

# ERN GENTURIS

## European Reference Network on Genetic Tumour Risk Syndromes



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## Background

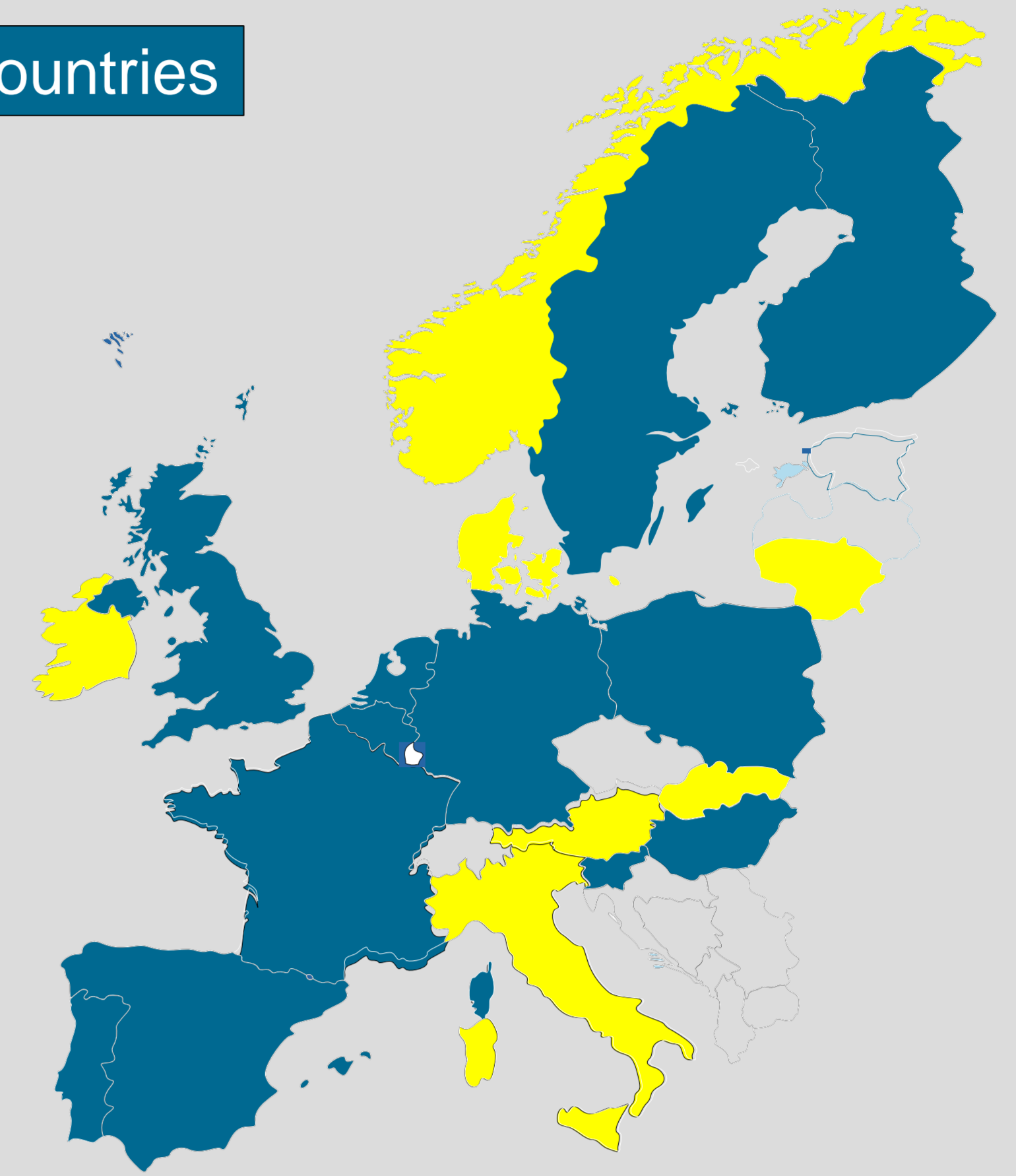
- ❖ Patients with Genetic Tumour Risk Syndromes (genturis) are at very high risk to develop tumours in multiple organ systems at a relatively young age.
- ❖ There are more than 40 different genturis.
- ❖ Hereditary tumours often look like common tumours, but behave differently and need a different approach in detection and treatment.
- ❖ Patients and their relatives deal with psychosocial issues related to hereditary diseases or to syndrome-specific issues.
- ❖ For all patients with genturis a personalized treatment, based on their germline mutation, is essential.
- ❖ Also healthy relatives should receive proper medical management in order to give optimal genetic and social counselling and prevent tumours.

## HCP members

23 endorsed HCP in 12 countries

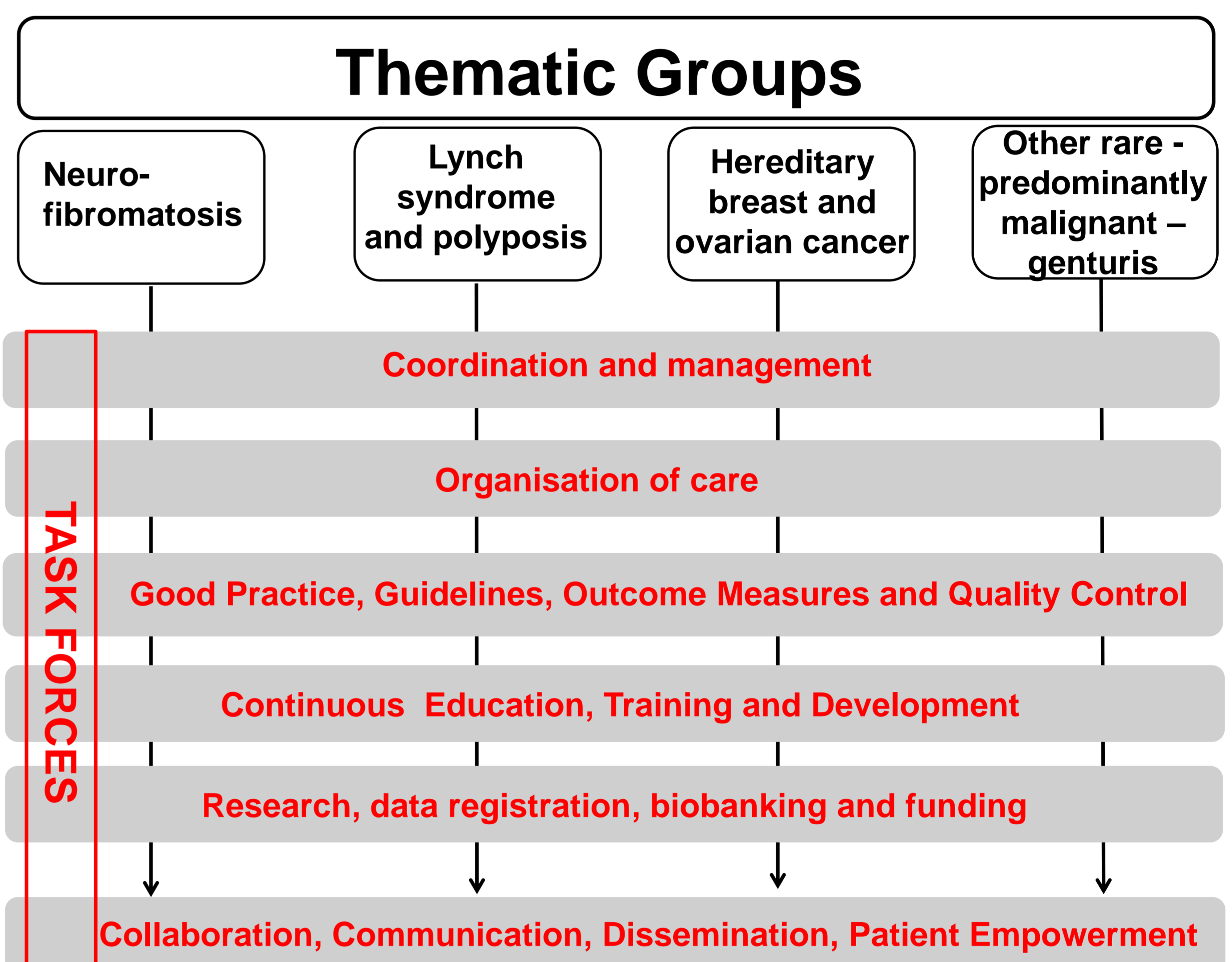
Endorsement in 2017?

No member yet

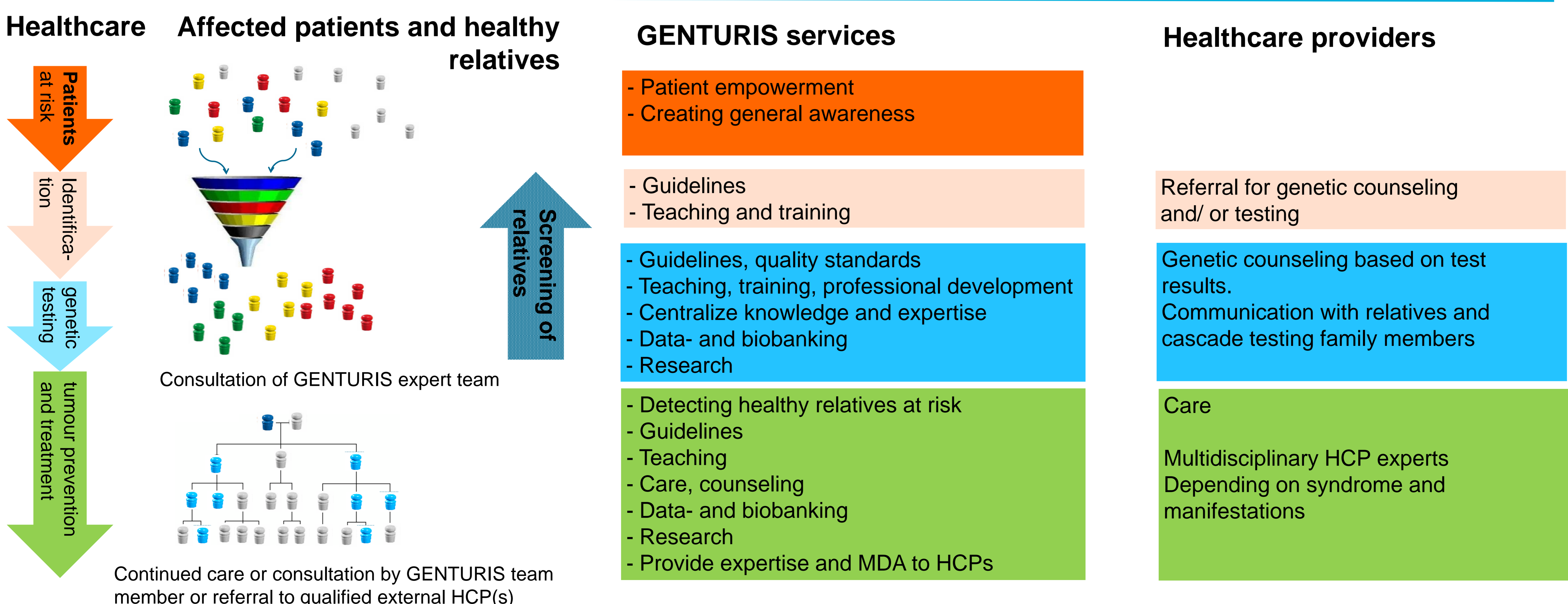


## Aims of ERN GENTURIS

- ❖ Improved identification of people living with a genturis
- ❖ Reduced variation in clinical practice and outcomes
- ❖ Development of evidence based clinical guidelines
- ❖ Development and use of patient registries, biobanks and research projects
- ❖ Defined health care pathways to facilitate improved access to international specialist clinical knowledge for patients and their families living throughout the EU
- ❖ Pan-European development and use of patient registries, biobanks and research studies
- ❖ Giving a home to all people with a genturis



## GENTURIS patient care pathway and related services provided



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