

## 79<sup>th</sup> ENCR Steering Committee (SC) Meeting Minutes – Videoconference

**Date and place:** 22 February 2022, Videoconference

**Attendees:** ENCR SC (2021-2023), Representatives from the European Commission Joint Research Centre (JRC)

### The new data call

#### Collaboration Agreement between the JRC and the ENCR registries

The first version of the collaboration agreement (CA) was discussed with the SC in September. In November the JRC organised 3 webinars where all the registries were invited. The CA was presented and questions from the registries were replied. All the registries were invited to forward the CA to their legal services and to provide feedback. Feedback received was taken into account and addressed by the JRC for the final version of the CA.

#### CA signature procedure

Once the CA is signed by the JRC, the JRC-signed copy will be sent out to each single registry. The CA needs to be signed in English, but will be accompanied by a working translation in the local language to facilitate comprehension of the text. Once the CA is signed, registries will be allowed to submit data to the JRC. The CA needs to be signed only once, and does not need to be renewed on future data calls.

#### Specific situations

- The Nordic registries: confirmed the decision to contribute to ECIS with aggregated data.
- IARC's CI5 project: IARC and the JRC investigated a possible mechanism having a coordinated data call that would allow a single submission for ECIS and CI5. Given a legal solution to allow the transfer is not yet available, and considering the tight calendar of the CI5 in its worldwide context, the CI5 Volume XII call for data was launched to the European registries independently from the ECIS call. A communication was sent in January to the European registries informing about that.

### Data access procedure

The JRC proposed a procedure to request access to the ECIS data. The JRC-ENCR Management Committee will assess the data requests based on the following aspects: information about the requesting researchers, foreseen output, added-value of the research and assurance of the data minimisation principle.

### ENCR recommendations

- The recommendation on **Coding Incidence Date** was endorsed. Members of the previous Steering Committees will be acknowledged as authors.
- The recommendations on **Recording and Reporting of Urothelial Tumours** is ready to enter the phase of consultation to the registries.
- **Multiple primaries:** The new publication on morphological groups and the recommendation on urological tumours should be reflected in the multiple primary tumours recommendation. A revision of the current rules taking into account the ICD-O-3.2 will be done.

- Work is ongoing for the Working groups dealing with **Basis of Diagnosis, Cancer entities, Treatment data harmonisation** and **ENCR standard dataset**.
- A new ENCR Working Group is proposed to address the topic of **Tumour recurrences**.

### **ENCR training and events**

In 2022, three topics have been identified for corresponding webinars:

- Training on modern diagnostic techniques
- Urological Cancers: a date for the training will be set up once the Recommendation on Recording and Reporting of Urothelial Tumours is endorsed
- IT tools for the new data call: the scope is to provide an overview and promote the use of the JRC-ENCR IT tools for the new data call.

### **Next ENCR conference**

Given the positive experience for the 2021 event, the SC agreed to have the next conference in 2023 again in a virtual setting.

### **Survival into ECIS**

With the overall goal of reaching alignment between incidence, mortality and survival indicators in ECIS, the ENCR SC expressed the opinion that the service of providing EU and Europe-wide survival statistics should run independently from targeted research projects. Survival statistics should therefore be computed and released directly from the cancer registry data collected from the ECIS data calls. JRC will investigate different options to the purpose.

### **ENCR site visits**

#### **Review of the Romanian National Childhood Cancer Registry**

The review was concluded after three virtual meetings. The draft report will be finalised and shared with the registry.

#### **Request from Madrid childhood CR review**

The JRC will organise the meeting(s) with the support from Members of the ENCR SC.

### **Release of childhood data in ECIS**

In December 2021 the JRC launched the new section in the ECIS web application, reporting on childhood tumours.