

Rare adult cancers: organisation into expert centres

COLLECTION
 Reports & summaries

RARE ADULT CANCERS:
 ORGANISATION INTO
 EXPERT CENTRES

STATE OF ORGANISATION IN 2012

INTENDED FOR USE
 BY HEALTH PROFESSIONALS

1. RARE CANCERS: DEFINITION AND FEATURES

The term “rare cancers”¹⁻² applies to the following cancers:

- those which are diagnosed in fewer than 3/100,000 persons per year;
- or requiring highly specialised management, owing to their unusual location, or to their occurrence at a specific or complex site.

These cancers are a priority for several reasons, i.e.:

1. Primarily the difficulty of diagnosis

Indeed, the rarity of cases may cause delayed diagnosis, or even misdiagnosis, which may in turn lead to inadequate treatment. It is therefore necessary to establish double reading of anatomocytopathological data and obtain early and definitive diagnosis.

2. But also a management problem

Some teams have acquired genuine expertise, but this is not readily accessible to all. Moreover, few recommendations or guidelines for good practice are available for these pathologies, and access to certain highly complex therapies is often limited to a few institutions. However, systematic referral of all these patients to highly specialised centres

would result in excessive travel for the patients, unnecessarily distancing them from their home environment, and overloading these expert centres. It is thus appropriate to promote sharing of management between expert teams and local cancer care teams. Multidisciplinary consultative meetings concerning treatment options must be organised in the regional or interregional expert centres. In this context, access to highly specialised technical platforms must be organised and guaranteed.

3. In third place, inadequate access to clinical trials, given the rarity of these cancers

It is therefore necessary to organise and consolidate the teams at national or even European level, to promote the development of translational and clinical research.

4. Finally, and above all, the rarity of these tumours, and the delayed diagnosis and/or treatment that they generate are factors that contribute to the strong feelings of isolation experienced by patients and those close to them.

Provision of information to patients and those close to them must be facilitated. Patient groups are key players in controlling these sources of suffering, which are superimposed on the illness.

1. Casali PG, *et al*, European Cancer Conference, Copenhagen, Sept. 2003

2. Gatta G, *et al*, Eur J Cancer 2003; 1 (5, Suppl): S312

▶ **Mesure 20**
 Support the anatomopathology specialty.

Action 20.3 Support the anatomopathology profession's quality process.

▶ **Mesure 23**
 Develop specific care management for patients with rare forms of cancer or genetic predispositions as well as for children, adolescents and the elderly.

Action 23.1 Certify rare cancer reference centres.

2. THE MANAGEMENT OF ADULT PATIENTS WITH RARE CANCERS IS ORGANISED BETWEEN EXPERT CENTRES AND LOCAL CANCER CARE TEAMS

In order to meet the specific challenges of rare cancers, and implement Action 23.1 of the Cancer Plan, INCa launched three calls for proposals aimed at organising care provision for these adult patients in 2009, 2010 and 2011. In 2009, organisation began with the establishment and funding of clinical expert centres for eight groups of rare cancers, together with three anatomopathological networks involved with these rare cancers. Organisation continued in 2010 for seven other groups of rare cancers, and in 2011 for two others. Thus, every patient affected by one of these pathologies may already benefit from management in the institution of his/her choice, but is assured of a definitive diagnosis through the double reading of slides, discussion of his/her file by several experts in different disciplines, a choice of appropriate treatments—often innovative in the context of a clinical trial—and the support of a patient association.

Structuring thus aims to develop collaborative networks between national and regional expert centres, with cancer teams working in authorised institutions, and with patient associations.

2.1 Description of structuring

For a given group of rare cancers, the management of affected patients relies on regional or interregional expert centres that cover the whole national territory, including the French Overseas Departments and Territories (DOM-TOM), and are coordinated at national level by a single national expert reference centre for which a single coordinating clinician is responsible.

Double reading, and access to the required molecular typing examinations, is organised according to the pathology, either in the context of one of the three national anatomopathological reference networks, or via groups of expert pathologists working under the direction of an expert pathologist designated at national level. The criteria for selecting these experts are defined. They assume responsibility for the organisation and quality of this double

reading for all patient cases presented at a regional or national referral RCP (réunion de concertation pluridisciplinaire, multidisciplinary meeting). The pathologist in charge will liaise with the national coordinator so that the organisation of this double reading will be dedicated to patients managed in the rare cancer network.

2.1.1 Missions of the national expert centre

The national expert centre fulfils the following missions:

- to select and set up the regional or interregional expert centres;
- to specifically guarantee its mission as a national reference.

The coordinator of the national expert centre selects the regional or interregional expert centres based on their ability to fulfil the specific missions of these centres. These are the health institutions authorised to treat patients for cancer.

The criteria for selection are described, i.e. multidisciplinary, activity in relation to rare cancers, involvement in research, and publications. One clinician in charge is nominated for each regional or interregional expert centre. The INCa seeks the opinion of the Regional Health Agencies (ARS) on this structuring.

The missions of a national expert centre, summarised in Appendix 19, are as follows:

- to organise, if required, a referral RCP at national level;
- to contribute to promoting research on these rare cancers through multicentre research studies—basic, translational and clinical—at national or international level;
- to participate in the formulation or execution of national recommendations for good clinical practice, drawing on European or international recommendations where necessary;
- to contribute to the epidemiological surveillance and observation of these cancers by establishing a database for collection of relevant data and monitoring of patients, thus enabling public health studies;
- to participate at national level in the training of health care providers;
- to participate in providing information to patients and those close to them, by developing relationships with national patient associations, and by involvement in communication to the public at large on this rare cancer;

- to establish and monitor activity indicators for all the expert centres, ensure their collection, and send them to the INCa in the context of an annual monitoring report;
- to liaise with the national reference pathologist to integrate double reading into this structure.

2.1.2 Missions of the regional or interregional expert centres

The regional or interregional expert centres are responsible for the following 4 missions (summarized in Appendix 20):

- to establish a regional or interregional referral RCP. Case files of patients with rare cancers are discussed at diagnosis, when a treatment decision is being made, during follow-up, or when the disease recurs;
- to participate in clinical research, promoting the inclusion of patients with rare cancers in clinical trials;
- to participate in training of health care providers and in providing information to patients and those close to them at the regional or interregional level;
- to develop coordination with institutions authorised to treat cancer in their region, so as to enable patients to access this continuum of care, while respecting the unique features of each case.

2.2. Funding, monitoring and assessment

The national expert centres benefit from annual funding through the LFSS (Loi de Financement de la Sécurité Sociale, social security funding Act) under MIGAC (mission of general interest and contract support). They account for their activity in the form of annual reports sent to the INCa.

3. MANAGEMENT OF RARE ADULT CANCERS

National clinical expert centres

Management of 17 rare adult cancers is organised and funded. It concerns the following pathologies:

- sarcomas of the soft tissues and viscera;
- rare sporadic and hereditary malignant neuroendocrine tumours;

- rare ENT cancers;
- malignant pleural mesotheliomas;
- cutaneous lymphoma;
- rare high-grade oligodendroglial cerebral tumours;
- rare ovarian cancers;
- cancers occurring during pregnancy;
- refractory thyroid cancers;
- primitive ocular and cerebral lymphomas;
- lymphomas associated with coeliac disease;
- malignant thymomas and thymic carcinomas;
- gestational trophoblastic tumours;
- von Hippel-Lindau disease and inherited predisposition to adult renal cancer;
- rare peritoneal cancers;
- adrenal cancers;
- virally induced cancers in transplant recipients.

National anatomopathological reference networks

Three national anatomopathological reference networks, in conjunction with the clinical expert centres, were set up and funded in 2009, for the following three pathologies:

- sarcomas of the soft tissues and viscera;
- malignant mesotheliomas of the pleura and rare tumours of the peritoneum;
- rare sporadic and hereditary malignant neuroendocrine tumours.

A national anatomopathological reference network for lymphomas was set up and funded at the same time.

Although lymphomas are not rare tumours strictly speaking, their extreme diversity is not only recognised, but is the subject of a new 2008 WHO classification, crucial for management. Some forms in particular are only rarely seen in non-specialised laboratories, and are a problem for diagnosis and therefore for treatment management.

RARE PATHOLOGIES AFFECTED BY THE 2009-2011 ORGANISATION

RARE CANCER GROUP	RARE CANCERS	ESTIMATED ANNUAL INCIDENCE
■ Sarcomas of the soft tissues and viscera	<ul style="list-style-type: none"> ■ Gastrointestinal stromal tumours (GIST) ■ Liposarcomas ■ Leiomyosarcomas ■ Other differentiated sarcomas ■ Poorly differentiated sarcomas ■ Unclassified sarcomas ■ Pulmonary, cardiac and other visceral sarcomas ■ Desmoid tumours 	■ 4,000 cases/year
■ Rare sporadic and hereditary malignant endocrine tumours (ET)	<ul style="list-style-type: none"> ■ Digestive tract and pancreatic ET ■ Typical and atypical bronchial carcinoid type ET and large cell neuroendocrine carcinomas ■ Thymic endocrine carcinomas ■ Other endocrine tumours (bladder, kidney, skin, etc.) ■ Medullary thyroid carcinomas ■ Sporadic malignant nonadrenal paragangliomas and familial paragangliomas 	■ 1,200 cases/year
■ Rare ENT cancers	<ul style="list-style-type: none"> ■ Malignant tumours of the facial bones ■ Malignant tumours of the salivary glands ■ Malignant tumours of the ear ■ Head and neck sarcomas ■ Others 	■ 900/year
■ Malignant pleural mesotheliomas		■ 900/year
■ Cutaneous lymphomas	<ul style="list-style-type: none"> ■ Cutaneous T cell lymphomas ■ Cutaneous B cell lymphomas 	■ 700/year
■ Rare high-grade oligodendroglial cerebral tumours	<ul style="list-style-type: none"> ■ Anaplastic oligodendrogliomas ■ Anaplastic oligoastrocytomas ■ Glioblastomas with an oligodendroglial component 	■ 600/year
■ Rare ovarian cancers	<ul style="list-style-type: none"> ■ Mucinous adenocarcinoma ■ Malignant sex cord stromal tumours ■ Malignant germinal tumours ■ Clear-cell adenocarcinoma ■ Small cell cancers with hypercalcaemia ■ Endocrine tumours on struma ovarii 	■ 500/year
■ Cancers occurring during pregnancy	<ul style="list-style-type: none"> ■ Breast cancers ■ Malignant haemopathies ■ Cervical cancers ■ Ovarian cancers ■ Digestive tract cancers ■ Others 	■ 500/year

RARE CANCER GROUP	RARE CANCERS	ESTIMATED ANNUAL INCIDENCE
■ Refractory thyroid cancers	<ul style="list-style-type: none"> ■ Iodine 131 refractory papillary and follicular cancers ■ Metastatic medullary cancers ■ Anaplastic cancers 	■ 400/year
■ Primitive ocular and cerebral lymphomas	<ul style="list-style-type: none"> ■ Primitive lymphomas of the brain, spinal cord, meninges and eye ■ Isolated primitive intraocular lymphomas 	■ 300 to 400/year
■ Lymphomas associated with coeliac disease	<ul style="list-style-type: none"> ■ Low-grade T-cell lymphomas (clonal refractory sprue) ■ High-grade T-cell lymphomas ■ High-grade B-cell lymphomas 	■ 350/year
■ Malignant thymomas and thymic carcinomas	<ul style="list-style-type: none"> ■ Malignant thymomas ■ Thymic carcinomas 	■ 250/year
■ Gestational trophoblastic tumours	<ul style="list-style-type: none"> ■ Invasive moles ■ Choriocarcinomas ■ Tumours at the placental implantation site ■ Epithelioid trophoblastic tumours 	■ 180/year
■ Von Hippel-Lindau disease (VHL) and inherited predisposition to adult renal cancer	<ul style="list-style-type: none"> ■ VHL disease ■ Type 1 hereditary papillary carcinoma ■ Birt-Hogg-Dubé syndromes ■ Hereditary leiomyomatosis with papillary renal carcinoma ■ Clear cell renal carcinomas associated with translocations ■ Familial forms of clear cell renal carcinomas not associated with the VHL gene ■ Bourneville's tuberous sclerosis and renal cancer ■ MODY 5 diabetes and renal carcinoma 	■ 160 to 240/year
■ Rare peritoneal cancers	<ul style="list-style-type: none"> ■ Pseudomyxomas ■ Peritoneal mesotheliomas ■ Primitive peritoneal serous carcinomas ■ Peritoneal desmoplastic tumours ■ Peritoneal psammocarcinomas 	■ 130 to 180/year
■ Adrenal cancers	<ul style="list-style-type: none"> ■ Adrenocortical carcinomas ■ Malignant pheochromocytomas ■ Malignant paragangliomas 	<p style="text-align: center;">} post-transplantation</p>
■ Virally induced cancers in transplant recipients (TR)	<ul style="list-style-type: none"> ■ Lymphoproliferative disorders in TR ■ Kaposi's sarcomas in TR ■ Anogenital cancers in TR ■ Merkel cell tumours in TR 	■ 100-110/year

NATIONAL EXPERT CENTRES FOR RARE ADULT CANCERS 2009-2011

RARE CANCERS	NETWORK NAME	NATIONAL COORDINATOR	NATIONAL EXPERT CENTRE (one or more sites)
Sarcomas of the soft tissues and viscera	NETSARC	Prof Jean-Yves BLAY	Centre Léon Bérard, Lyon Institut Bergonié, Bordeaux Institut Gustave Roussy, Villejuif
Rare malignant neuroendocrine tumours	RENATEN	Prof Patricia NICCOLI	Hôpital de la Timone, AP-HM
Rare ENT cancers	REFCOR	Dr François JANOT	Institut Gustave Roussy, Villejuif Hôpital Tenon, AP-HP
Malignant pleural mesotheliomas	MESOCLIN	Prof Arnaud SCHERPEREEL	CHRU Lille
Cutaneous lymphomas	GFELC (Network of centres of expertise for cutaneous lymphomas)	Prof Martine BAGOT	Hôpital Saint-Louis, AP-HP
High-grade oligodendroglial tumours	POLA	Prof Jean-Yves DELATTRE	Hôpital Pitié-Salpêtrière, AP-HP Hôpital de la Timone, AP-HM
Rare ovarian cancers	Observatory for rare malignant gynaecological tumours	Dr Isabelle RAY-COQUARD	Centre Léon Bérard, Lyon Hôtel-Dieu, AP-HP Institut Gustave Roussy, Villejuif
Cancers occurring during pregnancy	CALG	Prof Roman ROUZIER	Hôpital Tenon, AP-HP Hôpital Cochin, AP-HP Institut Gustave Roussy, Villejuif
Refractory thyroid cancers	TUTHYREF	Prof Martin SCHLUMBERGER	Institut Gustave Roussy, Villejuif Hospices civils de Lyon
Primitive lymphomas of the central nervous system	LOC (ocular and cerebral lymphoma)	Prof Khê HOANG-XUAN	Groupe Hospitalier Pitié-Salpêtrière, AP-HP Hôpital René Huguenin-Institut Curie, Paris
Lymphomas associated with coeliac disease	CELAC	Prof Christophe CELLIER	Hôpital européen G. Pompidou, AP-HP Hôpital Necker-Enfants malades, AP-HP
Malignant thymomas Thymic carcinomas		Dr Benjamin BESSE	Institut Gustave Roussy, Villejuif Hôpital Louis Pradel, HCL
Gestational trophoblastic tumours	MTG	Prof Daniel RAUDRANT	Centre hospitalier Lyon Sud, HCL
von Hippel-Lindau disease and inherited predisposition to renal cancer	PREDIR	Prof Stéphane RICHARD	Hôpital Bicêtre*, AP-HP
Rare peritoneal cancers	RENAPE	Prof François GILLY	Centre hospitalier Lyon Sud, HCL
Adrenal cancers	COMETE	Prof Xavier BERTAGNA	Hôpital Cochin, AP-HP Hôpital européen G. Pompidou, AP-HP Institut Gustave Roussy, Villejuif
Virally induced cancers in transplant recipients	K-VIROGREF	Prof Véronique LEBLOND	Groupe hospitalier Pitié-Salpêtrière, AP-HP

AP-HM: Assistance Publique-Hôpitaux de Marseille AP-HP: Assistance Publique-Hôpitaux de Paris HCL: Hospices Civils de Lyon

*: multisite national expert centre also including the following AP-HP hospitals: Necker, l'Hôpital Européen Georges Pompidou, Beaujon, Lariboisière, Cochin and Institut Gustave Roussy.

NATIONAL EXPERT CENTRES FOR RARE ADULT CANCERS 2009-2011

RARE CANCERS	NETWORK NAME	NATIONAL COORDINATOR	NATIONAL EXPERT CENTER (one or more sites)
Sarcomas of the soft tissues and viscera	CRéPS-TMV	Prof Jean-Michel COINDRE	Institut Bergonié, Bordeaux Institut Gustave Roussy, Villejuif Centre Léon Bérard, Lyon
Malignant pleural mesotheliomas and rare peritoneal tumours	MESOPATH-IM@EC	Prof Françoise GALATEAU-SALLÉ	CHU de Caen
Rare malignant neuroendocrine tumours	TNEpath	Prof Jean-Yves SCOAZEC	Hôpital Edouard Herriot, HCL
Lymphomas	LYMPHOPATH	Prof Georges DELSOL Prof Philippe GAULARD	CHU Toulouse Hôpital Henri Mondor, AP-HP

APPENDIX 1: CLINICAL EXPERT CENTRES AND NATIONAL ANATOMOPATHOLOGICAL REFERENCE NETWORK FOR SARCOMAS OF THE SOFT TISSUES AND VISCERA

NETSARC - **Prof Jean-Yves BLAY**, Centre Léon Bérard, Lyon
CRePS-TMV Network / **Prof Jean-Michel COINDRE**, Institut Bergonié, Bordeaux

CLINICAL EXPERT CENTRES	ANATOMOPATHOLOGICAL EXPERT CENTRES
Angers: CLCC Besançon: CHU Bordeaux: Institut Bergonié Brest: CHU Caen: CHU and CLCC Clermont-Ferrand: CHU and CLCC Dijon: CHU and CLCC Lille: CHRU and CLCC Limoges: CHU Lyon: CHU and CLCC Léon Bérard* Marseille: CHU and CLCC Montpellier: CLCC Nancy: CLCC Nice: CLCC Nantes: CHU and CLCC Paris: AP-HP: CHU Cochin, CHU Saint-Louis, CHU Pitié Salpêtrière, CHU Tenon; Institut Curie Reims: CHU and CLCC Rennes: CHU and CLCC Rouen: CLCC Saint-Étienne: Institut Cancérologie de la Loire Saint-Pierre de la Réunion/Mayotte: CHR/CH Strasbourg: CHU Toulouse: CLCC Tours: CHU Villejuif: Institut Gustave Roussy	Angers: CLCC Bordeaux: CHU and CLCC* Brest: CHU Caen: CHU and CLCC Clermont-Ferrand: CHU and CLCC Dijon: CHU and CLCC Lille: CHU and CLCC Limoges: CHU Lyon: CHU and CLCC Marseille: CHU and CLCC Montpellier: CHU and CLCC Nancy: CHU and CLCC Nantes: CHU Nice: CHU and CLCC Paris: AP-HP and Institut Curie Rennes: CHU Rouen: CHU and CLCC Strasbourg: CHU and CLCC Toulouse: CHU and CLCC Tours: CHU Villejuif: CLCC

In **purple and bold**: national expert centre
with *: the national coordinator's institution

APPENDIX 2: CLINICAL EXPERT CENTRES AND NATIONAL ANATOMOPATHOLOGICAL REFERENCE NETWORK FOR RARE SPORADIC AND HEREDITARY MALIGNANT NEUROENDOCRINE TUMOURS

RENATEN / **Prof Patricia NICCOLI**, CHU Marseille
TENpath / **Prof Jean-Yves SCOAZEC**, CHU de Lyon

REGIONAL EXPERT CENTRES AND INTERREGIONAL CLINICAL COORDINATING INSTITUTIONS	ANATOMOPATHOLOGICAL EXPERT CENTRES
<p>Amiens: CHU Angers: CHU⁸ + CLCC Paul Papin Bordeaux: CHU² et Institut Bergonié Brest: CHU Caen: CHU et CLCC François Baclesse Clermont-Ferrand: CHU** et CLCC Jean Perrin Dijon: CHU³ et CLCC G.-F. Leclerc Fort-de-France: CHU Grenoble: CHU Lille: CHRU⁶ + CLCC Oscar Lambret Limoges: CHU** Lyon: CHU** + CLCC Léon Bérard Marseille: CHU*⁷ + Institut Paoli-Calmettes Montpellier: CHU** + CLCC Val-d'Aurelle Nancy: CHU + CLCC Alexis Vautrin Nantes: CHU Nice: CHU + CLCC Antoine Lacassagne Nîmes: CHU Orléans: CHU Paris: AP-HP: CHU Beaujon Pointe-à-Pitre: CHU Poitiers: CHU Reims: CHU** + CLCC Jean Godinot Rennes: CHU + CLCC Eugène Marquis Rouen: CHU⁵ + CLCC Henri Becquerel Saint-Cloud: Hôpital René Huguenin-Institut Curie Saint-Denis-de-la-Réunion: CH Saint-Étienne: CHU Strasbourg: CHU¹ et CLCC Paul Strauss Toulouse: CHU** + CLCC Claudius Regaud Tours: CHU⁴ Villejuif: Institut Gustave Roussy**</p>	<p>Angers: CHU Bordeaux: CHU Clermont-Ferrand: CHU Dijon: CHU Grenoble: CHU Lille: CHRU Limoges: CHU Lyon: CHU* Marseille: CHU + Institut Paoli-Calmettes Montpellier: CHU Nantes: CHU Paris: AP-HP: CHU Ambroise Paré, CHU Bicêtre, CHU Bichat-Beaujon, CHU Cochin, CHU HEGP, CHU Pitié-Salpêtrière, CHU Saint-Antoine Reims: CHU Rouen: CHU Strasbourg: CHU Toulouse: CHU Tours: CHRU Villejuif: Institut Gustave Roussy</p>

In **purple and bold** with*: national expert centre

** Regional expert centre

1 Coordinating institution for Alsace-Lorraine

2 Coordinating institution for Aquitaine-DOM-TOM

3 Coordinating institution for Burgundy-Franche-Comté

4 Coordinating institution for Centre-Poitou-Charentes

5 Coordinating institution for Upper and Lower Normandy

6 Coordinating institution for Nord-Pas de Calais-Picardy

7 Coordinating institution for PACA-Corsica

8 Coordinating institution for Pays-de-la-Loire-Brittany

List on 1st July 2010

APPENDIX 3: EXPERT CENTRES FOR RARE ENT CANCERS

REFCOR - Dr François JANOT, Institut Gustave Roussy, Villejuif

Amiens: CHU
Besançon: CHU
Bordeaux: CHU and Institut Bergonié
Brest: CHU
Caen: CHU and CLCC François Baclesse
Clermont Ferrand: CHU and Centre Jean Perrin
Créteil: Centre Hospitalier Intercommunal
Grenoble: CHU
Lille: CHRU Limoges: CHU Lyon: CHU Marseille: CHU
Montpellier CHU and Institut Paoli Calmettes Nancy: CHU and Centre Alexis Vautrin
Nantes: CHU and Institut de Cancérologie de l'Ouest
Orléans: CHR
Paris: AP-HP: Hôpital Bichat, Hôpital Beaujon, Hôpital Européen Georges-Pompidou, Hôpital Lariboisière, Hôpital Pitié-Salpêtrière, Hôpital Tenon
Nice: CLCC Antoine Lacassagne Pointe-à-Pitre: CHU
Poitiers: CHU Reims: CHU Rennes: CHU
Rouen: CHU and Centre Henri Becquerel
Saint-Cloud: CLCC Hôpital René Huguenin-Institut Curie Saint-Étienne: CHU
Strasbourg: CHU and CLCC Paul Strauss
Suresnes: Hôpital Foch
Toulouse: CHU and Institut Claudius Regaud
Tours: CHU
Villejuif: Institut Gustave Roussy*

In **purple and bold**: national expert centre (2 sites)

with *: the national coordinator's institution

APPENDIX 4: EXPERT CENTRES FOR MALIGNANT PLEURAL MESOTHELIOMAS AND NATIONAL ANATOMOPATHOLOGICAL REFERENCE NETWORK FOR MALIGNANT PLEURAL MESOTHELIOMAS AND RARE PERITONEAL TUMOURS

MESOCLIN - Prof Arnaud SCHERPEREEL, CHRU Lille

REGION OR INTER-REGION	CITY - INSTITUTION
Alsace	Strasbourg: CHU
Lower Normandy	Caen: CHU and CLCC François Baclesse
Burgundy-Franche-Comté	Dijon: CHU ¹ and CLCC Georges-François Leclerc Besançon: CHU
Brittany	Brest: CHU ¹ and HIA Rennes: CHU
Centre	Tours: CHRU ¹ Orléans: CHU
Upper Normandy	Rouen: CHU
Île-de-France/Martinique-Guadeloupe/French Guiana	Paris: AP-HP: hôpital européen Georges Pompidou Villejuif²: Institut Gustave Roussy Créteil: centre hospitalier intercommunal
Languedoc-Roussillon	Montpellier: CHU and CRLC Val d'Aurelle-Paul Lamarque
Lorraine	Nancy: CHU
Midi-Pyrénées – Aquitaine – Limousin	Toulouse: CHU ¹ Bordeaux: CHU and Institut Bergonié Limoges: CHU
Nord-Pas de Calais/Champagne-Ardenne/La Réunion	Lille: CHRU*¹ et CLCC Oscar Lambret Reims: CHU
Pays de la Loire–Poitou–Charentes	Nantes: CHU ¹ and CLCC René Gauducheau Angers: CHU Poitiers: CHU Le Mans: CH
Picardy	Amiens: CHU
Provence–Alps–Côte d’Azur–Corsica	Marseille: CHU ¹ and Institut Paoli Calmettes Nice: CHU
Rhône-Alpes – Auvergne	Lyon: CHU ¹ and Centre Léon Bérard Grenoble: CHU Saint-Etienne: CHU Clermont-Ferrand: CHU

HIA: Hôpital d’Instruction des Armées (Military Teaching Hospital)

1. Regional (or interregional) coordinating institution

2. Coordinating institutio for Martinique-Guadeloupe-French Guiana

In **purple and bold**: national expert centre
with *: the national coordinator’s institution

MESOPATH-IM@EC / Prof Françoise GALATEAU-SALLÉ, CHU de Caen

ANATOMOPATHOLOGICAL EXPERT CENTRES

Bordeaux: CHU

Caen: CHU*

Créteil: CHI

Grenoble: CHU

Le Mans: CH

Lille: CHRU

Lyon: CHU

Marseille: CHU

Nancy: CHU

Nantes: CHU

Paris: AP-HP: CHU Bichat-Beaujon, CHU Pitié-Salpêtrière

Rouen: Centre Henri Becquerel

APPENDIX 5: EXPERT CENTRES FOR CUTANEOUS LYMPHOMAS

GFELC - Prof Martine BAGOT, Hôpital Saint-Louis, AP-HP, Paris

Amiens: CHU
Besançon: CHU
Bordeaux: CHU
Clermont Ferrand: CHU
Dijon: CHU
Fort-de-France: CHU
Grenoble: CHU
Lille: CHRU
Lyon: CHU et Centre Léon Bérard
Marseille: CHU et Institut Paoli Calmettes
Montpellier: CHRU
Mulhouse: CH
Nantes: CHU
Nice: CHU
Orléans: CHR
Paris: AP-HP: hôpital Avicenne, hôpital Bichat, hôpital Cochin, **hôpital Saint-Louis**
Pointe-à-Pitre: CHU
Reims: CHU
Rennes: CHU
Rouen: CHU
Strasbourg: CHU
Toulouse: CHU
Tours: CHRU

**APPENDIX 6: CLINICAL AND ANATOMOPATHOLOGICAL EXPERT CENTRES
FOR HIGH-GRADE OLIGODENDROGLIAL TUMOURS**

POLA / Prof Jean-Yves DELATTRE, CHU Pitié-Salpêtrière, AP-HP, Paris

CLINICAL EXPERT CENTRES	ANATOMOPATHOLOGICAL EXPERT CENTRES
Amiens: CHU	Amiens: CHU
Angers: CHU	Angers: CHU
Besançon: CHU	Besançon: CHU
Bordeaux: CHU	Bordeaux: CHU
Brest: CHU	Brest: CHU
Caen: CHU	Caen: CHU
Clermont-Ferrand: CLCC Jean Perrin	Clermont-Ferrand: CHU
Dijon: CLCC GF Leclerc	Dijon: CHU
Grenoble: CHU	Grenoble: CHU
Lille: CHRU	Lille: CHRU
Limoges: CHU	Limoges: CHU
Lyon: CHU	Lyon: CHU
Marseille: CHU	Marseille: CHU
Montpellier: CHU	Montpellier: CHU
Nancy: CHU	Nancy: CHU
Nantes: CLCC René Gauducheau	Nantes: CHU
Nice: CHU	Nice: CHU
Paris: AP-HP: CHU Pitié-Salpêtrière* , CHU Avicenne, CHU Bicêtre, CHU Bichat-Beaujon, CHU Henri-Mondor, CHU Lariboisière ;	Paris: AP-HP : CHU Pitié-Salpêtrière, CHU Bicêtre, CHU Henri-Mondor, CHU Lariboisière
HIA Val-de-Grâce	Poitiers: CHU
Poitiers: CHU	Reims: CHU
Reims: Polyclinique Courlancy	Rennes: CHU
Rennes: CLCC Eugène Marquis	Rouen: CHU
Rouen: CHU	Saint-Étienne: CHU
Saint-Étienne: CHU	Strasbourg: CHU
Strasbourg: CLCC Paul Strauss	Toulouse: CHU
Toulouse: CHU	
Villejuif: Institut Gustave Roussy	

In **purple and bold**: national expert centre
with *: the national coordinator's institution

APPENDIX 7: EXPERT CENTRES FOR RARE OVARIAN CANCERS

Observatory for rare malignant gynaecological tumours - **Dr Isabelle RAY-COQUARD,**
CENTRE LÉON BERARD - LYON

Besançon: CHU
Bordeaux: Institut Bergonié
Caen: CLCC
Clermont Ferrand: Centre Jean Perrin
Dijon: CLCC GF Leclerc
Grenoble: CHU et groupe hospitalier mutualiste
Limoges: CHU
Lyon: CHU et Centre Léon Bérard *
Marseille: Institut Paoli Calmettes
Montpellier: CRLC Val d'Aurelle
Nancy: Centre Alexis Vautrin
Nantes: Centre Catherine de Sienne
Orléans: CHR
Paris: AP-HP: Hôpital Hôtel-Dieu
Poitiers: CHU
Reims: Institut Jean Godinot
Rennes: Institut Rennais du cancer
Rouen: Centre Henri Becquerel
Saint-Brieuc: Clinique Armoricaïne de Radiologie
Saint-Pierre de la Réunion: CHR
Strasbourg: CHU et CRLC Paul Strauss
Toulouse: CHU et Institut Claudius Regaud
Villejuif: Institut Gustave Roussy

In **purple and bold**: national expert centre (3 sites)
with *: the national coordinator's institution

APPENDIX 8: EXPERT CENTRES FOR CANCERS OCCURRING DURING PREGNANCY

CALG - Prof Roman ROUZIER, HOPITAL TENON, AP-HP

Amiens: CHU
 Angers: CHU and Institut de Cancérologie de l'Ouest
 Besançon: CHU
 Bordeaux: CHU and Institut Bergonié
 Brest: CHU
 Caen: CHU and CLCC François Baclesse
 Clermont-Ferrand: CHU and Centre Jean Perrin
 Dijon: CHU and CLCC Georges-François Leclerc
 Fort-de-France: CHU
 Lille: CHU and Centre Oscar Lambret
 Limoges: CHU
 Lyon: Centre Léon Bérard
 Montpellier CHU and CRLC Val d'Aurelle-Paul Lamarque
 Nancy: CHU and Centre Alexis Vautrin
 Nantes: CHU and Institut de Cancérologie de l'Ouest
 Nice: CHU and Centre Antoine Lacassagne
 Marseille: CHU and Institut Paoli-Calmettes
PARIS: AP-HP: Hôpital Antoine Béchère, Hôpital Bicêtre, **Hôpital Cochin**, Hôpital Lariboisière, **Hôpital Saint-Louis**, Hôpital Tenon*;
 Institut Curie
 Pointe-à Pitre: CHU Poitiers: CHU
 Reims: CHU and Institut Jean Godinot
 Rennes: CHU and CRLC Eugène Marquis
 Rouen: CHU and Centre Henri Becquerel
 Saint-Cloud: CLCC Hôpital René Huguenin-Institut Curie Saint-Denis de la Réunion: CHR
 Strasbourg: CHU and CRLC Paul Strauss
 Toulouse: CHU and Institut Claudius Regaud
 Tours: CHU
Villejuif: Institut Gustave Roussy

In **purple and bold**: national expert centre (3 sites)
 with *: the national coordinator's institution

APPENDIX 9: EXPERT CENTRES FOR REFRACTORY THYROID CANCERS

TUTHYREF / **Prof Martin SHLUMBERGER**, Institut Gustave Roussy, Villejuif

Amiens: CHU
Angers: CHU and CLCC Paul Papin
Bordeaux: CHU and Institut Bergonié
Brest: CHU
Caen: CLCC François Baclesse
Clermont-Ferrand: CLCC Jean Perrin
Dijon: CLCC GF Leclerc
Lille: CHRU
Limoges: CHU
Lyon: CHU and CLCC Centre Léon-Bérard
Marseille: CHU and CLCC Institut Paoli-Calmettes
Montpellier: CHU and CLCC Val d'Aurelle
Nancy: CHU and CLCC Alexis Vautrin
Nantes: CHU and CLCC René Gauducheau
Nice: CHU and CLCC Antoine Lacassagne
Paris: AP-HP: CHU Cochin, CHU Pitié-Salpêtrière, CHU Saint-Louis
Pointe-à-Pitre: CHU
Reims: CLCC Jean Godinot
Rennes: CHU and CLCC Eugène Marquis
Rouen: CLCC Henri Becquerel
Saint-Cloud: CLCC René Huguenin
Saint-Pierre de la Réunion: CHR
Strasbourg: CHU and CLCC Paul Strauss
Toulouse: CHU and CLCC Claudius Régaud
Tours: CHU
Villejuif: Institut Gustave Roussy*

APPENDIX 10: EXPERT CENTRES FOR OCULAR AND CEREBRAL LYMPHOMAS

LOC - Prof Khê HOANG-XUAN, GROUPE HOSPITALIER PITIE-SALPÊTRIÈRE, AP-HP

Amiens: CHU
Besançon: CHU
Bordeaux: Institut Bergonié
Caen: CHU
Clermont-Ferrand: CHU
Dijon: CHU
Lille: CHRU
Limoges: CHU
Lyon: Centre Léon Bérard
Marseille: CHU
Nancy: CHU
Nîmes: CHU
Paris: AP-HP: Groupe hospitalier Pitié-Salpêtrière*
Poitiers: CHU
Reims: Polyclinique Courlancy
Rennes: CHU
Rouen: Centre Henri Becquerel
Saint-Cloud: CLCC Hôpital René Huguenin- Institut Curie
Toulouse: CHU
Tours: CHRU

APPENDIX 11: EXPERT CENTRES FOR LYMPHOMAS ASSOCIATED WITH COELIAC DISEASE

CELAC - Prof Christophe CELLIER, hôpital européen Georges Pompidou, AP-HP, Paris

Bastia: CH
Besançon: CHU
Bordeaux: CHU
Caen: CHU
Cayenne: CH
Clermont Ferrand: CHU
Dijon: CHU
Fort-de-France: CHU
Lille: CHRU
Lyon: CHU
Nancy: CHU
Nantes: CHU
Nice: CHU
Paris: AP-HP: hôpital Beaujon, **hôpital européen Georges Pompidou***, hôpital Necker- Enfants Malades, hôpital Saint-Antoine, hôpital Saint-Louis
Poitiers: CHU
Pointe-à-Pitre: CHU
Reims: CHU
Rennes: CHU
Rouen: CHU
Saint-Denis de la Réunion: CHR
Strasbourg: CHU
Tours: CHRU

APPENDIX 12: EXPERT CENTRES FOR MALIGNANT THYMOMAS AND THYMIC CARCINOMAS

Dr Benjamin BESSE, Institut Gustave Roussy, Villejuif

Besançon: CHU
Caen: CHU
Lille: CHRU
Lyon: CHU
Marseille: CHU
Montpellier: CHU
Nancy: CHU
Nantes: CLCC René Gauducheau
Paris: AP-HP: hôpital Henri-Mondor
Rennes: CHU
Rouen: CHU
Saint-Etienne: CHU
Strasbourg: CHU
Toulouse: CHU
Tours: CHRU
Villejuif: Institut Gustave Roussy*

APPENDIX 13: EXPERT CENTRES FOR GESTATIONAL TROPHOBLASTIC TUMOURS

MTG / Prof Daniel RAUDRANT, CHU Lyon

Amiens: CHU
Besançon: CHU
Bordeaux: CHU
Caen: CHU and CLCC François Baclesse
Clermont-Ferrand: CHU
Dijon: CHU
Lille: CHRU and CLCC Oscar Lambret
Limoges: CHU Limoges
Lyon: Hospices civils de Lyon and Centre Léon Bérard
Marseille: CHU
Montpellier: CHU
Nancy: Maternité Régionale Universitaire
Nantes: CHU
Paris: AP-HP - Hôpital Cochin/Maternité Port Royal - Hôpital Beaujon - Hôpital Bicêtre- Hôpital Tenon
Pointe à Pitre: CHU
Poitiers: CHU
Reims: CHU
Rennes: CHU and CLCC Eugène Marquis
Rouen: CHU
Saint-Pierre de la Réunion: CHR
Strasbourg: CHU
Toulouse: CHU
Tours: CHU
Villejuif: Institut Gustave Roussy

**APPENDIX 14: EXPERT CENTRES FOR VON HIPPEL-LINDAU DISEASE AND INHERITED
PREDISPOSITION TO ADULT RENAL CANCER****PREDIR / Prof Stéphane RICHARD, CHU Bicêtre, AP-HP, Paris**

Amiens: CHU
Angers: CHU
Besançon: CHU
Bordeaux: CHU
Brest: CHU
Caen: CHU
Clermont-Ferrand: CLCC Jean Perrin
Grenoble: CHU
Lille: CHRU
Limoges: CHU
Lyon: CHU
Marseille: CHU
Montpellier: CHU + CLCC Val d'Aurelle
Nancy: CHU
Nantes: CHU
Nice: CHU
Orléans: CHR
Paris: AP-HP: CHU Bicêtre*
Poitiers: CHU
Reims: CHU
Rouen: CHU
Saint- Pierre de la Réunion: CHR
Strasbourg: CHU
Toulouse: CHU
Tours: CHU

In **purple and bold** with*: multisite national expert centre, also including the following AP-HP hospitals (Paris public hospitals): Necker, l'Hôpital Européen Georges Pompidou, Lariboisière, Cochin and l'Institut Gustave Roussy.
Georges Pompidou, Beaujon, Lariboisière, Cochin and the Institut Gustave Roussy.

APPENDIX 15: CLINICAL EXPERT CENTRES FOR RARE PERITONEAL TUMOURS

RENAPE / **Prof François GILLY**, CHU Lyon

Angers: CLCC Paul Papin
Besançon: CHU
Bordeaux: Institut Bergonié
Brest: CHU
Caen: CLCC René Baclesse
Clermont-Ferrand: CHU and CLCC Jean Perrin
Dijon: CHU and CLCC G.-F. Leclerc
Grenoble: CHU
Lille: CHRU and CLCC Oscar Lambret
Lyon: Hospices civils de Lyon and CLCC Léon Bérard
Marseille: CLCC Institut Paoli Calmettes
Montpellier: CLCC Val d'Aurelle
Nancy: CLCC Alexis Vautrin
Nantes: CLCC René Gauducheau
Nice: CHU and CLCC Antoine Lacassagne
Paris: AP-HP: CHU HEGP, CHU Lariboisière, CHU Louis Mourier
Saint-Étienne: CHU
Strasbourg: CHU and CLCC Paul Strauss
Toulouse: CLCC Claudius Régaud
Villejuif: Institut Gustave Roussy

APPENDIX 16: EXPERT CENTRES FOR ADRENAL CANCERS

COMETE / Prof Xavier BERTAGNA, CHU Cochin, AP-HP, Paris

Angers: CHU
Besançon: CHU
Bordeaux: CHU
Brest: CHU
Caen: CHU et CLCC François Baclesse
Clermont-Ferrand: CHU
Dijon: CHU
Grenoble: CHU
Lille: CHRU¹
Limoges: CHU
Lyon: CHU et CLCC Léon Bérard
Marseille: CHU
Montpellier: CHU
Nancy: CHU
Nantes: CHU
Paris: AP-HP: CHU Cochin*, CHU HEGP, CHU Ambroise Paré, CHU Bicêtre, CHU Pitié-Salpêtrière, CHU Saint-Antoine
Pointe-à-Pitre: CHU
Poitiers: CHU
Reims: CHU
Rouen: CHU
Saint-Pierre de la Réunion: CHR
Strasbourg: CHU
Toulouse: CHU
Tours: CHU
Villejuif: Institut Gustave Roussy

In **purple and bold**: national expert centre

with *: the national coordinator's institution

* Coordinating institution for Nord-Pas-de-Calais-Picardy

APPENDIX 17: EXPERT CENTRES FOR VIRALLY INDUCED CANCERS IN TRANSPLANT RECIPIENTS

K-VIROGREF - Prof Véronique LEBLOND, Groupe hospitalier Pitié-Salpêtrière, AP-HP, Paris

Amiens: CHU
Besançon: CHU
Bordeaux: CHU
Caen: CHU
Clermont Ferrand: CHU
Dijon: CHU
Grenoble: CHU
Lille: CHRU
Lyon: CHU
Marseille: CHU et Institut Paoli Calmettes
Montpellier: CHRU
Nancy: CHU
Nantes: CHU
Paris: AP-HP: CHU Pitié-Salpêtrière*, **CHU Tenon**, CHU Saint-Louis, CHU Necker, CHU Henri-Mondor,
CHU Kremlin-Bicêtre- Antoine Bécclère-Paul Brousse, CHU Cochin
Reims: CHU
Rennes: CHU
Rouen: CHU + CLCC Henri Becquerel
Strasbourg: CHU
Toulouse: CHU
Tours: CHRU

APPENDIX 18: NATIONAL ANATOMOPATHOLOGICAL REFERENCE NETWORK FOR LYMPHOMAS

 Lymphopath / **Prof Georges DELSOL**, CHU de Toulouse et **Pr Philippe GAULARD**, CHU Henri Mondor, AP-HP

EXPERT REFERENCE CENTRES

Amiens: CHU
 Angers: CHU
 Bordeaux: Institut Bergonié
 Bordeaux: CHU
 Brest: CHU
 Caen: CHU
 Clermont-Ferrand: CHU
 Dijon: CHU
 Grenoble: CHU
 Lille: CHU
 Lyon: CHU et Centre Léon Bérard
 Marseille: Institut Paoli Calmettes
 Montpellier: CHU
 Mulhouse : CH
 Nancy : CHU
 Nantes: CHU
 Nice: CHU
Paris: AP-HP: CHU Henri Mondor*, CHU Saint-Louis, Hôtel Dieu, CHU Necker, CHU Saint-Antoine,
 CHU Pitié-Salpêtrière, CHU Avicenne
 Reims: CHU
 Rennes: CHU
 Rouen: Centre Henri Becquerel
 Saint-Étienne: CHU
 Strasbourg: CHU
Toulouse: CHU*
 Tours: CHU
 Villejuif / Clamart / Kremlin-Bicêtre : Institut Gustave Roussy / Hôpital Bicêtre, Hôpital Paul Brousse, Hôpital Antoine Béclère

APPENDIX 19: SPECIFIC MISSIONS OF A NATIONAL EXPERT CENTRE

MISSIONS	DESCRIPTION	INDICATORS
Selection and organisation of expert centres	Defining the selection criteria	
Clinical referral	Organising a referral RCP at national level, if required Liaising with the pathologist responsible for organising the double reading and molecular typing examinations	Number of national referral RCP; number of patients discussed for the first time at a referral RCP at national level, at diagnosis/in the event of a recurrence Total number of cases to have benefited from a double reading/total number of new patients Number of corrected diagnoses
Contribution to research	Promoting the development of multicentre basic, translational and clinical research studies	Number of cases sampled for tumour banking: for health/research Describe the studies begun in the year (including PHRC and STIC) and their state of progress Describe the studies completed in the year Total number of patients included in studies, including clinical trials List of publications referenced in Medline
Recommendation for good national clinical practice (RGP)	Involvement in design or update of RGP	RGP published or being written
Involvement in epidemiological surveillance and observation of cancers	Establishing a database for these rare cancers	National incidence National prevalence Characteristics of patients Characteristics of pathologies
Involvement in training	University training and training in the context of CPD	Types of training meetings Number of training meetings
Involvement in provision of information	Building relationships with national patient associations Involvement in communication for patients and wider public	Description of relationships with associations concerned Types of information meetings Number of information meetings
Monitoring of expert centres	Establishment and monitoring of indicators in all expert centres	INCa

PHRC: Programme Hospitalier de Recherche Clinique (hospital clinical research programme)

STIC: Soutien aux Techniques Innovantes Coûteuses (support programme for innovative and costly techniques)

CPD: Continual Professional Development

RCP: Réunion de Concertation Pluridisciplinaire (multidisciplinary meeting)

APPENDIX 20: MISSIONS OF AN EXPERT CENTRE (REGIONAL OR INTERREGIONAL)

MISSIONS	DESCRIPTION	INDICATORS
Clinical referral	Establishment of a regional or interregional referral RCP	Composition of referral RCP Number of patients discussed for the first time at a referral RCP at regional level, at diagnosis/in the event of a recurrence Total number of patients with rare cancers being followed annually in the region
Involvement in clinical research	Inclusion of patients in clinical trials	Number and type of samples for tumour banking Number of patients included in clinical trials
Training and provision of information	Involvement in medical and paramedical training Involvement in providing patients with information	Number of regional meetings organised that validate CPD Number of information meetings for patients in the region
Coordination	cancer treatment in the region	

CPD: Continual Personal Development

RCP: Réunion de Concertation Pluridisciplinaire (multidisciplinary meeting)



For further information
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