

Answers for France, provided by the Institut National du Cancer

Which are the NCCP priorities with regards to rare cancers?

Rare cancers were excluded from the first national plan for rare diseases (2005-2008) since a first national plan for cancer (2003-2007) including measures for rare cancers was already in place. A second National Plan for Cancers was launched on 2 November 2009 for the period 2009-2013. A specific action of the plan is dedicated to the development of specialised expert centres for rare cancer patients, labelled “reference centres for rare cancers”. The term “rare cancers” applies to the following cancers: those which are diagnosed in fewer than 6/100 000 persons per year; or those requiring highly specialized management, owing to their unusual location, or to their occurrence at a specific or complex site.

The French National Cancer Institute (INCa) published a report on the organization of healthcare for rare adult cancers. This organization was one of the key actions of the Second National Cancer Plan for the period 2009 -2013: this includes the creation of a system of national “Expert Centres” (Reference Centers) and a network of regional centres for rare adult cancers. Since 2009, 23 national clinical networks for 23 groups of rare adult cancers and four anatomical pathology networks - in charge of the double reading of sarcoma, rare malignant neuroendocrine tumours, malignant mesothelioma and lymphoma - have been set up and financed. Among their missions, these Expert Centres have to ensure diagnostic certainty by implementing a systematic second reading of the biopsy specimens, to assure a multidisciplinary expert discussion of the patient file for the choice of initial and subsequent treatments, and to facilitate the enrolment of patients in appropriate clinical trials.

A third French National Plan for Cancers is ongoing (2014-2019) during which organisation of care for adults with a complex cancer, improvement of the organisation of second opinion in pathology for rare cancers and organisation of care for every rare cancer in children are planned.

Where are rare cancer patients treated in France?

Each national network for rare cancers is composed of several (10 to 30) regional centres of expertise and coordinated by a national centre of expertise.

How have these hospitals been identified? Did you use any criteria?

Identification of these networks was conducted through 4 competitive calls for proposals. Missions of a national or a regional expert centre are clearly identified as follow:

- to contribute to research promotion on these rare cancers through multicentre research studies – basic, translational and clinical- at national or international level;
- to participate in the drafting or updating of national recommendations for good clinical practice, taking into account as appropriate European or international recommendations;

- to contribute to the epidemiological surveillance and observation of these cancers by establishing a database and collect all cases;
- to train health care providers;
- to provide information to patients and their relatives, through relationships with national patients associations, and communication to the general public on this rare cancer;
- to participate in the follow-up of this specific organizational framework implemented by INCa;
- to liaise with the expert pathologist and integrate double reading into this framework.

Accordingly, each and every patient affected by one of these pathologies should benefit from best care in the institution of his/her choice, with a definite diagnosis through the double reading process of his/her tumoral tissue samples, a multidisciplinary consensus conference on his/her case, the choice of an appropriate treatment – very often innovative in the context of a clinical trial- and the support of a patient association.