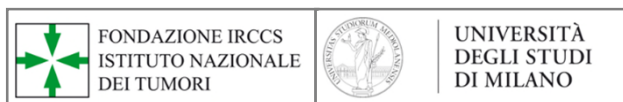




Joining forces for action



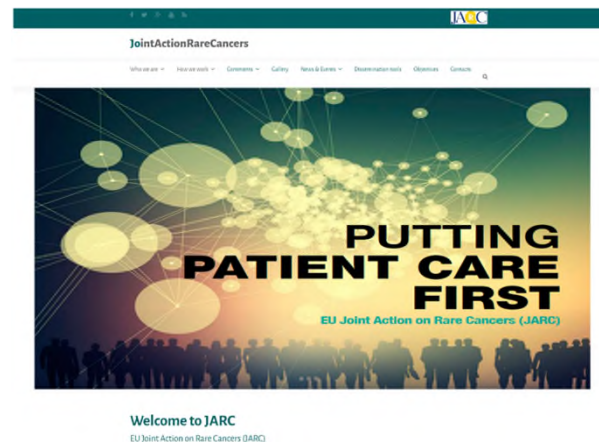
National cancer networks



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FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI



www.jointactionrarecancers.eu



JOINT ACTION ON **RARE** CANCERS



- **18 MSs**
- **34 ass. partners**







European
Reference
Networks

EpiCARE . BOND
. CRANIO . ENDO .
ERKNet . EYE . ERNICA .
VASCERN . LUNG . RND . SKIN
. EURACAN . GUARD-HEART
. EuroBloodNet . eUROGEN .
GENTURIS . ITHACA . MetabERN
. PaedCan . RARE-LIVER .
ReCONNET . EURO-NMD .
TRANSPLANT-CHILD .
RITA

Share. Care. Cure.





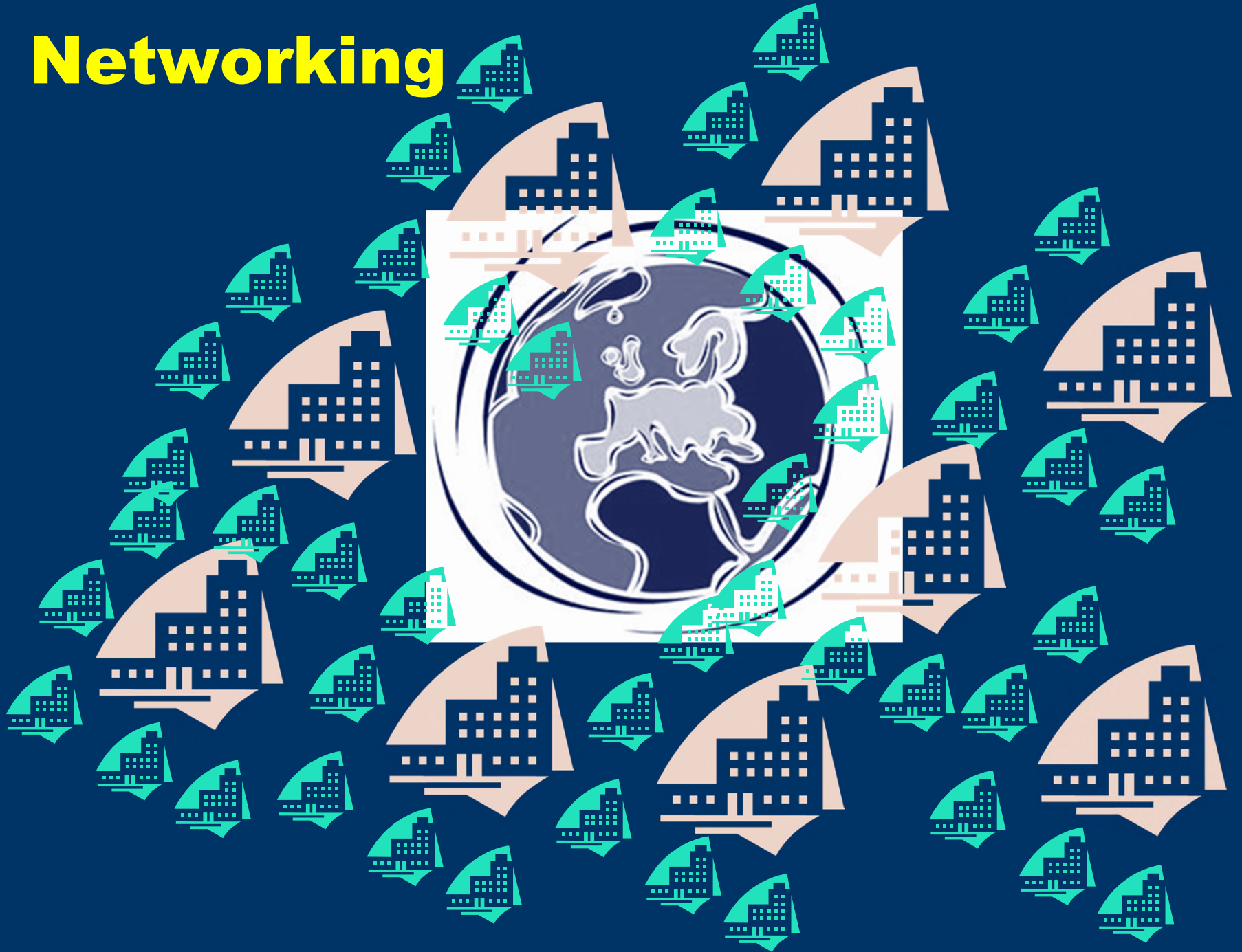
European Reference Networks

ERN BOND	European Reference Network on bone disorders
ERN CRANIO	European Reference Network on craniofacial anomalies and ear, nose and throat (ENT) disorders
Endo-ERN	European Reference Network on endocrine conditions
ERN EpiCARE	European Reference Network on epilepsies
ERKNet	European Reference Network on kidney diseases
ERN-RND	European Reference Network on neurological disease
ERNICA	European Reference Network on inherited and congenital anomalies
ERN LUNG	European Reference Network on respiratory diseases
ERN Skin	European Reference Network on skin disorders
ERN EURACAN	European Reference Network on adult cancers (solid tumours)
ERN EuroBloodNet	European Reference Network on haematological diseases
ERN eUROGEN	European Reference Network on urogenital diseases and conditions
ERN EURO-NMD	European Reference Network on neuromuscular diseases
ERN EYE	European Reference Network on eye diseases
ERN GENTURIS	European Reference Network on genetic tumour risk syndromes
ERN GUARD-HEART	European Reference Network on diseases of the heart
ERN ITHACA	European Reference Network on congenital malformations and rare intellectual disability
MetabERN	European Reference Network on hereditary metabolic disorders
ERN PaedCan	European Reference Network on paediatric cancer (haemato-oncology)
ERN RARE-LIVER	European Reference Network on hepatological diseases
ERN ReCONNET	European Reference Network on connective tissue and musculoskeletal diseases
ERN RITA	European Reference Network on immunodeficiency, autoinflammatory and autoimmune diseases
ERN TRANSPLANT-CHILD	European Reference Network on Transplantation in Children
VASCERN	European Reference Network on Rare Multisystemic Vascular Diseases



- **promote good quality and safe care to patients by fostering proper diagnosis, treatment, follow-up and management of patients across the Network**
- **empower and involve patients**
- **offer and promote multi-disciplinary advice for complex cases**
- **develop and implement clinical guidelines and cross-border patient pathways**
- **exchange, gather and disseminate knowledge evidence and expertise within and outside the Network**
- **promote collaborative research within the Network**
- **reinforce research and epidemiological surveillance, through setting up of shared registries**
- **exchange and disseminate knowledge and best practices, in particular by supporting national centres and networks**

Networking



1. Patient referral

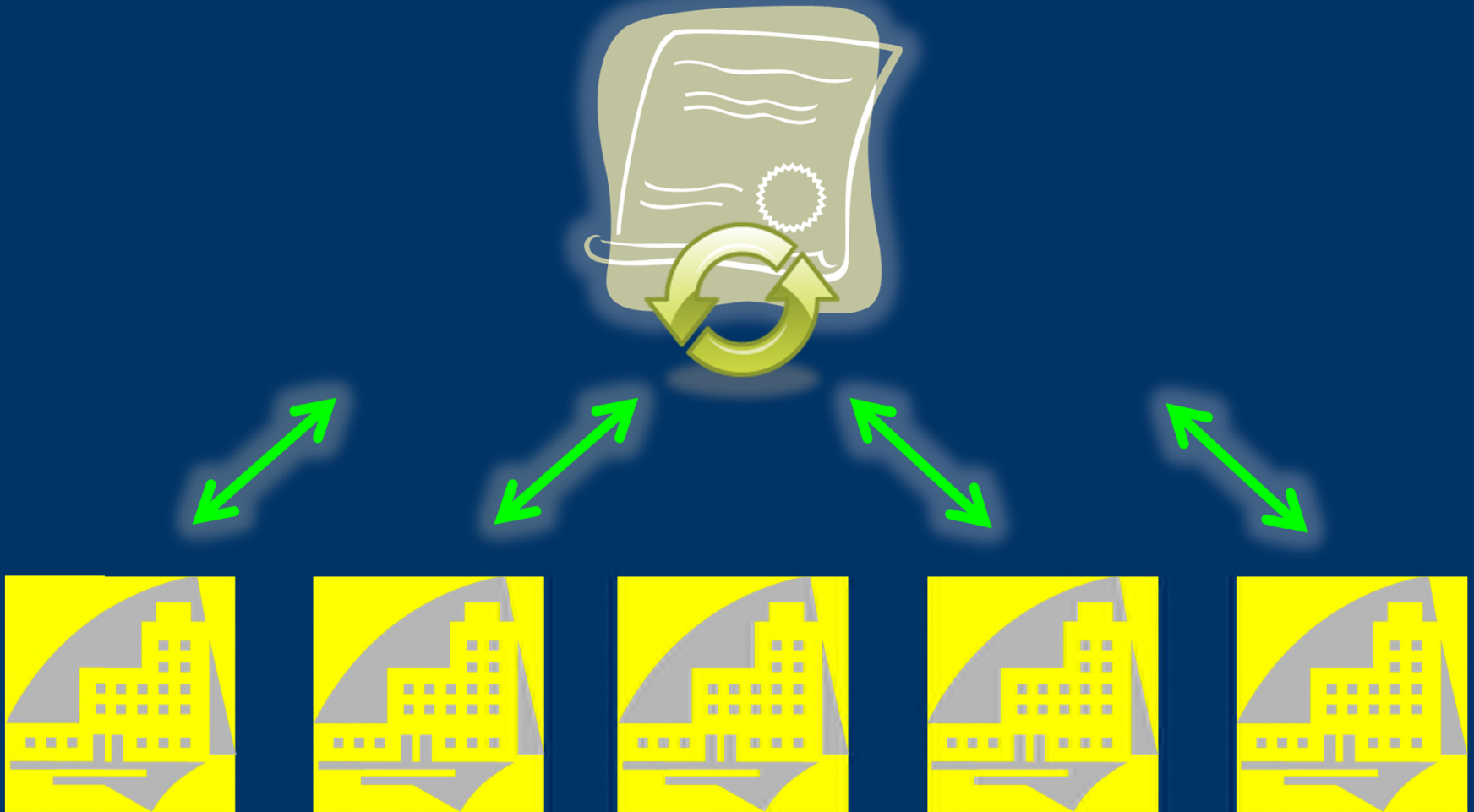


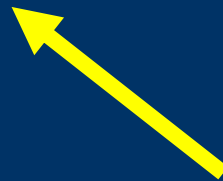
2. Teleconsulting

- **pathologic diagnosis**
- **strategic clinical decision**
- **continuous case sharing**
- **treatment**
- **.....**



3. Quality of care



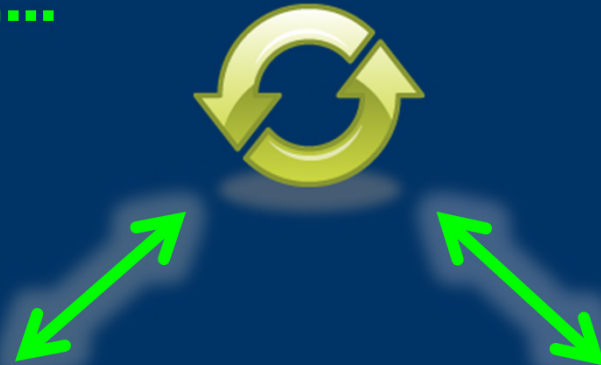


4. Medical & patient education



5. Research support

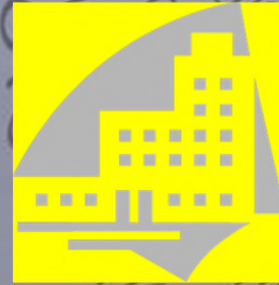
- **observational research → big data**
- **virtual tissue banking**
- **referral to open clinical trials**
- **.....**

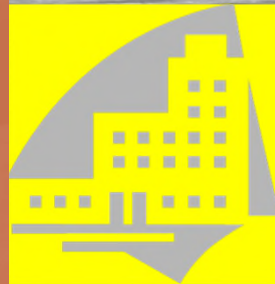
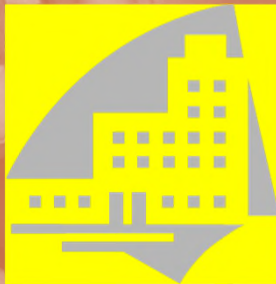
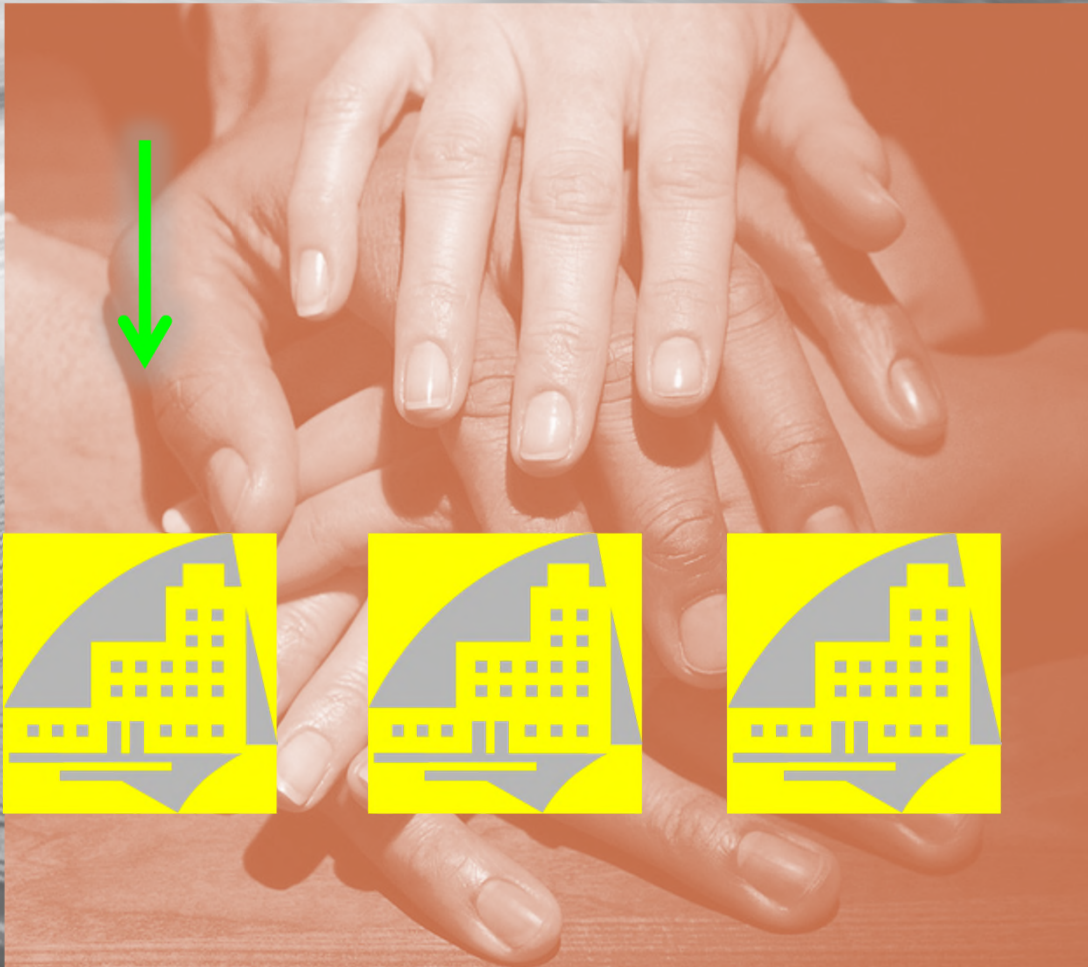


From the center of expertise...



...to the reference network





Centralized referral



- **expertise**
- **multidisciplinary**
- **research**

- **health migration**
- **implicit rationing**
- **failures in routine care**

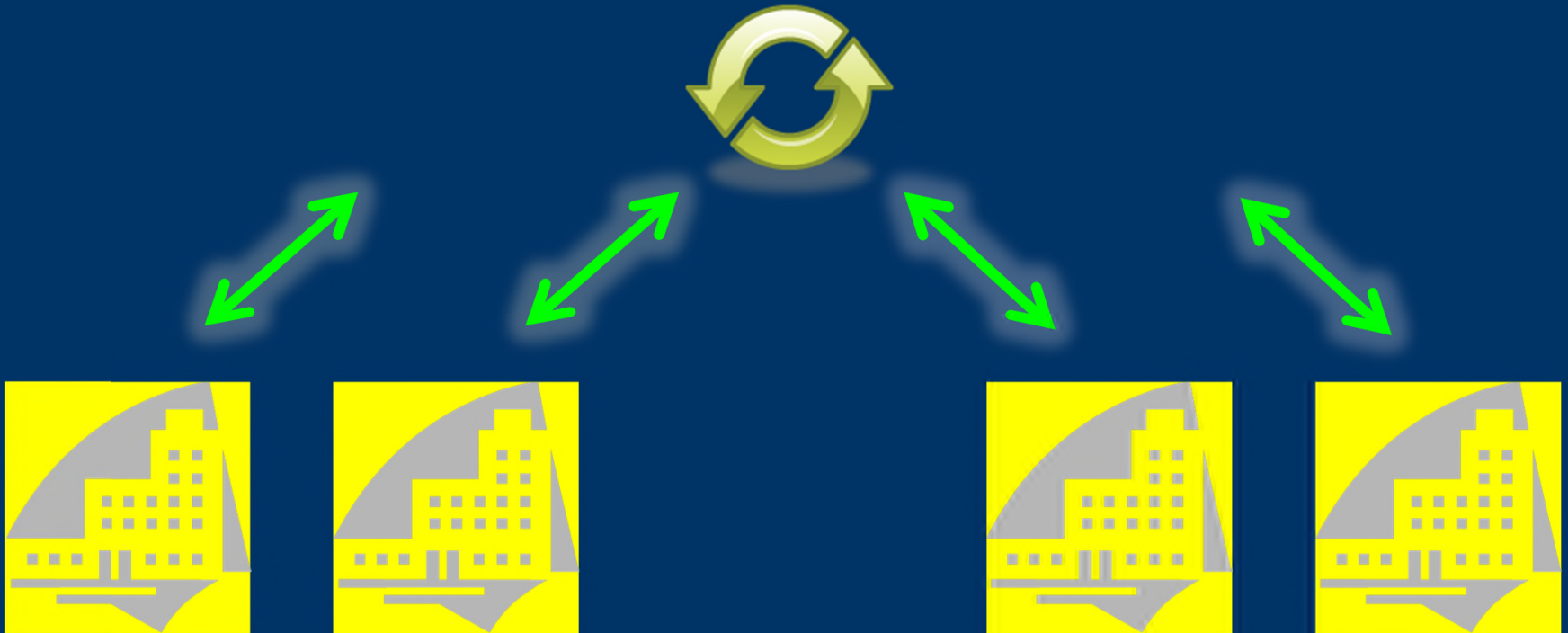


Networking

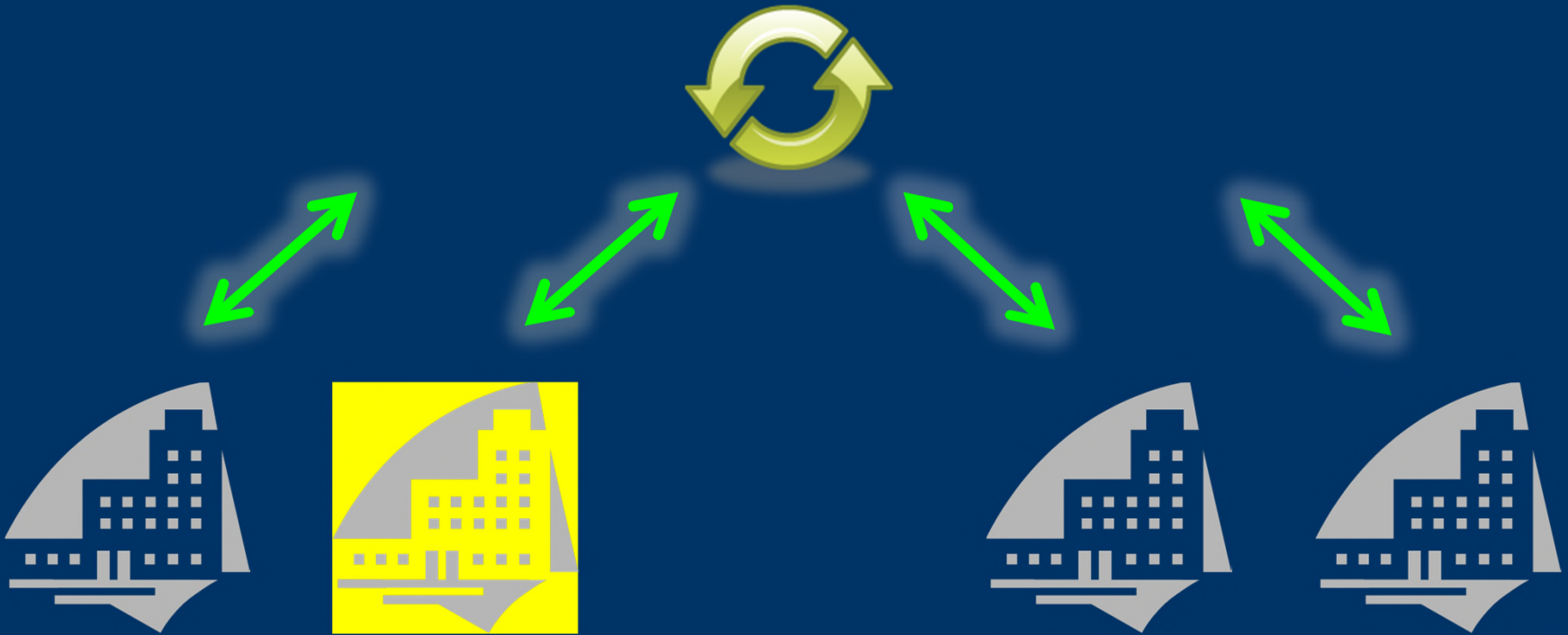
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 - **implicit rationing**
 - **failures in routine care**
- 

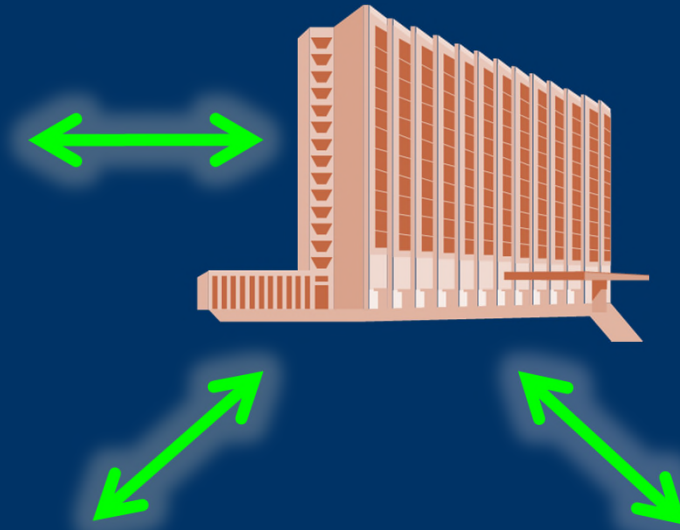
The health network...



**...is based
on centres of reference!**



The centre of reference...



Medical workload...!





«Network patient» quality criteria...





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