Rete Tumori Rari



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rete tumori rari





- ~ 100 strutture oncologiche attive
- ~ 5000 pazienti nel DB
- ~ 700 casi clinicamente condivisi /anno
- ~ 1300 consulti istologici /anno

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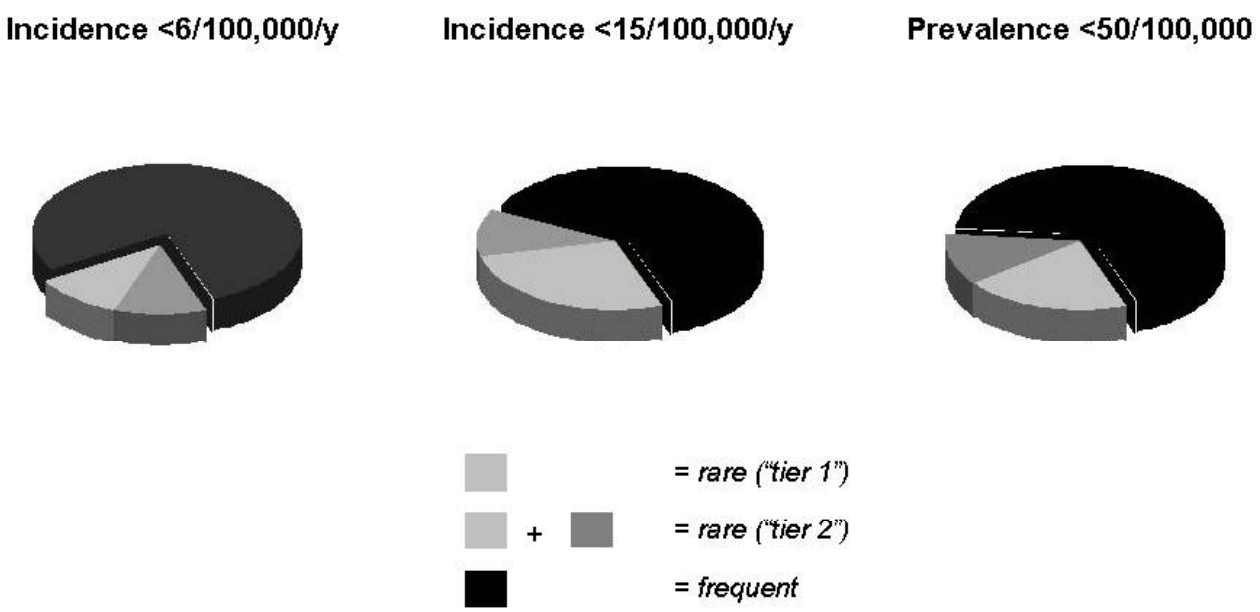
Rare cancers are not so rare: The rare cancer burden in Europe

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*

Table 3 – Data quality indicators and other characteristics of malignant cancers diagnosed in European cancer registries 1995-2002 and included in the analyses.

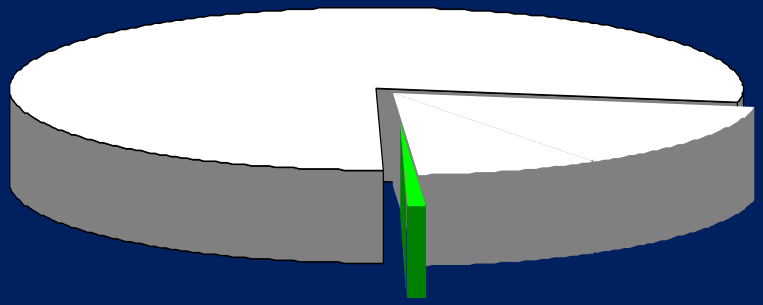
Country	Registry	Number of malignant cancers	Data quality indicators					
			Death certificate only (%)	Autopsy (%)	Microscopic verification (%)	Cases 1995-1998 censored before 5 years (%)	Morphology code NOS[a] (%)	Topography code NOS[b] (%)
Austria	Austria	304,495	8.9	0.0	85.2	5.9	10.1	0.6
Belgium	Flanders	144,715	0.0	0.2	89.8	0.0	7.3	0.5
France	Bas Rhin	13,113	0.0	0.0	95.8	3.3	3.9	0.2
	Calvados	5695	0.0	0.0	98.1	6.1	2.5	0.3
	Calvados digestive	2301	0.0	0.0	87.0	4.4	10.5	0.3
	Côte d'Or digestive	4376	0.0	0.0	82.8	0.5	17.5	0.2
	Côte d'Or haematol.	1884	0.0	0.0	100.0	7.2	0.0	0.5
	Doubs	5762	0.0	0.0	95.8	2.1	3.2	0.3
	Haut Rhin	9073	0.0	0.0	96.4	5.8	2.9	0.1
	Hérault	10,505	0.0	0.0	0.0	6.4	1.5	0.1
	Isère	13,526	0.0	0.0	94.1	4.6	4.1	0.1
	Loire Atlantique	3746	0.0	0.0	100.0	6.8	0.0	0.0
	Manche	6367	0.0	0.0	96.5	2.7	3.4	0.3
	Marne and Ardennes	168	0.0	0.0	100.0	3.6	0.0	0.0
	Somme	6481	0.0	0.0	94.2	6.6	5.5	0.8
	Tarn	4935	0.0	0.0	93.8	2.0	5.9	1.3
Germany	Saarland	54,132	3.9	0.0	91.8	5.8	8.0	0.5
Iceland	Iceland	8854	0.1	1.4	96.6	0.0	3.5	0.0
Ireland	Ireland	156,539	2.0	0.3	86.7	0.0	11.0	0.7
Italy	Alto Adige	18,676	0.7	0.0	89.5	0.0	9.2	0.5
	Biella	11,770	1.3	0.4	87.0	0.0	12.5	0.3
	Ferrara	23,760	1.1	0.0	88.1	0.4	9.7	0.6
	Firenze	66,087	0.9	0.1	80.4	0.4	17.7	0.8
	Friuli VG	76,882	0.6	1.9	91.0	0.3	9.8	2.1
	Genova	44,207	1.8	0.0	81.4	0.0	16.6	0.9
	Macerata	10,396	1.3	0.0	87.4	0.2	13.1	0.6
	Modena	34,967	0.5	0.0	88.6	0.4	11.8	0.5
	Napoli	8145	3.9	0.0	73.0	1.9	17.6	1.4
	Palermo	581	2.2	0.0	92.6	0.0	7.2	0.0
	Parma	23,856	1.0	0.0	86.0	0.3	13.1	0.7
	Ragusa	10,687	1.9	0.8	80.9	0.1	24.6	0.6
	Reggio Emilia	22,152	0.2	0.0	88.1	0.0	13.8	0.5
	Romagna	60,667	2.4	0.0	87.9	0.1	12.3	0.5
	Salerno	26,917	2.5	0.0	77.5	4.0	23.7	1.1
	Sassari	18,084	2.9	0.2	84.4	0.0	16.4	0.7
	Trento	17,788	2.0	0.0	85.0	0.3	27.8	3.8
	Umbria	45,221	0.7	0.0	84.0	0.1	12.6	0.6
	Varese	24,758	1.1	0.0	89.0	11.5	10.8	0.4
	Veneto	84,528	1.5	0.2	87.5	0.8	13.7	1.7

Eur J Cancer 2011;47:2493



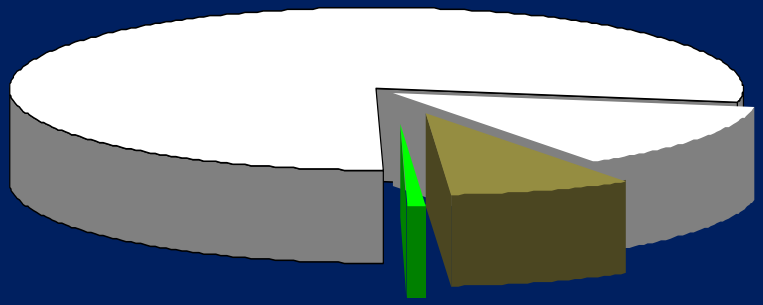
Casali PG et al, 2012, submitted

Tumori rari...



pediatrici

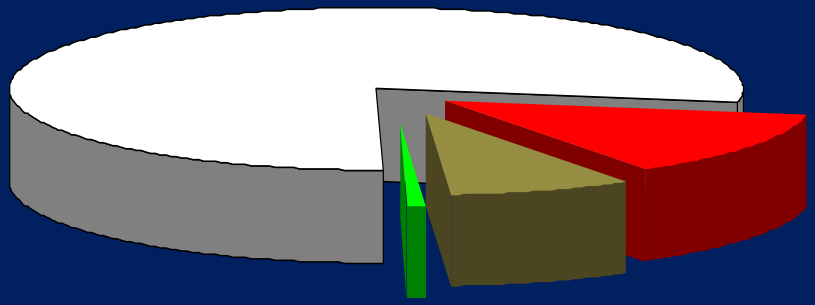
Tumori rari...



ematologici

pediatrici

Tumori rari...



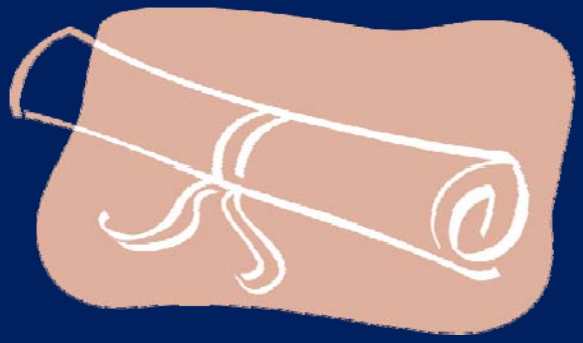
solidi dell’adulto

ematologici

pediatrici

Qualità di cura nei tumori rari...







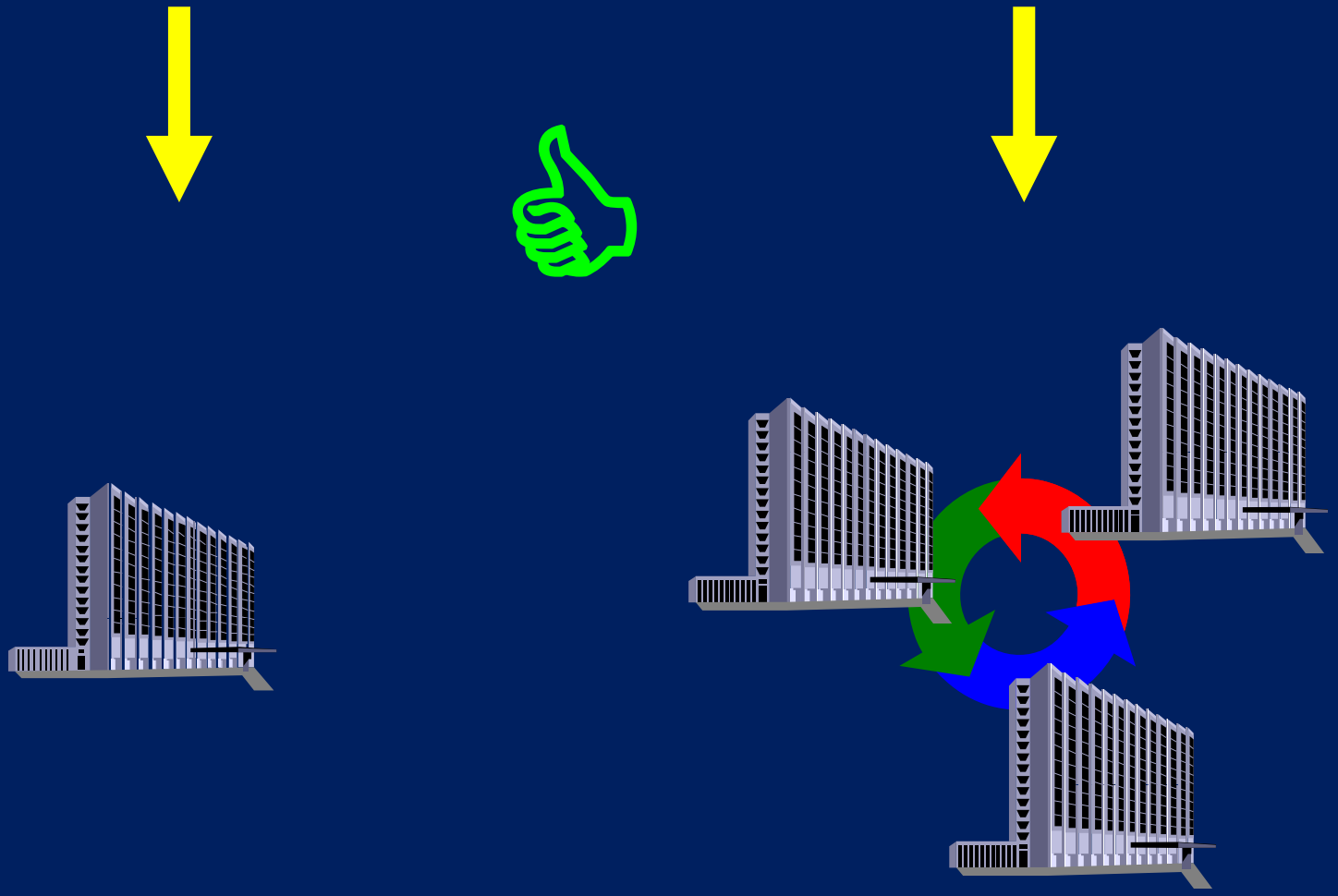
Organizzazione assistenza...

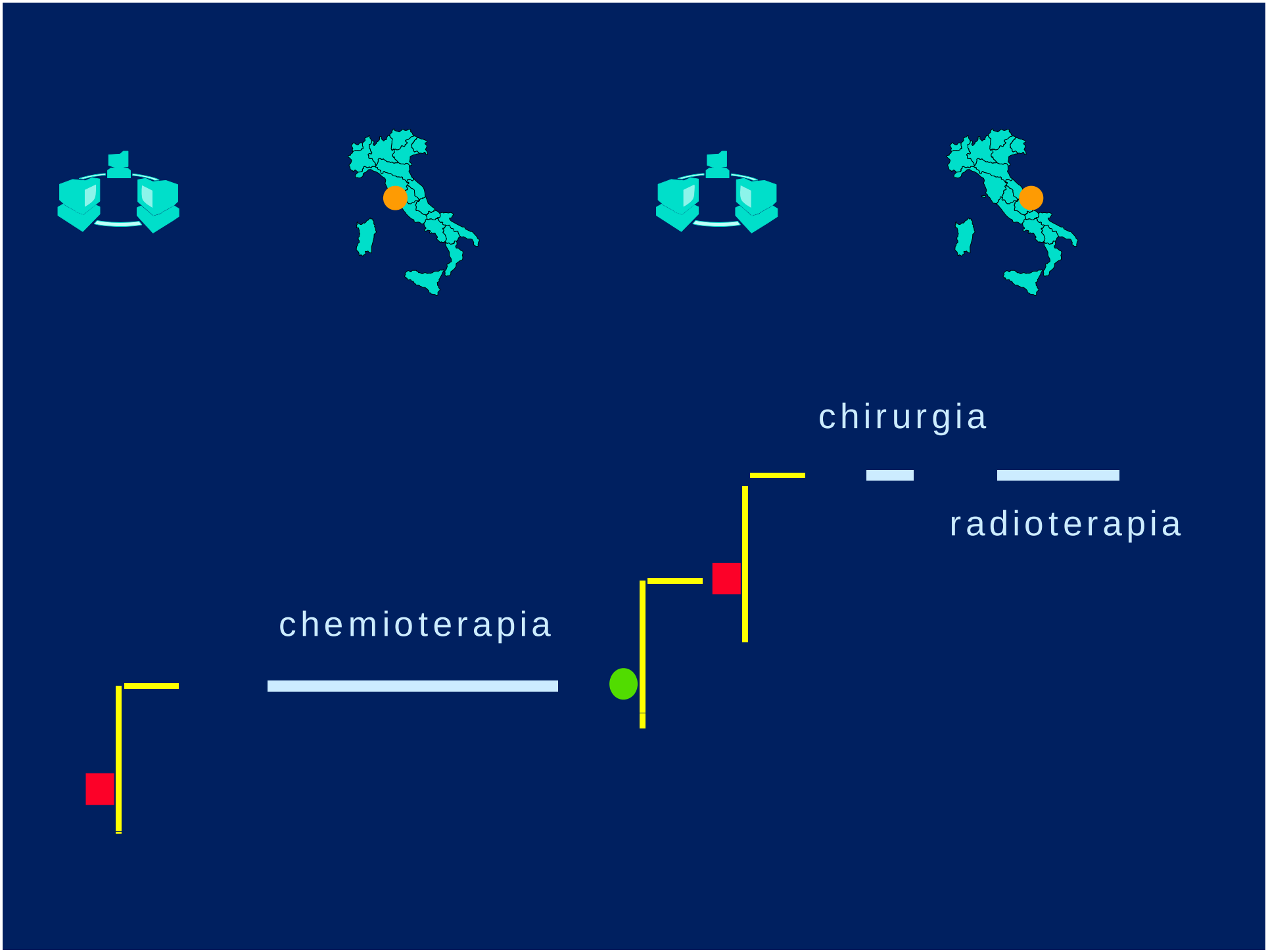






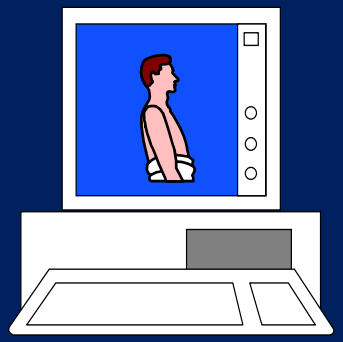
La centralizzazione in rete...



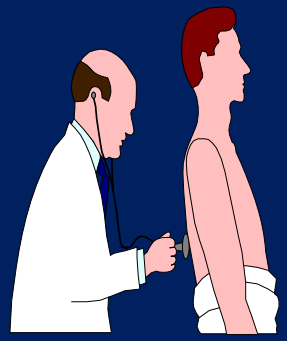

chirurgia
radioterapia
chemioterapia



paziente “logico”



paziente “virtuale”



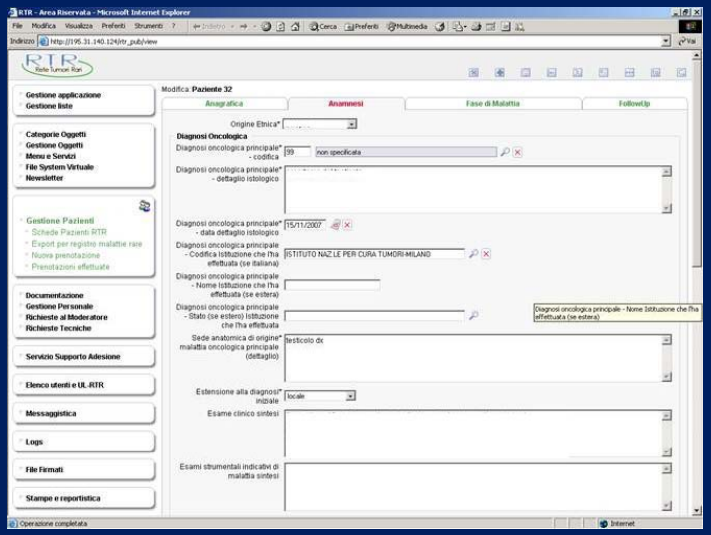
paziente “fisico”

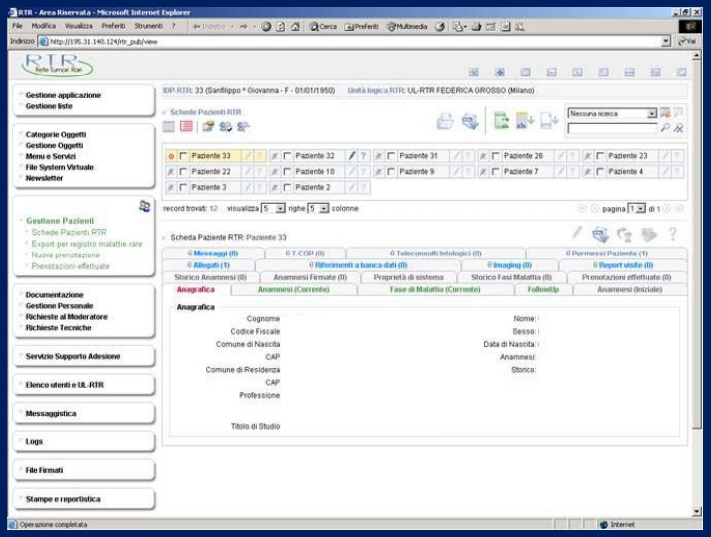
Qualità di cura
senza migrazione sanitaria



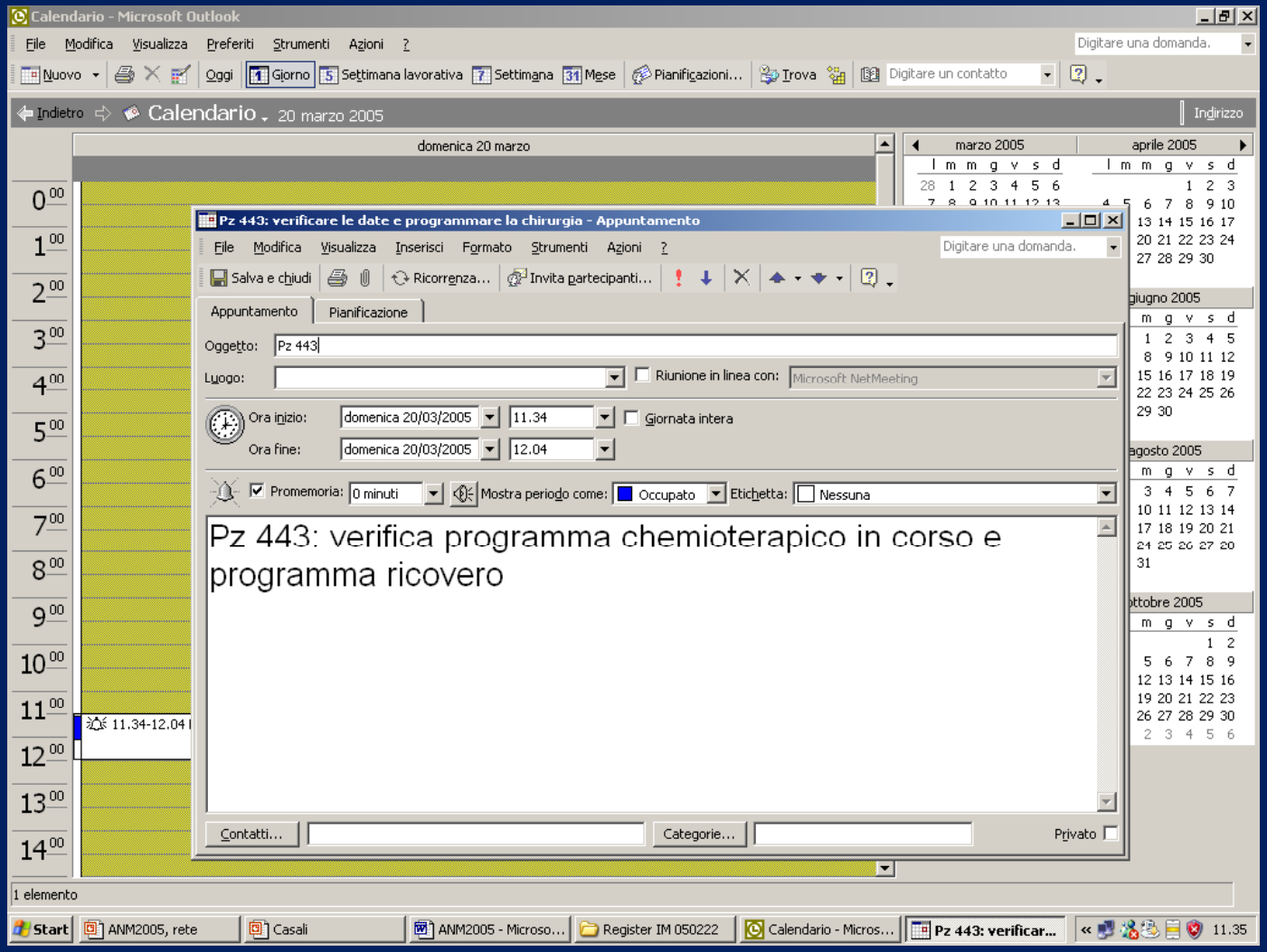


Teleconsulto





Telecondivisione continuativa



Strumento di rete...



Il tempo medico...!

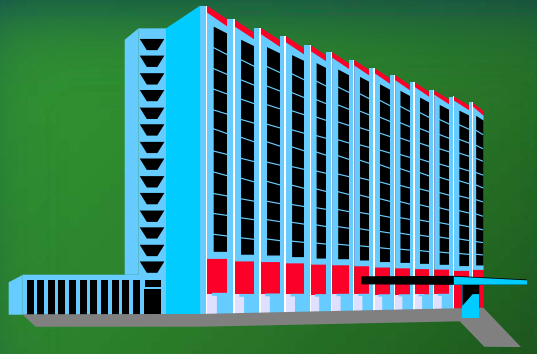




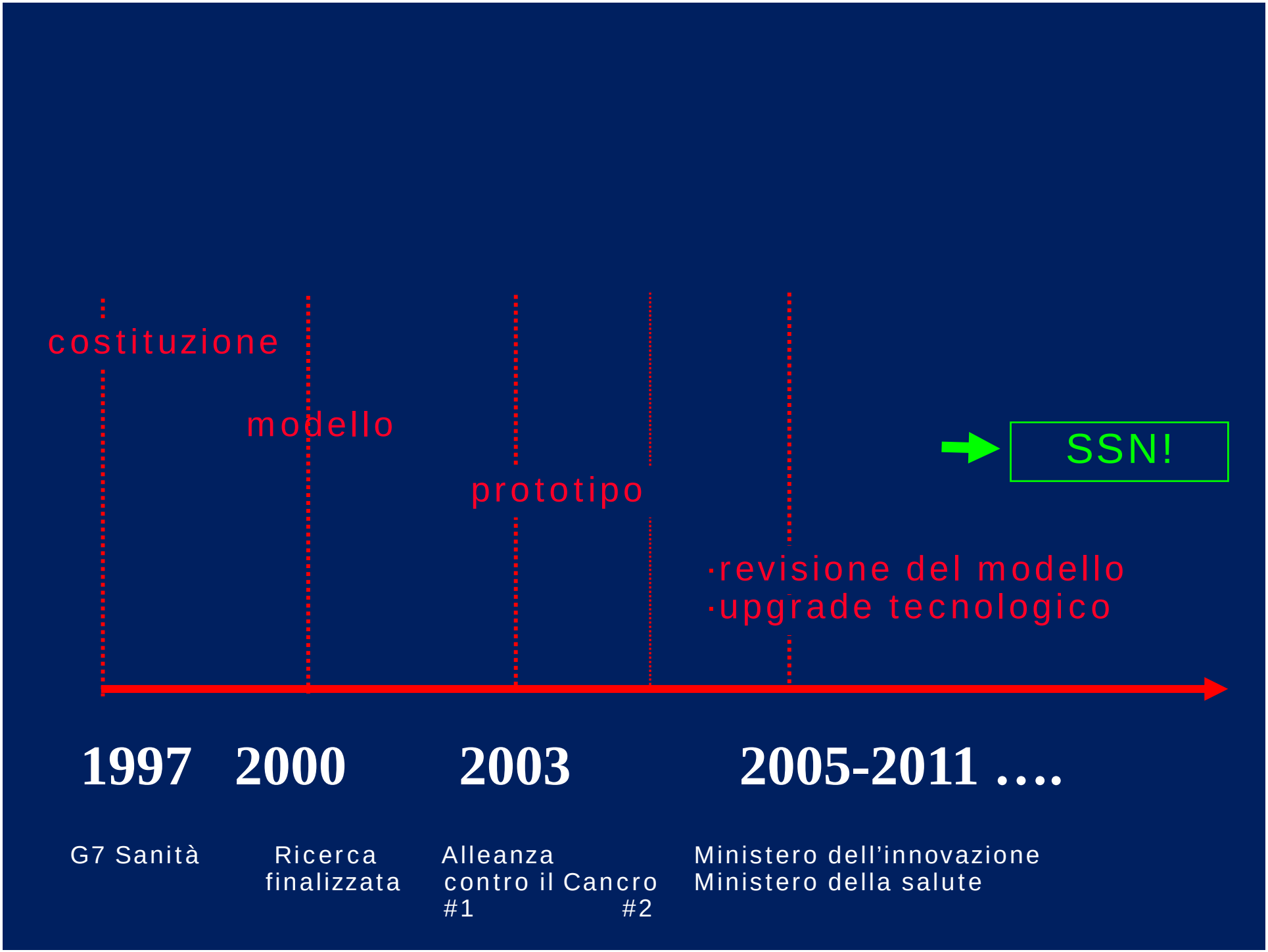
I costi...

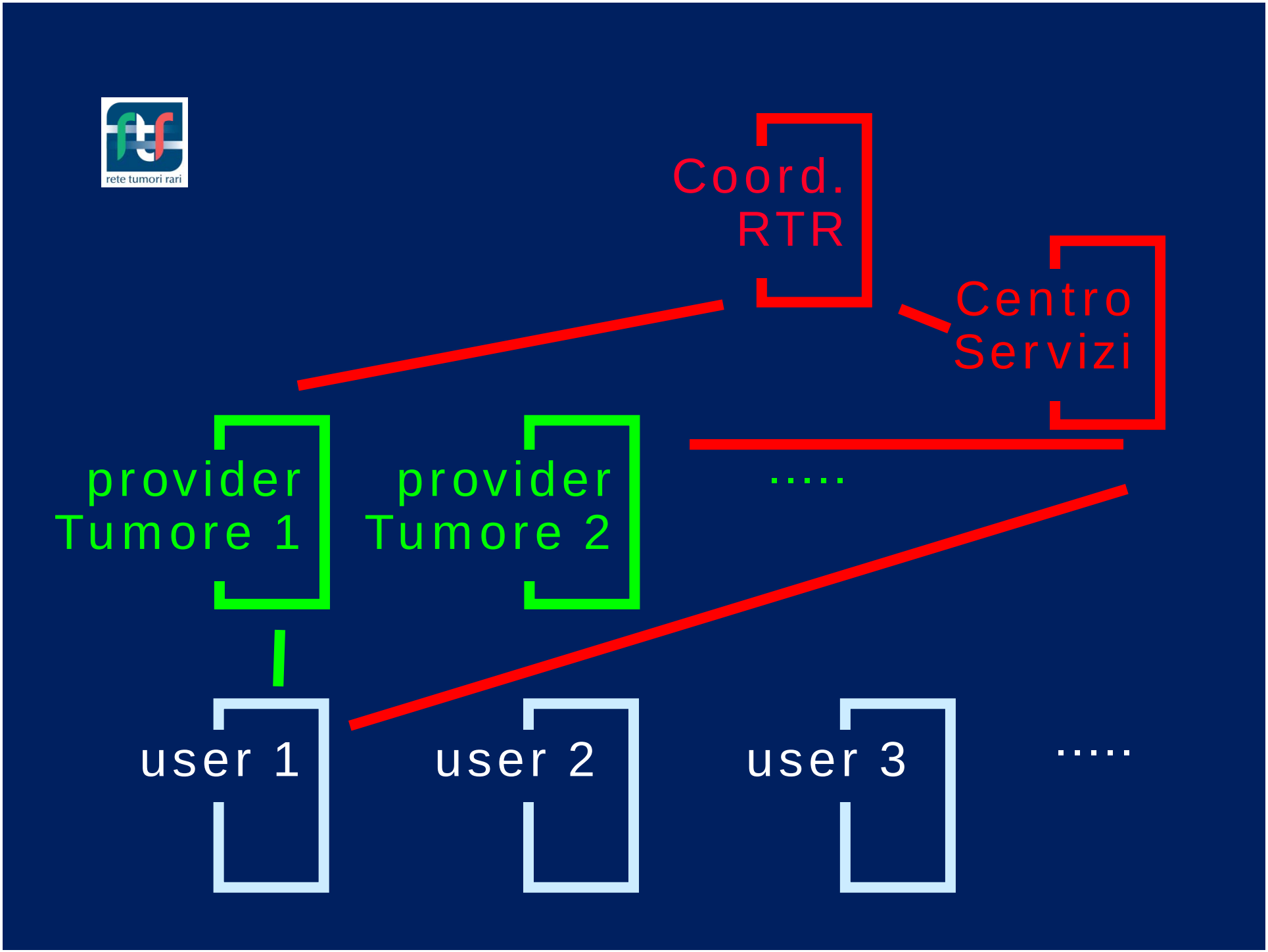






SSN


costituzione
modello
prototipo
SSN!
·revisione del modello
·upgrade tecnologico
1997
2000
2003
2005-2011 ….
G7 Sanità
Ricerca finalizzata
Alleanza contro il Cancro
#1
#2
Ministero dell’innovazione
Ministero della salute


rete tumori rari
Coord.
RTR
Centro
Servizi
provider
Tumore 1
provider
Tumore 2
.....
user 1
user 2
user 3
.....


RARE
CANCERS
EUROPE
Joining forces for action



ESMO
GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE
European Society for Medical Oncology

EURORDIS
Rare Diseases Europe

EUROPEAN
CANCER
PATIENT
COALITION

EORTC
European Organisation for Research and Treatment of Cancer

Conticanet

EuroBoNeT

ECL
Association of European Cancer Leagues

cmlsupport
chronic myeloid leukaemia support group

IBTA
INTERNATIONAL
BRAIN TUMOUR
ALLIANCE

orphanet

FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI

CML Advocates Network

IEO
European Institute of Oncology

SIOPE
SIOP Europe

ESO
European
School
of
Oncology
learning to care

EUROPEAN ONCOLOGY NURSING SOCIETY

European
Society of
Pathology

NOVARTIS
ONCOLOGY

Pfizer Oncology

sanofi aventis
Because health matters

European Society for Medical Oncology

Improving Rare Cancer Care in Europe

Recommendations on Stakeholder Actions and Public Policies

Whereas

A. Rare cancers[1] belong to the group of rare diseases that are normally defined as diseases with a prevalence of less than 50 out of 100,000. Even when defined more conservatively by taking into account some peculiarities of natural history and prognosis (e.g. by selecting those cancers with an incidence rate around or lower than 5/100,000/year), rare cancers represent about 20% of all cases of malignant neoplasms, including all cancers affecting children and teenagers and many affecting young adults;

B. There are significant variations in incidence and mortality rates for different types of rare cancers. There are also significant survival differences for the same types of rare cancers between the EU member states;[2]

www.rarecancerseurope.org



www.rarecancerseurope.org

rete tumori rari



RARE CANCERS EUROPE

Joining forces for action



ESMO

GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

European Society for Medical Oncology

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