

PERSPECTIVE ON THE LEGAL SITUATION FOR REGIONAL CANCER REGISTRATION IN JAPAN REFLECTIONS ON THE FRENCH EXAMPLE

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Regional cancer registration is necessary for the collection of cancer data, epidemiological analysis, and the dissemination of information throughout a given region. The exhaustivity of the recognition of cancer cases and the traceability of individuals have to be ensured for the delivery of timely, comparable, and high-quality cancer data. Data are therefore collected, stored, and released according to all the current requirements relating to data security and confidentiality.

In France, cancer registries operate under the approval of the Commission Nationale de l'Informatique et des Libertés (CNIL) and the Comité Nationale de Registre (CNR). Registration data are regularly collected from medical institutions and pathology histology laboratories by investigators. According to the law passed on January 6, 1978 (loi no. 78-17) (revised by the laws passed on July 1, 1994 (loi no. 94-548) and August 6, 2004), cancer registration in France is executed by the opt-out system. The law guarantees patients the right to refuse being registered in the cancer registry database, the right to access all data processed about them, and the right to demand the rectification, deletion, or blocking of data that are inaccurate or are not being processed in compliance with data security specifications. In reality, no registry in France has witnessed the frequent exercise of such rights by patients. By the revised Art. 57 in the law of 1978, primary doctors are required to provide patients with information regarding data transfer to the cancer registries. However, since the requirement for individual explanation after cancer notification is waived in the case of patients who are mentally unstable, this responsibility of the doctors appears to have become a mere facade.

In Japan, a number of prefectures and cities conduct efficient registration; however, it is becoming increasingly difficult to maintain the functionality of the registries. One of the reasons for this is the recent concern regarding the right to privacy after the enforcement of the Act on the Protection of Personal Information (May 30, 2003). In addition, since prefectural ordinances at the local level dominate all the peripheral rules—such as the Ethical Guideline for Epidemiological Research (Jun. 17, 2002)—that allow registries to obtain the personal information of patients, some prefectures have made the activities of registries difficult and complicated. One of the future options for Japanese cancer registries is to employ the French system, thereby guaranteeing patients the right to refuse registration. However, if this system is adopted, it is expected that a considerable number of patients in Japan will refuse to be registered due to a lack of sufficient medical literacy regarding the contribution of cancer registration in the country. Continued discussions on this issue and the proposal of an appropriate legal and ethical solution for the situation faced by cancer registries in Japan are necessary.