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# ***EUROCHIP-III***

European Cancer Health Indicator Project-III

Common Action

**ANNEX 09**

## **WP-5 ACTIVITIES ON GREECE CANCER REGISTRY**

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## **EUROCHIP-3 WP5 activities for the promotion of Cancer Registration in Greece**

### **Background**

At the start of EUROCHIP-3 in 2008, Greece and Luxembourg were the two EU countries not having any cancer registry (CR) data available. EUROCHIP-3 has among many goals the intention in WP-5 to stimulate these two countries and support them politically and scientifically in starting the cancer registry under the EU recommendations and on the basis of an EU solidarity approach and scientific network amongst experts.

As no EUROCHIP-3 contractual budget funds were allocated for local scientific activities in the framework of a Hellenic Cancer Registry (HCR), the EUROCHIP-3 WP-5 utilise funds only for meeting travel and subsistence aimed at facilitating the scientific exchange of expertise under the EU umbrella promoted by the EUROCHIP project.

### **Initial definition of activities**

In 2006 during EUROCHIP-2, the EUROCHIP Network started the collaboration with KEELPNO (Hellenic Centre for Diseases Control and Prevention) on the topic of cancer registration. This collaboration continued within EUROCHIP-3 as part of the mandate of WP-5. The rationale for the EUROCHIP promotion of exchange of cancer control knowledge is that the comparison and collaboration necessary for reaching a desired result are of great benefit to all parts involved.

During EUROCHIP-3, an initial meeting was organised on 11<sup>th</sup> March 2009 between EUROCHIP leaders and KEELPNO to contribute to the development of a national cancer registry in Greece, which became part of KEELPNO under the Law No 3370/11-7-05 and was transferred to KEELPNO on June 13<sup>th</sup> 2008. During the meeting, the following points to ensure the building of a national cancer registry sustainable in time were discussed and agreed by KEELPNO:

- ✓ **TRAINING:** Training of the CR personnel is required as a first step, and after some experience the trained staff will train all new personnel.
- ✓ **DOCUMENTS and STAFF:** Protocol and decisional committees have to be public. A National Committee for Cancer Registration formed on January 1<sup>st</sup> 2009 and consisting mainly of doctors should be expanded to other healthcare professions.
- ✓ **PURPOSE:** In the protocol, purposes of the CR must be assessed and defined (i.e. public health planning, evaluation of screening programmes, primary prevention, clinical evaluations, research, epidemiology). The utility of national cancer registration to the clinical oncological world interests must be strongly acknowledged and availed.
- ✓ **MEANS:**
  - A CR needs to be population-based (i.e. registration of all cancer patients in a defined area). In HL this means patients seen in all hospitals with clinical, cytology, haematology and pathology labs (public and private).
  - Coding should be done according to IACR/ENCR rules to be comparable to other countries.
  - The Creation of a National Coding board is essential to answer coding problems.
- ✓ **PILOT REGISTRY:** A pilot registry covering 3-4 regions would be a good way to start cancer registration in Greece. The regions could be chosen according to the willingness of hospitals/clinicians to participate. The pilot registry may then be extended to cover the whole country within a period of 3 years.

During the EUROCHIP-3 project, WP-5 followed the updates of all these points and the national activities performed by KEELPNO in Greece.

Here below we synthesized the updates on these points, with the intention of providing both a resume of the EUROCHIP- HCR interaction, as well as to frame the state of art of the Hellenic Cancer Registry for the recipients of our report.

## **Training**

During one week (21-24 September 2009) a training programme has been offered by the IKNO (Netherlands, now IKNL) through WP-5 with the aim of teaching the following topics to the 3 Greek cancer registrars who attended:

- relevance of a CR for different purposes and groups (politicians, clinicians, patients...)
- structure of a CR organisation related to sources, results and use of the CR
- coding system after having chosen the right items to be registered
- quality system to guarantee a reliable, complete and timeless CR

The KEELPNO staff got the opportunity to ask many questions related to the difficulties they experience locally.

An evaluation of the IKNO training course was edited by KEELPNO, the course was felt as a useful initiative by the Greece CR personnel.

During 2010 and 2011, the HCR staff used the SEER coding tool and contacted the IKNO Help Desk created to assist the HCR for cases characterized by complex questions.

In March 2011, HCR requested help from EUROCHIP in order to prepare a training course for the registrars in Greece. EUROCHIP encouraged the involvement of the HCR with ENCR educational activities. As a first contact, with ENCR a member of KEELPNO attended a workshop organised by the EUROCOURSE project in Cluj, Romania. Due to organizational complications however, a specific training from ENCR to HCR did not take place. The latest resolutions at HCR regarding training are that between 2012 and 2014, registrars will be trained on a regular basis and educational seminars will be run for each health region, roughly every 6 months.

## **Documents and staff**

In February 2011, cancer registration using registrars at national level in Greece obtained funding from the Ministry of Health for 2012 to 2014 ([http://www.keelpno.gr/Portals/0/Newsletter/HCDPC\\_NEWSLETTER\\_MARCH\\_2011.pdf](http://www.keelpno.gr/Portals/0/Newsletter/HCDPC_NEWSLETTER_MARCH_2011.pdf)).

In fact, it will be funded through the National Strategic Reference Network (NSRF) 2007–2013 program. The implementation of the HCR is the first action of the fifth axis of intervention of the National Cancer Plan 2011–2015.

In February 2012 the initiation of cancer registration using registrars was officially announced in the First Greek Cancer Congress (<http://www2.keelpno.gr/blog/?p=1398&lang=en>). On this occasion, 99 registrars attended and a half-day workshop was organised to introduce to the registrars the basics for cancer registration and the corresponding tools developed to aid this purpose. The number of registrars corresponds to 65% hospital coverage, with almost all of the big hospitals in the country represented.

Registrars are health officials, primarily health visitors, already employed as permanent hospital staff have been nominated to act as 'cancer registrars'. The registrars are responsible for collecting all the necessary and essential information required by HCR, for electronically entering the collected data in a single, web-based information system, and for working closely with the members of the Oncology Committees of the public hospitals and private clinics, who are by law in charge of the proper operation of their health institutions' cancer registry. The registrars are directly connected to and liaise with the HCR office in KEELPNO, for continuous training, education and support. A training programme for the 2-year period 2012-2014 has already been developed and the first 2-day seminar is being planned to be held in Athens during the last week of May 2012. In this seminar, registrars from Athens and the close by areas will attend.

A National Committee for Cancer Registration was never activated. In replacement, a group of experts was created by KEELPNO to help the reshuffling of HCR. The so called Committee of Experts for HCR, is composed of Dr Petroula Arapantoni-Dadioti, Director of the Pathology Laboratory of 'Metaxa' hospital, Dr Maria Demonakou-Vatopoulou, Director of the Pathology Laboratory of 'Sismanogleio' hospital, Dr Dimitris Karakasis, Director of the Hematology Department and Transplant Unit of 'Evangelismos' hospital, Dr Paris Kosmidis, Director of the Second Clinic of Oncology of the 'Hygeia' hospital and Dr Lia Tzala, Head of HCR at KEELPNO. In addition the Hellenic Society of Pathologists, the Hellenic Society of Haematological Malignancies and the Hellenic Society of Paediatric Haematology and Oncology have been asked to contribute.

To aid cancer registration the following material have been produced:

- A notification form with personal patient information (name, unique identifier, place of residence), information on diagnosis (primary site and date of diagnosis, basis of diagnosis, stage: localised, regional metastasis, distant metastasis), metastasis, initial course of treatment with corresponding dates as well as the outcome.
- A coding manual following the international standards using ENCR/ICD-O-3 rules given to all cancer registrars.
- A web-based program for electronic data entry and transfer. A manual for the use of the software has already been produced.

This material in Greek can be downloaded at:

[www.tumori.net/eurochip/material/WP5/Greece\\_HCR\\_material.zip](http://www.tumori.net/eurochip/material/WP5/Greece_HCR_material.zip)

The tools above were presented to the registrars during the Cancer Congress while the notification form, the coding manual as well as the manual for the web-based software were handed out.

### **Purpose**

The principal purpose and mission of the HCR are:

- To develop, operate and constantly improve the national population-based mechanism for registering all new and metastatic cancer cases throughout Greece, reported by primary and secondary sources of the public and private networks.
- To develop, operate and constantly improve the mechanisms for evaluation, assessment and proper dissemination of collected data and related results.

### **Means**

As instructed by the ministerial decisions numbers 136216/9-12-2011 and 1010/29-12-2011, in order to have complete cancer case registration and reliable population-based results data would be collected by all public and private hospitals in Greece. Cancer registration will be made online with strict ground-rules to secure the privacy and safety of personal and health-sensitive data. The necessary tools for online registration have been developed. The aforementioned tools will be tested during the first phase of the system's application and improvements made as necessary. Note that although data collection of cancer cases has started within the hospitals, no transfer to KEELPNO has been made due to awaiting formal notification of the Hellenic Data Protection Authority's favourable opinion for processing personal sensitive patient data.

**Pilot registry**

A Pilot with coding and staging and data quality checks with first assessments after 6 months was planned by KELPNO for 2010. However, this never took place as the idea of a pilot never reached a consensus at the higher scientific and political levels. As an alternative, the Greek Cancer Registry was implemented in all regions and public and private hospitals and inaugurated on February 1<sup>st</sup>, 2012.

**Conclusions**

As most of the population based cancer registries report their data to the IACR (International Association of Cancer Registries) and ENCR (European Network of Cancer Registries), we hope IACR and ENCR can ensure quality of data so that it can be considered internationally in scientific studies. We hope the HCR will be able to deliver data to policy makers, clinicians, the Greek cancer patients' association and the politicians. In this way it will be very important tool to support the development and implementation of a national cancer plan.

NOTE: Most of the information included in the present resume that are relative to the HCR developments during the period 2011-2012 were provided to EUROCHIP by KEELPNO as an update to be disseminated at the project final meeting held in Ispra at the end of February 2012. As this information reached us just a few days before the meeting, it was not possible for EUROCHIP to organise a meeting with KEELPNO for a close insight of these developments. We wish to congratulate KEELPNO for the achievements of February 2012 and for their dissemination at national level, and we strongly encourage the Greek HCR to keep the European involvement among its activities and collaborations.