Defining the roadmap towards revision of ENCR coding standards and training for cancer registries
Abstract:
The European Network of Cancer Registries (ENCR) and the Joint Research Centre (JRC) jointly support harmonising the activities of the European population-based cancer registries (CR) in providing reliable and valid data on cancer. The process to supply valid, complete and comparable data in different European Countries, implies that CR implement common rules to define and code cancer and receive similar training. For this reason, one of the main activities of the ENCR-JRC is to provide CR staff with specific recommendations on coding along with training. For ENCR-JRC the objective of this
workshop was to collate previous and current requests from CR and provide advice on the most pressing issues relating to recommendations and training. The workshop was planned during the ENCR Steering Committee (SC) meeting, which took place on November 2014, and JRC (the Secretariat of ENCR) was requested to organise it. A group of experts on cancer registration was identified. This group included the ENCR-SC members, representatives from Institutions and cancer research projects which collaborate with CR (i.e. IARC, Eurocare, Concord, Rarecare), representatives from national networks of CR, members of the Cancer Information group at the JRC, and other specialists in the field. Prior to the workshop, an anonymous questionnaire was sent to the group of experts. Moreover, all directors and staff of CR were invited to complete the questionnaire and provide comments in order for ENCR-JRC to get a more comprehensive overview of the situation. The questionnaire invited respondents to specify the five most urgent topics, to be addressed, on both recommendations and training. During the workshop, participants (around 30 people) were split into two groups: one to focus on recommendations and the other to focus on training. For each group a moderator facilitated the debate presented the responses to the questionnaire, which were discussed in detail using the Metaplan method. The results of the discussion were summarized in a final plenary section, where further clarifications were given and all the participants were involved in the discussion. In summary, the topics to be addressed by the ENCR-SC, in relation to recommendations, either as updates of current recommendations or for new specific ones, were: Multiple primary rules; Staging; Registration/reportability criteria; Death Certificate Only cases (DCO) – Death Certificate Notified cases (DCN); Date of incidence in relation to diagnosis; ‘Complicated' cancers (e.g. bladder, etc.); Haematological cancers; and coding of borderline malignancies. The group on training suggested that all the issues that were raised (Cancer Registration; Haematological malignancies; Analysis; Stage; Quality; Multiple primaries; many on Specific cancer types; and Grading) should be addressed making available on the web high quality, reliable and training-oriented documentations. JRC offered to translate these documents, if necessary, into other European languages. For training on specific technical methodology (analysis, data quality) it was suggested that traditional face-to-face courses be provided. The workshop highlighted that recommendations and training are interlinked and this implies that, in the future, any new recommendation should be issued together with training documentation to explain its practical application. The technical proposals made at the workshop will help the ENCR-SC to prioritize the future supporting activities to the real needs of CR.

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