

Deliberation 2019-083 of June 20, 2019 National Commission for Computing and Liberties Nature of the deliberation: Single decision Legal status: In force Date of publication on Légifrance: Saturday July 11, 2020 Deliberation n° 2019-083 of June 20, 2019 bearing single decision and authorizing the National Cancer Institute (INCa) to implement automated processing for research, study and evaluation purposes based on the INCa "Cancerology Data Platform"

(Request No. 918314)

The National Commission for Computing and Liberties, Seizure by the National Cancer Institute of a request for authorization relating to the automated processing of personal data for the purpose of carrying out processing for the purposes of research, study or evaluation based on the INCa Cancer Data Platform authorized in accordance with deliberation no. 2019-082 of June 20, 2019; Having regard to convention no. 108 of the Council of Europe for the protection of individuals automatic processing of personal data; Having regard to Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of individuals with regard to the processing of personal data and on the free movement of this data, and repealing Directive 95/46/EC; Having regard to Law No. 78-17 of January 6, 1978 as amended relating to data processing, files and freedoms, in particular its Articles 6 II, 44 3°, 66, 72 and following; Seen law n°2016-41 of January 26, 2016 on the modernization of our health system, in particular its article 193; Having regard to the Public Health Code, in particular its article L.1415-2; Having regard to decree n° 2019-536 of May 29, 2019 taken for the application of law n ° 78-17 of January 6, 1978 relating to data processing, files and freedoms; Having regard to the favorable opinion of the expert committee for research, studies and evaluations in the field of health (CEREES) of July 18, 2018; After having heard Mrs Valérie PEUGEOT, commissioner, in her report, and Mrs Nacima BELKACEM, government commissioner, in her observations, Makes the following observations INCa has an authorization for the creation of a warehouse, called the Cancerology Data Platform (deliberation no. 2019-082), necessary for the implementation of its public service missions. This warehouse is made up of data from the National Health Data System (SNDS), data from cancer registries and data from cancer screening management structures. annually implements around a hundred processing operations on the basis of the data appearing in this warehouse. 1978 amended (hereinafter the Data Protection Act). The processing operations described come under the processing authorization system for the purposes of research, study or evaluation. The Commission considered it appropriate, in view of the elements presented in the application file, and in particular the volume of processing envisaged, to authorize its implementation on the basis of the provisions of Articles 66-IV, 72 and following of the Data Protection Act, within the

framework of a single decision.

On the data controller The National Cancer Institute (INCa), whose missions are specified in Article L. 1415-2 of the Public Health Code, is the agency for health and scientific expertise in cancerology of the State responsible for coordinating actions to fight against cancer. information of professionals and the public on all the problems relating to cancer and the production, at the request of the ministers concerned, of any expertise on issues relating to oncology and the fight against cancer. On the application of the provisions s related to the SNDS The Commission recalls that all the legislative and regulatory provisions relating to the SNDS are applicable in this case and in particular the prohibition on using this data for the purposes described in Article L. 1461-1-V of the public health code.

On the lawfulness of processing and the conditions for processing data concerning health The processing carried out by INCa is part of its public service missions as specified above and is necessary for the performance of a mission of public interest. They are, as such, lawful under Articles 6, paragraph 1 point e) and meet a condition allowing the processing of data concerning health under 9 paragraph 2 point j) of the General Data Protection Regulation (hereinafter GDPR).

On the purpose of the processing and its nature in the public interest The processing requiring access to the data of the Cancer Data Platform i e are intended to carry out research, studies and assessments within the framework of the exercise of INCa's public service missions. To do this, studies and assessments will be carried out in particular: the development of survey covering the whole of oncology (for example: expenditure relating to anti-cancer drugs in hospitals or outpatient settings, chemotherapy activities according to the type of cancer or the healthcare establishment); studies relating to care trajectories (monitoring a group of people to identify the occurrence of an event or observe the sequences of care); studies requested by ministries. The Commission considers that the purpose of the processing is determined, explicit and legitimate, in accordance with the article 5 paragraph 1 point b) of the GDPR. Furthermore, it considers that this processing serves a purpose of public interest, in accordance with article 66-I of the Data Protection Act.

categories of data processed The Commission recalls that the data controller must only process, within the framework of this single decision, the data that is strictly necessary and relevant to the objectives of the processing and contained in the Cancerology Data Platform. The categories of data processed likely to be processed are those whose processing is authorized under deliberation no. 2019-082, namely: data from the SNDS for which INCa has, under Articles R. 1461-12 and R.1461-14 of the Public Health Code, permanent access; data from cancer registries; data from cancer screening management structures. The Commission recalls that, in accordance with Article 30 of the GDPR, the data controller must keep the list of processing implemented in the context of this single decision up to date, in the register of processing activities.

The adequacy, p relevant and limited to what is necessary with regard to the purposes for which the data are processed, the geographical area concerned and the historical depth of the data consulted must be justified for each processing operation implemented within the framework of this single decision in the register processing activities. On the data retention period The duration of this single decision, during which processing for the purposes of study, research or evaluation carried out using data from the warehouse may be implemented, is set to six years. The retention period for each processing must be limited to the period necessary for the implementation of this processing and may not exceed two years after the last publication of the results or, in the absence of publication, exceed the date of signature of the final report of the study. On the publication of the results The Commission recalls that, when the result of the data processing is made public, the Direct or indirect identification of the persons concerned must be impossible, in accordance with Article 68 of the Data Protection Act. The results of the studies carried out within the framework of this single decision may in particular be sent to the public, to the public authorities or subject of scientific publications. On the categories of data recipients Only INCa has access to the data within the framework of this single decision. INCa maintains up-to-date documents indicating the competent person(s) within it to issue the authorization to access the data, the list of persons authorized to access this data, their respective access profiles and the methods of attribution. , management and control of authorizations. Only persons authorized by the data controller may have access to the data. These categories of persons are subject to professional secrecy under the conditions defined by Articles 226-13 and 226-14 of the Criminal Code. The qualification of authorized persons and their rights must be regularly reassessed, in accordance with the methods described in the authorization procedure established by INCa. On information and the rights of persons The persons concerned are informed of the processing and can exercise their rights in accordance with the methods described in the aforementioned deliberation. In any event, INCa undertakes to make available on its website collective information relating to the repository as well as information on subsequent research projects carried out from the data it contains. and including all of the information provided for in Article 14 of the GDPR for each research project. On the security of donations data and the traceability of actions Only processing carried out in the approved INCa environment in accordance with the aforementioned deliberation can be carried out within the framework of this single decision. Principle of transparency The provision of data from the SNDS and its components is designed to account for their use to civil society. To this end, Article L. 1461-3 of the Public Health Code makes access to data from the SNDS and its components subject to the communication to the INDS of several elements by the data controller, before and after the studies. Thus, the data controller

undertakes to register the studies carried out within the framework of this single decision with the public directory kept by the INDS. This registration, to be carried out before the start of processing by the data controller or the person acting on his behalf, is accompanied by the transmission to the INDS of a file comprising: the protocol, including the justification of the public interest, as well as a summary, according to the model made available by the INDS; the declaration of interests of the controller, in relation to the purpose of the processing. At the end of the studies, the method and the results obtained must be communicated to the INDS for publication. The recording of the treatments and the transmission of the results are carried out in accordance with the procedures defined by the INDS. Finally, the Committee notes that the INCa makes available on its website a page dedicated to cancer data, in which the results appear. assessments carried out in the field of epidemiology, prevention and risk factors, screening, care, research and innovation, and life with cancer (<http://lesdonnees.e-cancer.fr>). Under these conditions, the Commission authorizes, in accordance with this deliberation, INCa to implement the processing described above for a period of six years, from the effective availability of the data within the Cancer data platform, with the obligation to submit a report to the Commission at the end of this period. specific formalities with it. Decision DE-2011-058 authorizing INCa to implement personal health data processing for the purpose of creating dashboards and studying the trajectory of patients with cancer based on SNIIRAM data (authorization request no. 911297) is repealed. President Marie-Laure DENIS