

Deliberation 2020-024 of February 6, 2020 National Commission for Computing and Liberties Nature of the deliberation:

Opinion Legal status: In force Date of publication on Légifrance: Saturday July 11, 2020 Deliberation No. 2020-024 of February 6, 2020 providing an opinion on a draft decree relating to the use by the "Epidemiology of Childhood and Adolescent Cancer" research team (EPICEA) of the National Institute of Health and Medical Research of the national inter-scheme directory of beneficiaries of health insurance for the purpose of ensuring long-term monitoring of the state of health and quality of life of persons suffering from cancer in childhood

(request for opinion no. 19013345)

The National Commission for Computing and Liberties, Seizure by the Ministry of Solidarity and Health of a request for an opinion concerning a draft order relating to the use by the EPICEA research team of the Institute of health and medical research of the national inter-scheme directory of health insurance beneficiaries for the purpose of ensuring long-term monitoring of the state of health and quality of life of people with childhood cancer; Having regard to Convention No. 108 of the Council of Europe for the protection of individuals with regard to automatic processing of personal data; Having regard to Regulation (EU) 2016/679 of the European Parliament and of the Council of April 27, 2016 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC; Having regard to the Social Security Code , in particular its articles L. 161-32 and R. 161-34 to R. 161-38; Having regard to law n° 78-17 of January 6, 1978 as amended relating to data processing, files and freedoms, in particular its articles 64 and following; 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; Considering the decree of October 22, 1996 relating to the National inter-regime directory beneficiaries of health insurance, as well as the deliberation of the National Commission for Computing and Liberties No. 96-070 of September 10, 1996 providing an opinion on the draft decree; Having regard to decision DR 2013-198 of the National Commission for Computing and Liberties authorizing the Institute for Health and Medical Research to implement data processing for the purpose of implementing a common database for the national register of malignant hemopathies in the Child (RNHE) and the National Registry of Solid Tumors in Children (RNTSE) in order to respond best to their objectives in epidemiological research and their health monitoring mission; On the proposal of Mrs Valérie PEUGEOT, commissioner, and after having heard the observations of Mrs Nacima BELKACEM, government commissioner, Issues the following opinion: The Commission was seized on June 27, 2019 for opinion by the Ministry of Solidarity and Health of a draft decree (hereinafter the

draft) relating to the use by the Childhood Cancer Epidemiology research team and adolescents (EPICEA) of the National Institute of Health and Medical Research (INSERM) of the national inter-regime directory of health insurance beneficiaries (hereinafter the RNIAM) as part of the project d COHOPER study (COHort of the PEdiatric cancer Registries) hereafter the study. cancer in childhood, insured p from the National Childhood Cancer Registry (RNCE). The extension of this monitoring into adulthood should allow monitoring of their health and quality of life over the long term, as well as the delivery of adequate and personalized information on the risks of sequelae, their management and the existence of screening and prevention training modules. The RNCE, managed by the EPICEA team under the responsibility of INSERM, contains the data of around 38,000 minors monitored during the first years following their diagnosis on the period 1990-2015. Of these 38,000 minors, 21,000 have now reached adulthood and are concerned by the study. articles 72 and following of the law n° 78-17 of January 6, 1978 modified. The first part of the study, retrospective, will consist of the reconciliation of data from the National Childhood Cancer Registry (RNCE) with data from the National Health Data System (SNDS). The second part of the study, prospective, will allow the realization of surveys on health, medical follow-up and lifestyle with a sample of former registered patients. To carry out the study, the research team EPICEA has the last known address of the persons concerned, recorded in the RNCE when they were minors and which was not updated when they reached majority. Also, the EPICEA team wishes to access the RNIAM in order to collect the current address of these people and, if necessary, the indication of their vital status, with a view to proposing that they take part in the study. Article R 161-37-V of the Social Security Code prohibiting the use of RNIAM for research purposes except in the cases expressly provided for by law and providing that such use may be authorized, in the interest of health of the persons concerned or because of the risk of communicable disease, by an order of the Minister responsible for health, issued on the advice of the National Commission for Computing and Liberties, the Commission received a request for an opinion on this draft decree. On the purpose of the processing and its legal basis: The purpose of the processing envisaged is to allow and organize the use of the RNIAM by the EPICEA research team of INSERM, in order to research and collect the address of the people concerned by the study and t, where applicable, an indication of their vital status. These data should enable the research team to solicit them to propose that they participate in the various aspects of the study (survey by questionnaire and support). To this end, article 1 of the draft decree provides that the INSERM's EPICEA research team is authorized to use the RNIAM in order to obtain, through the organizations providing health insurance benefits, the addresses of the people concerned by the study. The Commission notes that the purpose pursued by the planned

processing is in the interest of the health of the persons concerned, as provided for in the provisions of Article R. 161-37-V of the Social Security Code. On the nature of the data processed: The Commission notes that Article 1 of the draft provides that the RNIAM is consulted in order to collect the addresses of the persons concerned, whereas Article 4 of the draft provides that the personal data collected from the RNIAM and transmitted to the team of r ePICEA research are: surname, first names in the order of civil status, the address of the persons and, where applicable, the indication of death. The Commission notes that Articles 2 and 4 of the draft d decree have been modified in order to specify the data that will be collected in the context of the use of the RNIAM. It nevertheless suggests that Article 1 also mentions first names in the order of civil status and, where indication of death. In addition, article 3 of the draft mentions that the National Health Insurance Fund for Salaried Workers (CNAMTS) consults the health insurance organizations in order to obtain the place of birth of the persons concerned, whereas that this data has already been sent to it by the EPICEA team (article 2 of the draft). The Commission therefore wonders whether it is necessary to collect this data again from the health insurance organisations. consider that the data whose processing is envisaged are adequate, relevant and not excessive with regard to the purpose pursued, in accordance with the provisions of Article 5-1-c) of the General Data Protection Regulation. On information and the rights of individuals :The Commission notes that the draft does not provide for any method of informing data subjects and no method of exercising their rights. The Commission understands that it is not possible to provide individual information to data subjects prior to the consultation of the RNIAM, the purpose of access to this database being precisely to allow INSERM to have their address in order to inform them of the study project. b of the GDPR, the obligation to provide individual information to the data subject may be subject to exceptions in the event that the provision of such information proves impossible, would require disproportionate effort or would be inconvenient. would seriously promise the achievement of treatment goals. In such cases, in accordance with the General Data Protection Regulation, the controller is obliged to take appropriate measures to protect the rights and freedoms, as well as the legitimate interests of the data subject, including by making the information publicly available. .Consequently, the Commission requests that INSERM implement appropriate measures (distribution on the website, posting, etc.) prior to the use of the RNIAM. It also invites INSERM to report on this in the information documents that will be sent individually to the persons concerned in order to suggest that they participate in the various aspects of the study, which must also detail the procedures for exercising the rights of persons. On data security: The Commission notes that the draft does not mention the security measures that will be implemented to ensure data security. technical and organizational

security measures adapted to the risks in accordance with Articles 5-1-f) and 32 of the GDPR. On the retention period of data:

Article 5 of the draft provides that the data will be kept for the duration of the study. Insofar as the duration of the study has not been specified, the Commission requests that the retention period of the data in the context of the processing consisting in the use of the RNIAM is provided for by the decree and set independently of those provided for the different parts of the study, which constitute separate data processing.

For the President,

The Deputy Vice-President, Sophie LAMBREMON