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Joint Action and European Reference Networks on Rare Cancers

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Rare cancers are not so rare, together they represent 22% of all new cases diagnosed in Europe each year. Diagnosis and treatment of rare cancers may not reach optimal standards in all EU countries. This is more likely when healthcare is delivered by institutions with limited expertise, suboptimal multidisciplinary organisation of cancer care and/or low case volumes. Moreover, clinical and translational research would need a high level of centralisation and international collaboration if we expect better outcomes. From the Health Organisation's point of view, in the EU, an opportunity is provided by the creation of European Reference Networks for rare diseases (ERNs) which will become reality in the coming years. In fact, there is a wide consensus on networking as the most appropriate answer to the issues pertaining to rare diseases in general, as well as to rare cancers: however, these last belong to the "world" of cancer, i.e., one of the leading diseases and causes of death worldwide. Thus, the creation of EU-based networking on rare cancers is a huge opportunity launched by the DG SANCO with a specific call. However, there are risks that such an opportunity may be missed, as long as the peculiarities of rare cancers, as compared to rare non-neoplastic diseases, are not recognised. In this framework, and in parallel to the setting-up of European Networks on rare diseases (cancer included), the DG SANCO launched a new initiative for a Joint Action on Rare Cancers (JARC). Coordinated by the Italian Ministry of Health and the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (Italy), JARC will start in September 2016 taking advantage of a strong partnership of 34 partners, from 19 different European Member States, including the OECE, which will be acting as coordinator of the WP on Quality.

JARC aims to (a) prioritise rare cancers in the agendas of the EU and Member States and (b) to develop innovative and shared solutions for ERNs on rare cancers, in the areas of quality of care, innovation, education and state of the art definition on prevention, diagnosis and treatment.

The objectives of JARC will be achieved by the creation of a platform for competent national authorities, institutions, scientific and professional societies, as well as patient organisations, to produce

consensus-based recommendations, with a special view to the new ERNs, seen as a great opportunity for improvement of rare cancer patient outcomes in the EU.

For the purposes of JARC, the following “families” of rare cancers will be singled out, following the RARECARENet (www.rarecarenet.eu) list of rare cancers:

1. Head and neck cancers
2. Thoracic rare cancers
3. Male genital and urogenital rare cancers
4. Female genital rare cancers
5. Neuroendocrine tumours
6. Tumours of the endocrine organs
7. Central Nervous System tumours
8. Sarcomas
9. Digestive rare cancers
10. Rare skin cancers and non-cutaneous melanoma
11. Haematological rare malignancies
12. Paediatric cancers (all)

Each rare cancer family deals with a relatively homogeneous, disease-based community of physicians, clinical researchers and patients, but needs comparable hospital based infrastructures, technologies and environment. In the context of the first call for ERNs, three main networks will be organised: (a) Solid rare cancers in adults (regrouping the families from 1 to 10) (b) Haematological rare malignancies, (c) Paediatric cancers.

In actual fact, the burden of these three groups of rare cancers is slightly disproportionate.

According to the RARECARENet project estimations, the incidence of all rare solid tumours is 75% of all rare cancers. The corresponding percentages are 23% and 1.6% for haematologic and paediatric cancers, respectively.

Following a recent meeting that was jointly organised in Brussels by OECI and ESMO, a consensus has been reached among several cancer centres and hospitals including: RARECARENet, EORTC, ECPC and EANO. An ERN application for rare cancers in adults will be coordinated by Professor Jean Yves Blay, General Director of the Institut Léon Bérard in Lyon.

Any improvement in care and research on rare cancers is expected to impact on patient outcomes, i.e., overall survival and quality of life.

JARC is meant to serve as a reference source of policy recommendations on rare cancers in Europe. Therefore, the outputs of the JARC will essentially be consensus-based recommendations on:

- 1) epidemiological surveillance of rare cancers; 2) quality of healthcare, primarily through shaping of the new ERNs; 3) clinical practice guidelines on rare cancers; 4) innovation, especially with regard to clinical research regulations, as well as practices and semantics regarding patient data and tissues; 5) medical and patient education; 6) health policy measures on rare cancers at the EU and national level; 7) patient empowerment.

In particular, the list of rare cancers will be updated in order to improve surveillance. The recommendations on standardisation of epidemiological analyses will allow each member state to have information on rare cancer burden, to estimate survival differences by European regions, to support better healthcare planning and resource allocation and to develop recommendations in reducing health inequalities. JARC will also promote medical education on rare cancers, as well as clinical practice guidelines, especially on specific pathways. Empowerment of rare cancer patients needs information and education. JARC, in collaboration with the European Cancer Patients Coalition and the OECI, will contribute by developing guidelines to inform, educate and motivate patients. Information will not only reach them but also originate from their communities.

Armed with this new project, the JARC Consortium, including the OECI, will work tirelessly towards keeping rare cancers an important topic on the EU and Member States’ agendas.