

Round table number 6 : Establishing epidemiological cohorts in France within the framework of governmental plans – Alzheimer's disease, cancer, rare diseases : why, for whom, how and with what means ?

A need for interface and cooperation

Within the framework of governmental plans, whether they deal with cancer, rare diseases or Alzheimer's disease, there are important needs. Other more reactive countries are able to set up Alzheimer's disease cohorts whilst we are still in the process of asking ourselves how to do it. There is a real need to understand how others proceed and to use successes like the ones in the field of high blood pressure.

'Despite the political surge in this field visible through the 10th project of the CSIS which stimulates the development of epidemiological tools, such initiatives remain complicated and expensive. Cohorts are such a useful tool that they are rare ; we have few resources and we must not dissipate our efforts. We must track cohorts over a period of 10 years at least, which involves strong mobilization to organize long-term monitoring. Following the call for projects released within the context of the public loan on cohort setup, all epidemiologists are ready for action. So it is time to find an agreement on how to proceed.

This is a subject on which we need to work collectively and our workshop has undertaken to point out priorities whilst sharing the work load. On that note, academics, manufacturers and usual ordering parties agree on the need to use these resources well and to share them for the sake of patients who take part in them as well as the information required. We agree on the definition of a cohort : it is a prospective, long-term and expensive type of monitoring. The largest research infrastructures may involve an investment of several millions of euros per year. Yet, cohorts do not make up the ideal tool to practise descriptive epidemiology and decision makers often expect incidence and prevalence data. Nevertheless, participants in this round table note real progress in this area. Initiatives launched within the context of research carried out on Alzheimer's disease, cancer and rare diseases show that one must not go towards a sole model and that it is necessary to share knowledge with partners in order to

make progress. These national large scale plans require organization. For example manufacturers could agree to come together and deal with the academics in charge of setting up the cohort. That way, access to the resulting data would be negotiated beforehand. One of the main difficulties discussed deals with the loyalty of patients who are useful to observe during a number of years. Indeed, surveys on well identified groups such as the members of a mutual insurance company or a well federated professional branch lead to reliable results. The recruitment of subjects is one thing but monitoring them in the long-term is another.