Priorities and recommendations on rare cancers in adults and children in National Cancer Control Plans (NCCPs)

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TYPE	STATUS	LAST UPDATE	
Guidance	Report completed and ready for use	July 2020	BELGIUM ● NATION-WIDE Europe ● Health Systems ● Diagnosis and treatment

PROBLEM & OBJECTIVE

PROBLEM

Rare cancers tend to have less social visibility and attract less research interest than other cancer diseases.

OBJECTIVE

Analyse the EU National Cancer Control Plans (NCCPs) in order to compare the different policies that exist for rare cancers in adults and children.

KEY COMPONENTS / STEPS

- Dissemination as peer-reviewed literature (1)
- Update of the information concerning rare cancers in children and AYA (adolescents and young adults) in collaboration with SIOPE (European Society for Pediatric Oncology) (2023-24).

KEY CONTEXTUAL FACTORS

- According to some estimates, there are around 200 different types of rare cancers, including rare adult solid tumours and rare haematological cancers as well as all childhood cancers.
- Rare cancers comprise 24% of the total cancer cases diagnosed every year in the EU (2).
- Despite being rare, pediatric cancers remain the 1st cause of mortality by disease among young people in Europe with 6,000 deaths per year (3).
- Clinical research and the development of new treatments are considered 'underserved' in this area.

MAIN IMPACTS / ADDED VALUE

- Rare cancers are hardly addressed in NCCPs. Of the NCCPs examined, 8 considered rare cancers in adults to some extent (10 in the case of children and AYA), while 7 contained no information (5 in the case of children and AYA).
- Due to the rarity of each single cancer disease, rare cancers have a strong European added value as no one country alone can tackle this issue.
- Policies and recommendations based on common EU MS priorities have been developed to address the challenges posed by rare cancers.

LESSONS LEARNED

- Centralising care for patients with rare cancers in reference centres emerges as a necessary condition for effecting change in the organisation of services.
- Care for rare cancers should be based on expert multidisciplinary teams, which should in turn be articulated with other levels of care.
- The possibility of treating a rare cancer (e.g. sarcoma) in one centre should not prevent collaboration with other centres in the case of a pathological subtype (e.g. bone sarcoma).
- Continuity of care is a critical dimension. The health system should manage the possible changes in centres, services and reference professionals derived from patients' changing needs.

REFERENCES & DOCUMENTATION

- JARC Report: Link to the JARC_WP10_Task 1
- Paper for adults: JCP

(1) Joan Prades, Ariane Weinman, Yann Le Cam, Annalisa Trama, Anna Maria Frezza, Josep M. Borras. Priorities on rare cancers' policy in National Cancer Control Plans (NCCPs): A review conducted within the framework of EU-JARC Joint-Action. J Cancer Policy 24 (2020).

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(3) International Agency for Research on Cancer. (2018). Cancer Today. Retrieved from Cancer Today website: https://gco.iarc.fr/today/home

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