preliminary analyses pilot study RARECAREnet

Centralisation ... Not yet

Centres of expertise? ... with 1 to 4 patients/operated/year?
Additional criteria are needed

European reference networks? ... a possible long way to go
...calling for a collective rethinking of the health care organisation



● ● ● ● ●
RARECAREnet
● ● ● ● ●

IS WORKING TO PUT
RARE CANCERS ON THE MAP

www.rarecarenet.eu