

77th ENCR Steering Committee (SC) Meeting Minutes – Videoconference

Date and place: 24 June 2021, Videoconference

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

Collaboration Agreement (CA) between the JRC and the ENCR registries

A CA is being finalised, which will regulate the collaborative research project between the JRC and the ENCR registries and set out rights and obligations of the partners. A specific part on data protection is included in the CA. Each registry should sign an Accession document to become Party of the CA. The CA would enter into effect between the JRC and each Registry when has been signed by the JRC and by that Registry. The coordination would be ensured by a Management Committee with members from the ENCR SC and two representatives from the JRC.

The CA addresses individual data transfers, as well as transfer of aggregated data.

ENCR recommendations

- **Basis of diagnosis:** a call for expression of interest to participate in such a working group could be announced through the ENCR newflash with the view to organise a first meeting to initiate discussion on the topic in autumn.

ENCR events 2021

- **Trainings:** JRC presented the trainings having taken place already in 2021, together with the feedback received after each event.
For the planning of next trainings, it was proposed to have monthly events hooked to cancers awareness dates/months. Topics suggested for next trainings are on childhood cancers, cancer staging, haematological malignancies, prostate cancer and prevalence software.
A training for the recommendation on urological tumours can be organised after the recommendation is finalised.
- **ENCR Scientific meeting, 16-18 Nov 2021:** 83 abstracts were received and will be revised by the ENCR SC members. Three keynote speakers will open the three days.
The ENCR General assembly will not be held on the ENCR scientific meeting.

Treatment data harmonisation initiative

27 experts from cancer registries, research groups and JRC participated in the online meeting of the working group (WG) on 18th June. The discussion focused on which treatment data should be collected (e.g. first line treatment, second line), the coding systems in place and the available sources of information. It was decided to initiate the work focusing first on breast cancer treatment. Monthly meetings are envisaged for the WG, with the aim of finalising the work by the end of the year.

Discussion on lifetime risk

The age span to be considered for the lifetime risk reported in ECIS and cancer factsheets (currently set at 0-74 years) is being revisited. An update of the age span of lifetime risk should consider the longer expectancy of life now recorded in Europe. The JRC presented an analysis on the possible age span to be used and the effects of this change. The conclusion was to consider for the cancer factsheets a lifetime risk computed on all ages.

Second COVID-19 survey

A second survey on the impact of COVID-19 was prepared. The SC members agreed to test the survey with their registries before making it publically available and inviting the other registries.