



A Trama

Evaluative Epidemiology Unit

Fondazione IRCCS Istituto Nazionale dei Tumori

Milan - Italy

JointActionRareCancers

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**PUTTING
PATIENT CARE
FIRST**
EU Joint Action on Rare Cancers (JARC)

Welcome to JARC
EU Joint Action on Rare Cancers (JARC)

www.jointactionrarecancers.eu

Conflict of interest

I have no actual or potential conflict of interest in relation to this presentation

Objectives

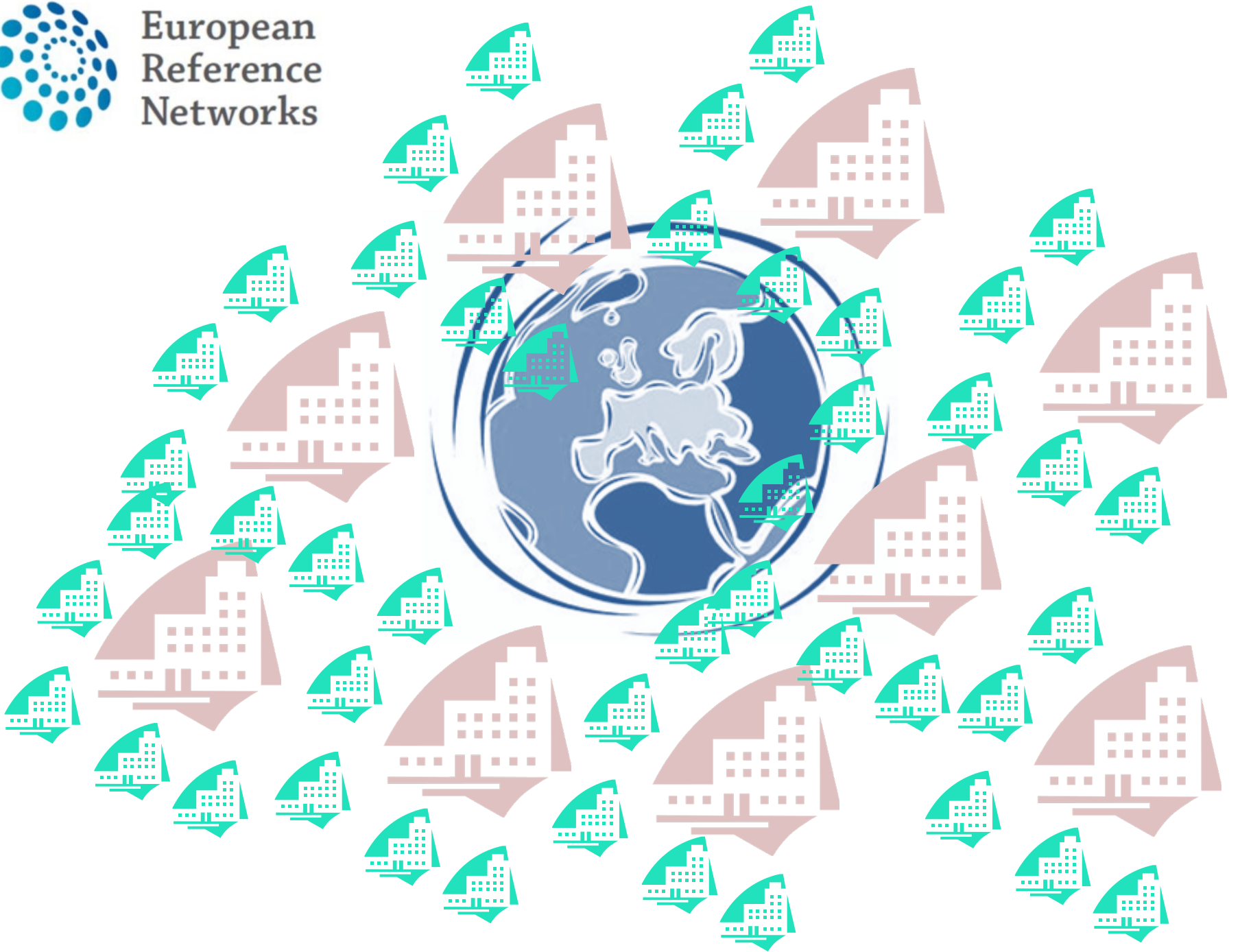
1. To prioritise rare cancers in the agenda of the EU and Member States
2. To develop innovative and shared solutions, mainly to be implemented through the future ERNs
 - Quality of care through ERNs
 - Clinical practice guidelines
 - Innovation/research
 - Medical and Patient education
 - Health policy measures
 - Patient empowerment
 - Epidemiological surveillance



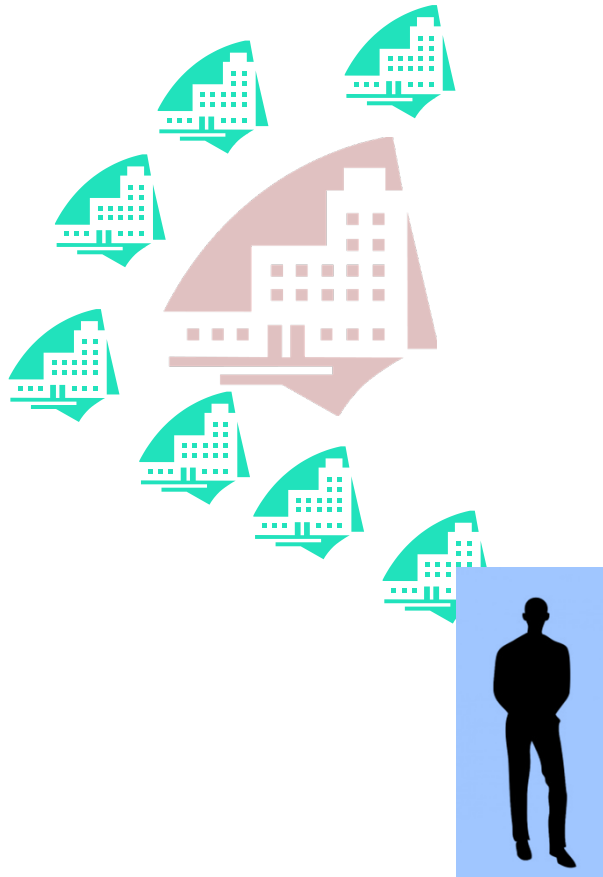
European
Reference
Networks



European
Reference
Networks

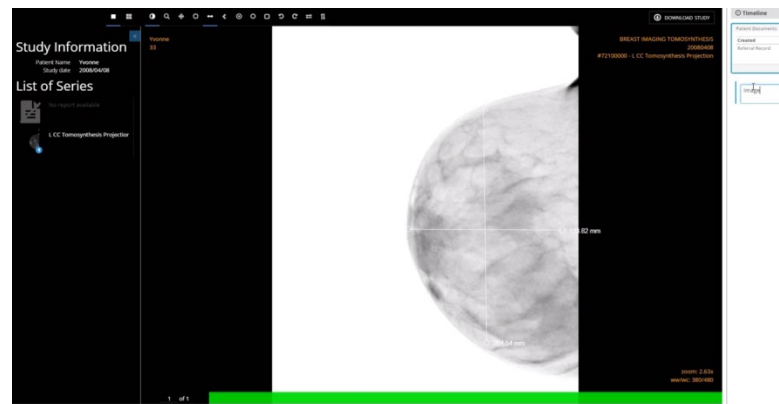


The “network rare cancer” patient indicators

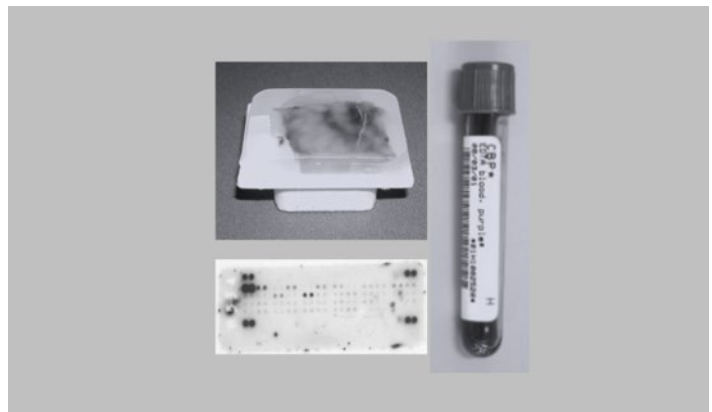


CPMS

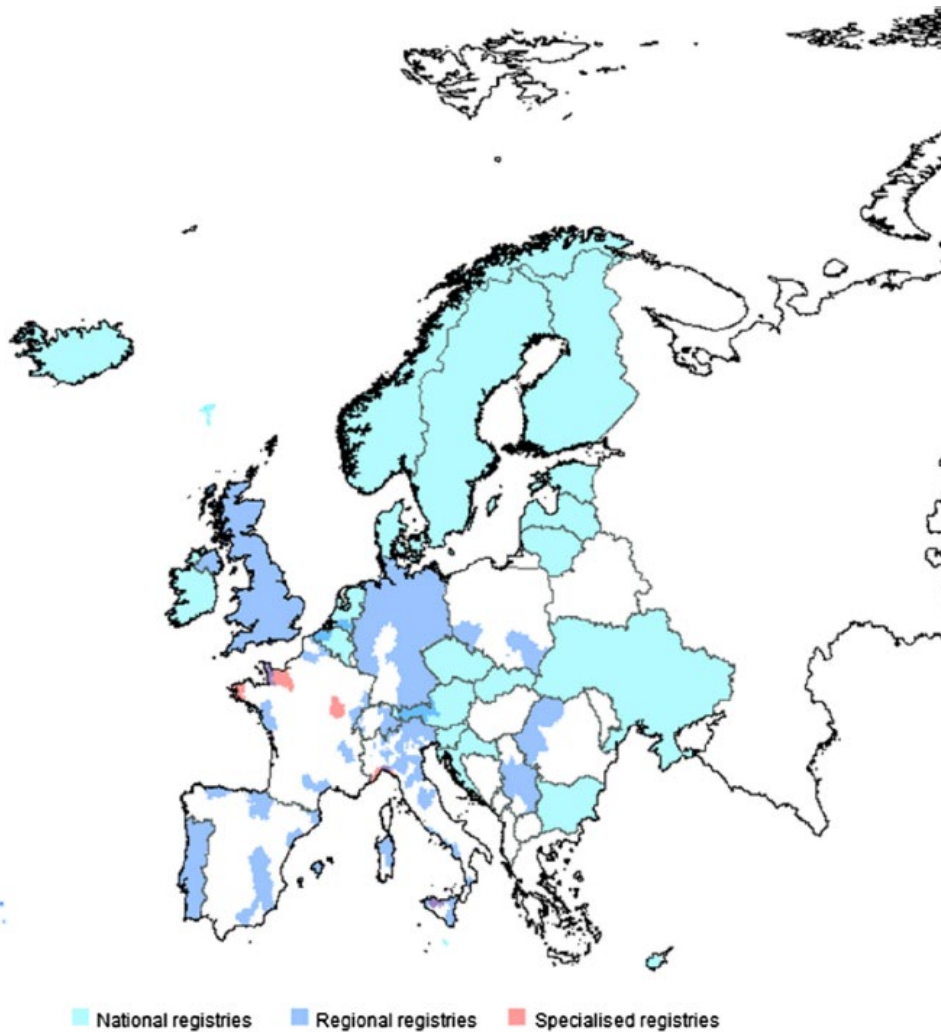
A screenshot of a patient enrollment form. A large red arrow points downwards from the top left of the form. The form includes sections for 'Enrol Patient', 'Qualification check', 'Consent for Care', 'Consent for research', 'Consent for EBN databases/Registries', and 'Entering data'. The 'Entering data' section contains fields for 'First name' (Kirsten), 'Last name' (Walker), 'Gender' (Female), 'Date of birth' (31/08/1933), and 'Record Label' (Walker, Kirsten OOB: 31/08/1933 (Female)).



Clinical registries & Biobanking



Population based cancer registries



Steliarova-Foucher et al. The European Cancer Observatory: A new data resource . European Journal of Cancer (2015) 51, 1131– 1143



<https://www.enrcr.eu/>

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.

<https://ecis.jrc.ec.europa.eu/>

