

Acronym of the network: RENATEN

Family : Rare malignant neuroendocrine tumours

**Application file**

**Designation of national reference networks for rare adult cancers, incorporating the organisation of double reading of malignant paediatric tumour samples**



**Objective 2: Guaranteeing the safety and quality of care**

**Online submission:** [***http://www.e-cancer.fr/aap/sp/rares2019***](http://www.e-cancer.fr/aap/sp/rares2019)

**Application submission deadline: 21 January 2019**

**1-Identification of the Rare Cancer network structure**

**1.1 National reference network for rare cancers concerned**

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| **Rare Cancer family[[1]](#footnote-1):** | **Rare malignant neuroendocrine tumours** |
| **Name of the rare cancer network:** |  |
| **Acronym of the network(s)** | **RENATEN** |
| **Structuring date:** |  |
| **INCa designation in 2014-2015** | Yes  No |

**1.2 Coordinator of the national reference network for rare cancers and institution with which the coordinator is affiliated**

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| **Last name, first name of medical coordinator:** |  |
| **Institution with which he/she is affiliated:**  **Legal representative:**  **Address of head office of institution:** |  |
| **Last name and first name of person responsible for administrative follow-up of the application:**  **e-mail:**  **Telephone:** |  |

**1.3 In the case of a multisite reference centre (not more than 3 sites in total), co-coordinator(s) and institution(s) with which this/these co-coordinator(s) is/are affiliated**

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| **Last name, first name of site 2**  **medical co-coordinator:** |  |
| **Institution with which he/she is affiliated for site 2:**  **Legal representative:**  **Address:** |  |
| **Last name, first name of site 3**  **medical co-coordinator:** |  |
| **Institution with which he/she is affiliated for site 3:**  **Legal representative:**  **Address:** |  |

**1.4 Steering committee (if applicable)**

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| **Number of members** |  |
| **Functions or fields represented** |  |
| **Operating procedure and frequency of meetings** |  |

**1.5 Structure of the national network**

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| **Network characteristics** | Anatomoclinical  Clinical  Anatomopathological |
| **Number of expert centres identified** |  |
| **Last name, first name of the pathologist coordinator for the double reading** |  |
| **Institution with which he/she is affiliated:**  **Legal representative:**  **Address of head office of institution:** |  |

**1.6 Current scope of the national network for rare cancers**

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| **Number of rare cancer sub-groups identified in the call for proposals application initially submitted** | 5 |
| **List of sub-groups and list of rare cancers in each of the sub-groups** | TNE digestives  TNE bronchiques et pulmonaires  TNE primitif inconnu  carcinomes medullaires thyroidiens  pargangliomes |

**1.7 List of publications of the coordinator (2015-2017) on the rare cancers concerned**

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2- Overview of the review framework of the specific organisation for rare adult cancers

This application file follows the outline of the self-review guidelines for rare disease reference centres drafted under the aegis of HAS and the 2014 version of the INCa Rare Cancer network application file in 2014.

**The document structure includes:**

* + **organisation of assessment items according to the stages of an improvement process**

For the review, it is necessary to endeavour to identify measurable indicators representative of improvement of the quality and organisation of care, reduction of loss of chance, harmonisation of practices and coordination of the care pathway.

Some indicators are quantitative:

* this is the case for the review of the double reading of tumour samples with the percentage of cases in which this double reading gives rise to a change in patient care;
* or the rate of revision of surgical excisions in soft tissue sarcomas, the reduction of this rate reflecting an improvement in care from the diagnostic phase.

**Some of the activity data figures correspond to the activity data provided by you to INCa in the last 3 years (2015-2017).** They are pre-entered. However, should you wish to edit them, you must explain the reason for this request.

Areas for improvement or change are given by way of example and other areas may be proposed.

* + **Identification of nine missions:**

1. Expertise mission: double reading of tumour samples, referral RCP;
2. Care practice and equity safeguarding mission: drafting and/or updating of national best practice guidelines;
3. Referral mission: patient access to medical teams, technical platforms or highly specialised or innovative treatments (proton therapy, immunotherapy, etc.);
4. Observation mission: exhaustive recording of cases in an interoperable national clinicobiological database;
5. Research contribution mission: translational research, clinical research, publications;
6. Healthcare professional training mission;
7. Patient and relative information mission, role of patient associations;
8. Structuring and coordination mission;
9. Monitoring mission of this specific organisation.

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| **Mission 1: Expertise mission** | |
| The national reference networks for rare adult cancers must **ensure access to medical expertise for all patients suffering from such a cancer on national territory, regardless of the institution attended**.  This access to expertise includes:   * on one hand, **access to anatomopathological expertise**, through the **arrangement of double reading** of rare cancer tumour samples where justified. * on the other, **access to clinical expertise**, through the **arrangement of regional, interregional and/or national referral RCPs**. The referral RCP focuses specifically on the rare disease in question and enables the case review of a rare cancer patient at all stages of his/her pathway. Its members are predefined, so as to ensure representation of the specialists involved in care. Its organisation procedure is circulated to all healthcare professionals concerned (location, date and time, physical presence, web-conferences, etc.). | |
| **Double reading of rare adult cancer tumour samples** | |
| **Organisation**   * Number of anatomopathological departments identified for double reading * Expertise criteria applied for the selection of these centres * **List of these departments and their heads (to be appended)** * Description of prerequisites prior to sending slides * Description algorithms for assisting diagnosis in place * Anatomopathological report standardisation and computerisation * Description of transmission procedure of results to healthcare professionals concerned: detail the recipients of the anatomopathological double reading report * Description of the partnership arrangements set up between different networks for rare cancers * Description of any other organisational procedures: national "triple reading", etc. |  |
| **Activity (2015 to 2017 data)**   * Number of cases sent by the referral RCP | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of cases sent by a pathologist outside the rare cancer organisation | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of cases reviewed in-house (tumour samples taken in one of the centres included in the network) | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 284 |  |  | |
| * Number of external cases (sent by a pathologist not identified as an expert pathologist) sent for opinion (with no rare cancer diagnosis) | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of external cases (sent by a pathologist not identified as an expert pathologist) sent for rare cancer diagnosis confirmation | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Major therapeutic impact: Number of patients for whom the new diagnosis modifies treatment in external cases sent for confirmation | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 10 |  |  | |
| * Major therapeutic impact: Number of patients for whom the new diagnosis modifies treatment in external cases sent for opinion and for confirmation |  |
| * Major therapeutic impact:   Evaluation method of this impact (by the pathologist, the clinician, both?) |  |
| * Analysis of the impact of double reading on treatment by rare cancer sub-group |  |
| * Number of cases requiring "triple reading" |  |
| * Major therapeutic impact of this triple reading: Number of patients with modified treatments |  |
| * Number of paediatric cancer cases who benefited from double reading in this network | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| **Areas for change**   * In the light of this analysis, restriction of indication of double reading of tumour samples to certain rare cancer sub-groups? |  |
| * Other area for change? |  |

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| **Specialised RCP/referral RCP** | |
| * RCP type: specialised? referral? * Frequency * Media * Quorum: provide details * Computerisation of minutes of specialised RCP and/or referral RCP, oncology communication file, interoperability, etc.) |  |
| * Number of referral RCPs available on national territory |  |
| * Description of official links with other networks for rare cancers for the review of cases in referral RCP |  |
| * Total number of patient cases reviewed in referral RCP throughout the national rare cancer network at initial treatment stage ("new patients") | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 1905 | 1651 | 2672 | |
| * Total number of these cases for whom the double reading report is available |  |
| * Total number of patients referred to referral RCP | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 2887 | 4291 | 4638 | |
| * Estimation of the coverage rate of these referral RCPs (number of "new" patients reviewed in referral RCP / estimated total number of incoming cases) |  |
| * Review of consistency between treatment proposed in referral RCP and treatment administered in an institution outside the rare cancer network: methodology, results |  |

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| **Mission 2: Care practice and equity safeguarding mission:**  **national best practice guidelines** | |
| The dissemination of expertise and harmonisation of practices also involve putting in place **national good clinical practice recommendations or guidelines**. The national reference networks for rare adult cancers must participate in the drafting or **updating** of these documents, drawing on European or international guidelines if applicable, and circulating and implementing them. They must have identified the challenges, i.e. the clinical scenarios where a lack of guidelines may give rise to a loss of chance for the patient. They must also have identified the priority targets (specialists, GPs, paramedics, etc.) of each of these guidelines. These guidelines must be endorsed by all heads of expert centres, including the coordinators. A **circulation** plan according to the targets must be envisaged for each of these guidelines: publication on websites of the rare cancer networks, circulation to regional oncology networks, patient associations, and communication actions aimed at priority targets. | |
| **Activity:**   * List of national recommendations or guidelines meeting the above criteria dating back to within the last 5 years * Description of circulation procedure of these guidelines to the identified targets |  |
| **Areas for change**   * List of national guidelines planned for the next 5 years |  |

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| **Mission 3: Referral mission** | | |
| **Referral is defined by the transfer** of the rare cancer patient for hospitalisation in an expert or reference centre of the rare cancer network. This term does not cover patients already followed up in one of the centres included in the network.  This transfer may be due to:   * access to highly specialised treatments: proton therapy, immunotherapy, clinical trial, etc. * access to a highly specialised environment: procedure, technical platform, etc. * access for some rare cancers to oncogenetic consultations and to oncogenetic laboratories   The approval scheme of healthcare institutions for cancer treatment is currently under review. This review shall ultimately include a ranking of care. Proposals may be made to INCa by coordinators of the networks for rare cancers, and, following an impact study, INCa may subsequently incorporate them in the general proposals to be made to DGOS. | | |
| **Organisation of referral** | | |
| **Environment**   * Highly specialised techniques required for the rare cancer * Number of sites located in national territory (append map) | |  |
| **Activity** (2015-2017 data)   * Number of patients transferred to an expert or reference centre * Provide details of the number according to the reason for transfer * diagnostic procedure * treatment, including a highly specialised or innovative treatment (specify) * inclusion in a clinical trial * other reason (specify) | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  | 661 | 816 | |
| * Number of patients who required access to highly specialised techniques | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| **Access to oncogenetic consultations** | | |
| **Evaluation** (2015-2017 data)   * Number of patients who benefited from an oncogenetic consultation | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | | |
| * Patient register of subjects with a genetic predisposition to cancer in the network | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | | |

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| **Mission 4: observation mission**  **National database** | |
| The national reference networks for rare adult cancers must collect data in interoperable computerised **specific national databases** to enable processing of such data. | |
| * Database type: * Anatomoclinical * Clinicobiological (in this case, name and date of INCa designation) * other (specify) * Description of minimum dataset collected (to be appended) * List of data sources * Collection and computerisation procedure * Interoperability of these data * Data checking procedure (consistency check and set-up of a correction and update circuit) |  |
| **Activity** (2015-2017 data)   * Number of new cases recorded | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 1155 |  |  | |
| * Total number of cases recorded in database since inception |  |
| * Evaluation of exhaustive nature and quality of data collected:   -Missing value rate in minimum set  -Medium-term and long-term follow-up data: relapse-free survival, overall survival for rare cancer sub-groups |  |
| * Description of use of these data: number of studies set up, number of cohorts, number of cases exported for research analysis, number of cases analysed for modification of best practices, publications |  |
| **Areas for change** in 5 years |  |

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| **Mission 5: Research contribution mission** | |
| The national reference networks for rare adult cancers must contribute to **research, particularly translational and clinical research**, and promote **multicentre studies with a national or international scope** in the field of the rare cancers in question.  The research activity must be formalised through **partnerships with research units** within INSERM or CNRS or other research bodies and European or international groups.  These cancer networks are expected to contribute to progress in knowledge. To this end, they must at least make the clinical data and biological samples in their possession available to research teams or make use of them themselves. They must attract interest from other researchers when they are unable to conduct research projects themselves. As the research section of their activity is not funded directly, the endeavours made to promote the network structure for a given cancer and to set up **clinical and biological databases and biological collections (tumour bank, serum bank, DNA**, etc.) should be evaluated. This is measured in terms of number of projects, whether joint or not, initiated on the basis of these data and these biological resources, publications, as well as the **number of patients included in clinical trials**, or in a research programme. | |
| **Organisation of clinical data and biological sample collection** | |
| * Number of samples used for research projects |  |
| * Number of research projects initiated using collected samples |  |
| **Translational research** | |
| * Description of links with the research teams involved |  |
| **Activity** (2015-2017 data)   * Number of translational studies initiated/in progress/finalised | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |

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| **Clinical research** | | |
| * Designation of a Cooperative Intergroup for rare cancer research. * If yes, date of designation | |  |
| * Description of national and/or international research partnerships | |  |
| **Activity** (2015-2017 data)   * Number of open clinical trials in the rare cancer network | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of reference and/or expert centres taking part in these trials | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 8 | 15 | 15 | |
| * Number of phase 2 and 3 clinical trials devoted to rare cancers set up | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 3 | 12 | 14 | |
| * Number of open PHRCs supported by the rare cancer organisation | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of patients included in the "AcSé rare cancer immunotherapy" trials | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of international clinical trials with participation of the network for rare cancers | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Number of patients included in phase 2 and 3 clinical trials | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 136 | 69 | 46 | |
| * Number of new drugs that have been granted a marketing authorisation through these clinical trials | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| * Other impacts of this clinical research | |  |
| * Number of clinical trial findings sent to and/or accessible to patients | | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |
| **Improvement of scientific knowledge of these rare cancers** | | |
| **Activity** (2015-2017 data)   * List of scientific publications on this them by all the members of the Rare Cancer network in peer-reviewed journals. |  | |

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| **Mission 6: Healthcare professional training participation mission** | |
| Healthcare professionals are often unfamiliar with the specificities of the warning signs and treatments of rare cancer patients. One of the missions of the national reference networks is to contribute to the training of these healthcare professionals on the rare cancers within their remit.  The various medical and paramedical professionals potentially involved must be identified and be the subject of targeted training. | |
| * Description of university education on the rare cancer in which one or more members of the network participate * Description of CPD (continuous professional development) training for professionals * Caregivers concerned: specify   oncologists, organ specialists, pathologists, geneticists, general practitioners, home caregivers, etc. |  |
| **Activity** (2015-2017 data)   * Number of university educational programmes set up | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 9 | 6 | 6 | |
| * Number of non-university training programmes set up by expert centres in their region | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | | 41 | 66 | 35 | |
| * Within the scope of CPD, number and type of healthcare professionals trained | |  |  |  | | --- | --- | --- | | 2015 | 2016 | 2017 | |  |  |  | |

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| **Mission 7: Patient and relative information mission**  **and links with patient associations** | |
| While the organisation of care for a rare cancer patient falls within the scope of the more general organisation of oncology, particularly guaranteeing cross-disciplinary quality measures in approved institutions for cancer treatment (announcement procedure, personalised care plan, etc.), the line between rare disease and rare cancer is finest in the area of patient information. Patients are major stakeholders: as part of national or international associations, they drive changes in health and research policies. There are over 400 disease-specific associations in France, as well as a federation of rare disease associations (Alliance Maladies Rares) and a European federation (EURORDIS).  **Orphanet** (INSERM) is a major organisation in information for healthcare professionals, patients and the general public.  Where there are one or more associations involved in a rare disease, the national reference network for rare adult cancers must **incorporate them in its activities**: the associations take part in the drafting of national best practice guidelines, information and consent documents for clinical trials, information brochures for patients and their families, information published on the Internet on a dedicated website.  The patient association(s) participate(s) in the **governance of the rare cancer network**, particularly by joining the steering committee if it exists. | |
| * List of national patient associations concerned by the disease | APTED/AFNEM/le Sourire de Sabrina |
| **Activity** (2015-2017 data)   * Description of actions conducted with the patient association(s) in question * In the absence of patient associations, description of the resources and actions in respect of information for patients and their friends and family |  |
| * Append a letter from each patient association involved, describing the actions conducted in partnership with the network |  |
| * Address of dedicated website |  |
| * Date of latest update of dedicated website |  |
| * Site link with regional oncology network site |  |
| * Information sharing mode on the Rare Cancer network with the regional health board of the reference centre |  |

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| **Mission 8: Structuring and coordination mission** | |
| The specific organisation in national networks for rare adult cancers has been in place since 2009.  The coordinator is INCa's contact for network mission follow-up.  He/she structures the network so as to ensure access to expertise throughout national territory. As such, he/she limits the number of expert centres and defines the criteria for selecting the head of each of these centres.  He/she describes the incentive measures (funding, CRA time, etc.) for regional or interregional expert centres.  The terms of partnership between the different national reference networks for rare adult cancers must be defined and reviewed.  The reference networks are at the forefront of a care pathway combining proximity and access to expertise. The regional or interregional expert centres must form links with other institutions approved for cancer treatment in their territory. As such, all rare cancer patients can benefit from care close to their home, while being assured of access to expertise.  The clarity of this specific organisation is essential on a national, European and international level. | |
| Activity and scope of the **national reference network** for rare cancers | |
| **Evaluation** (2015-2017 data)   * Number of new patients in each of the rare cancer sub-groups  |  |  |  |  | | --- | --- | --- | --- | | Cancer sub-group | 2015 | 2016 | 2017 | | TNE digestives | 1300 | 1824 | 2420 | | TNE bronchiques et pulmonaires | 189 | 251 | 348 | | TNE primitif inconnu | 93 | 188 | 280 | | carcinomes medullaires thyroidiens | 142 | 250 | 146 | | pargangliomes | 123 | 73 | 153 | |  | 136 | 72 |  | |  |  |  |  | |  |  |  |  | |  |  |  |  | |  |  |  |  | | |
| **Areas for change**  Proposal to restrict (or broaden) the scope of expertise - justify |  |

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| **Coordination resources of the national reference network for rare cancers** | |
| * Description of the coordination procedure of the rare cancer network |  |
| **Evaluation** (2015-2017 data)   * Type and number of staff (FTE) assigned to coordination |  |
| **Activity of each of the expert centres** | |
| * Criteria applied: * number of double reading cases * number of referral RCPs * number of new patients referred to referral RCP * number of patients included by the expert centre in a national clinical trial * other criteria * Specify the incentive measures for these expert centres |  |
| **Evaluation** (2015-2017 data)   * Number of active expert centres/number listed and published in Orphanet records in February 2016 ([http://www.e-cancer.fr/content/download/213770/2901359/file/Re%CC%81seaux%20nationaux%20pour%20cancers%20rares%20de%20l'adulte%20-%20Liste%20centres%20-%20Les%20cahiers%20d'Orphanet%20(fe%CC%81vrier%202016).pdf](http://www.e-cancer.fr/content/download/213770/2901359/file/Réseaux%20nationaux%20pour%20cancers%20rares%20de%20l'adulte%20-%20Liste%20centres%20-%20Les%20cahiers%20d'Orphanet%20(février%202016).pdf) ) * **List of these centres and their heads (to be appended)** |  |
| **Expertise shared with other national networks for rare adult cancers** | |
| * Description of terms of partnership |  |
| **Activity** (2015-17 data)   * Number of cases from this network reviewed in the relevant referral RCP (of another rare cancer network) * Number of cases actually registered in the relevant database (of another rare cancer network) |  |
| * Participation in the EUROCAN European reference network * Participation in another European reference network * Participation in another international structure for rare cancers |  |
| **Continuity of care between paediatric sectors and adults sectors for these rare cancers** | |
| **Implementation**   * Description of resources used: common adult-paediatric referral RCP? * Shared databases? |  |
| **Evaluation** (2015-2017 data) |  |

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| **Mission 9: Monitoring mission of this organisation** | |
| The coordinator shall propose one to three **indicators of quality and safety of care** deemed relevant to assess the benefit for patients of this specific organisation as a network for rare cancers: indicators in respect of structure (human resources, equipment), processes (time to access a particular treatment), results (network coverage, relapse-free survival, overall survival, results of therapeutic trials, etc.). | |
| **Monitoring of this specific organisation** | |
| * List the 2 or 3 indicators selected and justify their choice |  |
| **Evaluation** (2015-2017 data)   * Data for indicator 1 * Data for indicator * Data for indicator 3 |  |
| **Areas for change**  Proposal of tracking of other indicators |  |

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| **Conclusion** |
| Main progress associated with the set-up of the rare cancer network and benefits for patients: |
| Main problems encountered: |
| Proposals for improvement in the next 5 years: |

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| **Information relative au traitement de vos données personnelles**  **qui seront renseignées dans le dossier de candidature**  **----------------------------** |
| Dans le cadre de ses missions de service public, l’Institut national du cancer conduit des appels à projets dans le domaine de la cancérologie. Afin d’effectuer l’évaluation des projets reçus et de constituer une base de données permettant d’assurer le recensement et le suivi des appels à projets financés par l’Institut, ce dernier doit recueillir des données relatives à l’identité et la vie professionnelle du coordonnateur, du représentant légal ou de la personne dûment habilitée de l’organisme bénéficiaire, de la personne chargée du suivi administratif du dossier, du responsable d’équipe et, le cas échéant, du personnel de l’équipe et des personnes désignées par le coordonnateur ne devant pas avoir connaissance du projet, ces dernières pouvant de par leurs liens en tirer un avantage direct ou indirect.  Les personnes dont les données personnelles figurent dans le dossier de candidature doivent être informées par celui qui les a désignées que l’Institut les utilisera selon les modalités ici décrites.  L’Institut est le responsable du traitement de ces données. Il conservera celles nécessaires à l’évaluation des projets pour une durée de cinq ans si votre projet n’est pas retenu ou, de dix ans s’il l’est, à compter de la date de notification du résultat de la sélection par l’Institut. Les données nécessaires au recensement et au suivi des appels à projets qu’il finance seront conservées pour une durée de quinze ans à compter de la même date. Conformément au Règlement général sur la protection des données 2016/679 et à la loi informatique et libertés n°78-17 modifiée, vous disposez durant la durée du traitement d’un droit d’opposition, d’un droit d’accès, de rectification, d’effacement et à la portabilité de vos données et d’un droit à la limitation du traitement de vos données. Pour les exercer, veuillez adresser votre demande par mail à l’adresse suivante : servicejuridique@institutcancer.fr. Vous trouverez les coordonnées de l’Institut, de son représentant et de sa déléguée à la protection des données sur e-cancer.fr. Vous disposez, par ailleurs, du droit d’introduire une réclamation auprès de la Commission nationale de l’informatique et des libertés (CNIL). |

**4- Engagements et signatures**

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| Engagement du coordonnateur du réseau national de référence |
| Je soussigné -**Nom et prénom: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  Coordonnateur du réseau cancers rares *(indiquer le nom du réseau)* \_\_\_\_\_\_\_\_\_\_\_  Je déclare avoir pris connaissance de l’appel à candidatures « Labellisation des réseaux de référence pour cancers rares de l’adulte » et du présent dossier de candidature.  Je certifie que les informations figurant dans le dossier de candidature intègrent l’ensemble des données recueillies auprès des centres de compétence du réseau  Je m’engage à mener les missions liées à la coordination du réseau national de référence pour cancers rares ci-dessus, à participer à la réalisation de ces missions et à établir et transmettre à l’INCa annuellement les données d’activité sur l’état de ces différentes missions.  Je déclare avoir pris connaissance des modalités de traitement de mes données personnelles et de mes droits tels que décrits précédemment sur la page d’information dédiée et, le cas échéant, de l’obligation que j’ai d’informer les personnes dont j’ai cité le nom dans le dossier de candidature selon lesdites modalités.  Signature : Fait à \_\_\_\_\_\_\_\_\_\_\_\_\_ |

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| Engagement du représentant légal de l’établissement de rattachement du coordonnateur du réseau national de référence cancers rares |
| Nom de l’établissement de santé : \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Après avoir pris connaissance de l’appel à candidatures « Labellisation des réseaux nationaux de référence pour cancers rares de l’adulte » et du présent dossier de candidature concernant le réseau : (indiquer le nom du réseau)\_\_\_\_\_\_\_\_\_\_\_  Je, soussigné(e), \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ *(nom, prénom)*  Représentant légal  Personne dûment habilitée  (cette personne est soit le représentant légal de l’organisme, soit toute autre personne dûment habilitée et bénéficiant d’une délégation de pouvoir ou de signature établie par le représentant légal. En cas de délégation de pouvoir ou de signature, joindre la copie de délégation)  - m’engage à permettre au coordonnateur de mener à bien les missions de coordination du réseau national de référence décrites dans l’appel à candidatures et à participer à la réalisation de ces missions ;  - m’engage à ce que le coordonnateur transmette à l’INCa annuellement les données minimales d’activité sur l’état de ces différentes missions ;  - m’engage à mobiliser intégralement les crédits obtenus pour les missions précitées et dans les meilleurs délais dès leurs versements. L’attribution des crédits au titre desdites missions du réseau ne serait plus effectuée auprès de mon établissement, si le coordonnateur n’y était plus rattaché.  Je déclare avoir pris connaissance des modalités de traitement de mes données personnelles et de mes droits tels que décrits précédemment sur la page d’information dédiée et, le cas échéant, de l’obligation que j’ai d’informer les personnes dont j’ai cité le nom dans le dossier de candidature selon lesdites modalités.  Signature : Fait à \_\_\_\_\_\_\_\_\_ , le \_\_\_\_\_\_\_\_\_\_\_\_  Cachet de l’organisme |

**La signature n’est pas exigée sur le document électronique. Elle est impérative sur le document papier.**

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| Modèle d’engagement des responsables des centres de compétence (dont la liste sera définitivement arrêtée à l’issue de l’évaluation) et de leur organisme de rattachement. |

**Ce document sera à compléter et signer ultérieurement**

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| Engagement du responsable du centre compétence membre du réseau national de référence [[2]](#footnote-2)  Nom du réseau cancers rares \_\_\_\_\_\_\_\_\_\_\_  *(indiquer le nom du réseau)* |
| Je soussigné,  **Nom et prénom du responsable : \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  Je déclare avoir pris connaissance de l’appel à candidatures « Labellisation des réseaux nationaux de référence pour cancers rares de l’adulte », du dossier de candidature, de la liste des responsables des centres composant le réseau national, définitivement arrêtée au terme de l’évaluation.  Je m ’engage à :   * participer aux missions du réseau national de référence ci-dessus coordonné par M \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (*indiquer le nom*) * transmettre annuellement à ce coordonnateur les données minimales d’activité du centre de compétence dont je suis responsable.   Je déclare avoir pris connaissance des modalités de traitement de mes données personnelles et de mes droits tels que décrits précédemment sur la page d’information dédiée et, le cas échéant, de l’obligation que j’ai d’informer les personnes dont j’ai cité le nom dans le dossier de candidature selon lesdites modalités.  Signature : Fait à \_\_\_\_\_\_\_\_\_\_\_\_\_ |

**Ce document sera à compléter et signer ultérieurement**

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| Signature du représentant légal de l’établissement de rattachement du responsable du centre compétence membre du réseau national de référence  Nom du réseau cancers rares \_\_\_\_\_\_\_\_\_\_\_  *(indiquer le nom du réseau)* |
| Nom de l’établissement : \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Après avoir pris connaissance de l’appel à candidatures « Labellisation des réseaux nationaux de référence pour cancers rares de l’adulte », du dossier de candidature et de la liste des responsables des centres composant le réseau national, définitivement arrêtée au terme de l’évaluation,  Je, soussigné(e), \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (nom, prénom)  Représentant légal……………..  Personne dûment habilitée….  (Cette personne est soit le représentant légal de l’organisme, soit toute autre personne dûment habilitée et bénéficiant d’une délégation de pouvoir ou de signature établie par le représentant légal. En cas de délégation de pouvoir ou de signature, joindre la copie de délégation)  - m’engage à permettre au responsable du centre de compétence membre du réseau national de référence de participer aux missions dudit réseau décrites dans l’appel à candidatures.  - m’engage à ce que ce responsable transmette au coordonnateur du réseau annuellement les données minimales d’activité de ce centre.  Je déclare avoir pris connaissance du traitement de mes données personnelles et de mes droits et, le cas échéant, de l’obligation que j’ai d’informer les personnes dont j’ai cité le nom dans le dossier de candidature  Signature : Fait à \_\_\_\_\_\_\_\_\_ , le \_\_\_\_\_\_\_\_\_\_\_\_  Cachet de l’organisme |

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| **Date limite de soumission : 21 janvier 2019** |

**Attention** : pour les réseaux déjà constitués, l’INCa a pré rempli les données d’activité en sa possession. Ainsi ces dossiers de candidatures personnalisés devront être demandés au Dr Jeanne-Marie BRECHOT.

* **Envoi papier : 2 exemplaires : un original et une copie**

Le dossier de candidature, version anglaise et française, strictement superposable au dossier soumis en ligne (à l’exception du formulaire d’engagement dûment signé par les personnes responsables).

L’original dument signés et sa copie sont envoyés dans le respect des délais mentionnés au point 10 (le cachet de la poste faisant foi), à l’adresse suivante :

Institut National du cancer

**AAC Cancers rares**

52, avenue André Morizet

92 513 Boulogne-Billancourt Cedex

**ET**

* **Soumission en ligne**

Procédure de soumission en ligne, à partir du site de l’INCa :

[**http://www.e-cancer.fr/aap/sante-publique-et-soins/rares2019**](http://www.e-cancer.fr/aap/sante-publique-et-soins/rares2019)

* l’identification du coordonnateur (nom, prénom et email),
* l’identification du projet (titre, durée),
* le dépôt par téléchargement du dossier complet comprend le fichier Word

**[Uniquement Word 97-2003]. La taille du fichier complet Word 97-2003 ne doit pas excéder 4 Mo. Aucun format PDF ne sera accepté.**

1. As per the list of families featured in appendix 2 of the call for applications document [↑](#footnote-ref-1)
2. Engagement et signature de chacun des co coordonnateurs et de leurs représentants légaux en cas de centre de référence multisite. [↑](#footnote-ref-2)