Appendix :

The Gironde CNS registry was created in May 1999 and records all primary tumors, benign or malignant, of the CNS diagnosed since 1st May 1999 in adults and children, for patients domiciled in Gironde at the time of diagnosis. This diagnosis might be clinical and radiological, confirmed or not by an anatomical-pathological sample. Recurrences of CNS tumors, metastases, pituitary and ophthalmic tumors as well as diagnoses prior to 1st May 1999 are excluded from this register.

It is the only specific CNS tumor register in France. It participates fully in the epidemiological surveillance of cancers in France, in close collaboration with Santé Publique France and the Institut National du Cancer (INCa) which funds it, the biostatistics department of the Hospices Civils de Lyon which participates in the analysis of the data, and the FRANCIM network which disseminates the epidemiological information.

The information circuit allowing the collection of histological diagnoses and therefore the inclusion of patients is formalized in such a way as to obtain exhaustiveness in this register. This is made possible above all by the multiple sources of reporting:

- A network of practitioners in the public or private sector involved in the management of these conditions. These practitioners have at their disposal anonymous reporting forms which they transmit to the register by fax or e-mail

- Weekly visits to the neuropathology laboratory (regional reference center for public and private laboratories) and to the neurosurgery and neurology departments of the Bordeaux University Hospital Centre (CHU) in order to identify cases of CNS tumors that have or have not undergone surgery

- Annual cross-referencing with data from the Programme de Médicalisation des Systèmes d'Information (PMSI) for all departments of the Bordeaux University Hospital

- PMSI data from health establishments in Gironde (excluding the CHU) and also outside Gironde

- Long-term conditions (ALD 30) of the three main health insurance schemes: Régime Général (RG), Mutualité Sociale Agricole (MSA) and Régime Social des Indépendants (RSI)

- Occupational medicine

- General cancer register of the Gironde (RCG)

- National register of solid tumors in children (RNTSE)

- Gironde register of hematological malignancies (RHM) for brain lymphomas

The variables collected are the same for all cases, using a standardised data collection form.

Before verifying the accuracy of the diagnosis of a primary CNS tumor, a radio-clinical and anatomo-pathological expertise approach is implemented.

- For cases with a histological diagnosis: anatomopathological expertise. A pathologist not involved in the initial diagnosis systematically rereads the slides, enabling a comparison with the initial result.

- For cases that have not benefited from a histological diagnosis (approximately 50 per year): radio-clinical expertise. The diagnosis is established via a set of clinical arguments (symptomatology, response to treatment, history) and paraclinical arguments (mainly radiological). These files will be assessed by clinicians, blind to the initial diagnosis.

In addition, all incidental findings reported by clinicians will be assessed at monthly meetings (1 neuroradiologist, 1 radiotherapist and 1 neurosurgeon).

Additional verification of the patient's residence in Gironde is not systematically carried out. In principle, it is considered that the address on the inclusion form is correct. Checks are only carried out if the address provided is marked "Chez madame or Chez Monsieur....". This often implies that the patient is not domiciled in Gironde. In these cases, an active search is carried out in the medical file and by means of letters to the town hall of the patient's supposed residence.

All the clinical information collected on the inclusion form is entered into the registry database, with the exception of the detailed history. Only a history of cancer, other CNS tumors and genetic history directly related to CNS tumors are kept.