Deliberation 2023-018 of March 9, 2023 National Commission for Computing and Liberties Nature of the deliberation: Other authorization Legal status: In force Date of publication on Légifrance: Friday March 31, 2023 Deliberation n° 2023-018 of March 09, 2023 authorizing the National Agency of public health to implement automated processing of personal data for the purpose of a study on the measurement of the impregnation of the populations of Martinique and Guadeloupe by chlordecone and by other environmental pollutants of interest, entitled "Kannari -2"

(Request for authorization no. 922266)

The National Commission for Computing and Liberties, Seizure by the National Public Health Agency of a request for authorization concerning the automated processing of personal data for the purpose of a study relating to the measurement of the impregnation of populations of Martinique and Guadeloupe by chlordecone and by other environmental pollutants of interest, entitled Kannari-2; Having regard to Regulation (EU) 2016/679 of the European Parliament and of the Council of April 27, 2016 relating to the protection of natural persons at with regard to the processing of personal data and the free movement of such data, and repealing Directive 95/46/EC (general regulation on data protection); Having regard to Law No. 78-17 of January 6, 1978 relating to data processing, files and freedoms, in particular Articles 66, 72 et seq.; Having regard to the favorable opinion of the West III Committee for the Protection of Persons of October 26, 2022; Having regard to the file and its additions; On the proposal by Ms. Valérie PEUGEOT, commissioner, and after having heard the observations of Mr. Benjamin TOUZANNE, government commissioner, Makes the following observations:On the data controllerThe data controller for this study is the National Public Health Agency (ANSP) .On the subcontractorsSeveral subcontractors will be involved in the implementation of this study, in particular the company IPSOS, the regional health observatories (ORS) of Guadeloupe and Martinique, the general health insurance funds (CGSS) of Guadeloupe and Martinique, medical biology laboratories, approved transporters of biological samples, biobanks and assay laboratories. The processing of data by subcontractors must be governed by a contract or a legal act in accordance with Article 28 of the General Data Protection Regulation (GDPR). On the categories of people concerned by the study Subject to the exercise of the right of opposition, this study will include the entire general population aged three years and more, residing in Martinique and mainland Guadeloupe for at least six months, beneficiaries of the sickness branch of the CGSS who integrate the general scheme, of the self-employed, of the agricultural social mutuality (MSA), and of the national establishment for invalids of the Navy (ENIM). On the purpose of the processing and its nature in the public interest other environmental pollutants of interest, entitled "Kannari-2". More specifically, this study

is intended to: describe the levels of impregnation by chlordecone and by other pollutants of interest in the adult populations of Guadeloupe and Martinique; study the evolution of the distribution of the levels of impregnation by chlordecone; describe the levels of impregnation by chlordecone and by other pollutants of interest of the more sensitive population sub-groups (women of childbearing age and children ) or more at risk of elevated chlordecone exposure (agricultural workers and fishermen), and population subgroups of interest (women of childbearing age) and to investigate associated factors. This study will include two components: a pilot phase on 150 people drawn at random in order to evaluate in particular:
the survey system; the relationship between the different phases of the survey; the relationship between the different actors and in particular the subcontractors involved in carrying out the study. a large-scale study, including the estimate is 3,000 participants. This request for authorization concerns both the pilot phase and the large-scale study. The purpose of the processing is determined, explicit and legitimate, in accordance with Article 5.1.b of the GDPR and this processing presents a purpose of public interest, in accordance with article 66.I of the law "Informatique et Libertés" of January 6, 1978 ("Informatique et Libertés" law). On the legality of the processing and the conditions allowing the processing of data concerning HealthThe processing carried out by the ANSP is necessary for the performance of the public interest mission entrusted to it. This processing is, as such, lawful under Article 6.1.e of the GDPR. In addition, this processing, necessary for scientific research purposes, also fulfills the condition provided for in Article 9.2.j of the GDPR allowing the processing of data concerning health. This research project is subject to the provisions of Articles 44.3°, 66.III and 72 et seq. of the "Informatique et Libertés" law, which provide, in the absence of compliance with a reference methodology, that processing for the purposes of research, study or evaluation in the field may only be implemented after authorization from the Commission. On the points of non-compliance with the reference methodology concerned The application file mentions that the treatment envisaged complies with the provisions of the reference methodology MR-001 , with the exception of the nature of the data processed, the recipients of the directly identifying data and the procedures for informing the persons concerned. Apart from these exceptions, this processing must comply with the framework provided for by the reference methodology MR-001. Reuse of data from existing databases The data reused in the context of this study will come from: the CGSS of Guadeloupe and Martinique; from the ENIM. The draw will be carried out by the ANSP from a "beneficiary" database , created specifically for this purpose, containing neither directly identifying data nor data relating to the health of the beneficiaries. Only data that is strictly necessary and relevant to the purposes of the processing should be transmitted by the CGSS and the ENIM to the ANSP. In this respect, filtering will be

carried out upstream of this transmission by the organisations. For the pilot phase, the beneficiary base allowing the drawing of lots must be limited according to the number of people to be selected, in proportion to the number of people who will be randomly drawn during the large-scale study. On the special categories of data processed The collection of surnames, first names, as well as contact details (postal, electronic and telephone) of people is necessary to: avoid confusion between people within the in the same household; providing information to participants; monitoring participants during the study; sending them their results at the end of the study, with regard to their impregnation with chlordecone and other environmental pollutants; carry out the geocoding of the place of residence. Participants are informed of this. Directly identifying data must be processed and transmitted separately from health data and be recorded in a separate database. In addition, only a strictly limited number of authorized persons and subject to professional secrecy will be able to access directly identifying data. E-mails sent to participants must not reveal any information on the real or supposed state of health of the participant. and the rights of individualsAs regards the methods of information:As a preliminary, the surname, first names, and contact details (postal, electronic and telephone) will be collected and processed during a draw for participation in the study based on data from the CGSS of Guadeloupe and Martinique and ENIM. Regarding people likely to be drawn by lot: A derogation from the obligation to provide individual and prior information to study participants is envisaged, under the conditions provided for in article L.1122-1-4 of the public health code (CSP). and Martinique, will be implemented using various paper (flyers, posters, etc.) and electronic (emailings, social networks) media, in particular with: journalists; relay targets (town halls, associations of mayors, associations and organizations local non-governmental organizations, health professionals, unions of fishermen, farmers, producers and sellers of fishing or agricultural products, etc.); partners (local authorities, CGSS of Martinique and Guadeloupe, ORS, etc.). elsewhere, a collective information note will be published on the controller's website. It must include all of the information provided for by the RGPD. These information methods will be carried out before the constitution of the databases by the CGSS of Martinique and Guadeloupe, and of the ENIM allowing the realization of the draw. With regard to persons drawn by lot: At the end of the draw, all participants will receive an individual information note. With regard to underage participants: A derogation from the obligation to inform the two exercise of parental authority is envisaged, under the conditions provided for in article 70 of the law "Informatique et Libertés" in the event of impossibility of informing the second holder of the exercise of parental authority or if he cannot be consulted within a time frame compatible with the methodological requirements specific to carrying out the research. In this case, an information note intended for the other holder of the exercise of parental

authority will be systematically sent to the parent contacted with a view to inclusion and he will be invited to send it to him. Minors participating in the The study will also receive an individual information note. All information notes must include all the information provided for in Article 13 of the GDPR. These information methods are satisfactory with regard to the provisions of the GDPR and the law. data processing and freedoms. Regarding the procedures for exercising rights: In accordance with the provisions of article 74 of the law "data processing and freedoms", individuals have the right to oppose the processing of their data for the purposes of research. They must be informed of this in the collective information note published on the data controller's website. Persons who have exercised their right of opposition by refusing to participate in the study must not be contacted. may exercise their rights with the data protection officer of the data controller throughout the duration of the study. These procedures for exercising rights are satisfactory with regard to the provisions of the GDPR and the Data Protection Act. accessors and recipientsAs part of the implementation of the "Kannari-2" study: ANSP staff members will have access to: the pseudonymised data of all the beneficiaries of the health branch of the Guadeloupe and Martinique CGSS, and of the ENIM in order to carry out the draw of participants; the pseudonymised health data of the participants in order to carry out the analysis of the data for the needs of the study; the members of the IPSOS company will have access to the nominative and health data of the participants to ensure the follow-up of inclusions and the collection of data through the administration of the questionnaires; the members of the ORS of Martinique and Guadeloupe will have access to participants' pseudonymised health data in order to analyze the declarative health data from the questionnaires. The data controller has indicated that the participants' personal data must be collected and processed in order to send them their results at the end of the study. For confidentiality purposes, these results must be sent by the company IPSOS. Documents kept up to date indicate the competent person(s) for the data controller and each subcontractor allowing the authorization to access the data to be issued, the list of persons authorized to access this data, their respective access profiles and the procedures for granting, managing and controlling authorizations. These categories of persons are subject to professional secrecy under the conditions defined by Articles 226-13 and 226 -14 of the Penal Code. The qualification of authorized persons and their access rights must be regularly reassessed, in accordance with the procedures described in the authorization procedure established by the data controller and its subcontractors. On data security and traceability of actionsAs a preliminary, the application file mentions that the planned processing complies with the security measures provided for in MR-001.The data controller has carried out and transmitted in support of the authorization request an analysis of impact relating to data protection specific to the processing

envisaged. This must be updated to take into account the different phases of the study (pilot and large-scale), specify the technical and organizational measures as well as the action plan adopted. Within the framework of the pilot phase, no data from the study will only be hosted on the controller's internal servers. The data will be consolidated and analyzed on the Secure Data Access Center (CASD) platform. For the large-scale study, the Commission notes that the controller's internal servers will comply with the state of art, in particular to security measures equivalent to the requirements mentioned in the data warehouse repository in the field of health. Project spaces must then be provided for any provision, internal or intended for the ORS, any provision or export of non-anonymous data being excluded. If these conditions are not met, accommodation and provision to the CASD will be made. The controller must ensure compliance with security requirements at all stages of the processing carried out by the various participating organizations, including for the paper sheets. Random pseudonyms, dedicated to each type of actor and data flow, are provided for the data flows. Any correspondence table must be deleted as soon as possible after delivery of the individual results to the participants, consolidation of the database and generation of new random pseudonyms for it. For any provision, pseudonyms dedicated to each project space must be generated. Data exchanges will be carried out via encrypted communication channels and ensuring the authentication of the source and the recipient. The encryption algorithms used and the key management procedures must comply with appendix B1 of the general security reference system. The security measures, which must be operational during the implementation of the processing, must meet the requirements provided for by Articles 5.1.f and 32 of the GDPR taking into account the risks identified by the data controller. It will be up to the data controller to carry out a regular reassessment of the risks for the persons concerned and an update, if necessary, of these security measures. On data transfers outside the European Union The data controller provides to transfer certain pseudonymised data of study participants to Canada. Taking into account judgment C-311/18 delivered by the Court of Justice of the European Union on July 16, 2020, the Commission recalls that any transfer of data outside the European Union must be carried out according to the conditions provided for in Chapter V of the GDPR. When this transfer is made to a country that does not provide an adequate level of protection, it must be carried out subject to appropriate guarantees (standard contractual clauses, binding corporate rules, code of conduct, certification mechanism ).In accordance with the provisions of Article 46 of the GDPR, in the absence of an adequacy decision, the controller or the processor may only transfer personal data to a third country if it has provided appropriate safeguards and on condition that the persons concerned have enforceable rights and effective remedies. (EU) 2021/914 of the European Commission of June 4, 2021. It is the

responsibility of the data controller to assess whether the level of protection required by European Union law is respected in Canada so that the guarantees provided by the standard contractual clauses can be respected. Where applicable, these contractual clauses may only constitute appropriate guarantees within the meaning of Chapter V of the GDPR on the condition that they have been supplemented by additional measures in order to guarantee a level of protection essentially equivalent to that provided for in the Space. European economy. The data controller is also required to ensure that the legislation of the third country does not encroach on these additional measures in such a way as to deprive them of effectiveness. On the data retention period With regard to persons not drawn by lot: The data will be kept for a period of three months, then destroyed. With regard to persons refusing to participate in the study: The data will be destroyed at the time of their refusal. With regard to the data of persons participating in the study: the administrative data of identification surname, first name, telephone, electronic and postal contact details will be kept for six months after the transmission of the last results to the participants then they will be destroyed; the biological samples will be kept for five years then destroyed. The study will be kept on an active basis for a period of seven years, then will be subject to intermediate archiving for a period of fifteen years. At the end of this period, the data will be deleted or transferred to the national archives, in accordance with the provisions of the Heritage Code.These data retention periods do not exceed the periods necessary for the purposes for which they are collected and processed, in accordance with the provisions of Article 5.1.e of the GDPR.On the reuse of data and biological samples The constitution of a database associated with a collection of biological samples falls under, except in the case of collection of express consent in accordance with the provisions of the GDPR, the regime of prior formalities provided for by the general provisions of section 3 of chapter III of Title 2 of the "Informatique et Libertés" law for the processing of personal data in the field of health (declaration of compliance with the "health data warehouse" standard or filing of an authorization request). to deliberation no. 2018-327 of October 11, 2018 relating to data protection impact analyses, the processing of health data necessary for the constitution of a long-lasting database associated with a collection of biological samples requires the prior performance of such an analysis.Any new study that would be implemented from the samples and data collected will have to be the subject of formalities with the Commission.Special observationsIn order to correct the selection effects induced by the non- participation of certain people selected at random, the data controller wishes to implement statistical methods for processing selection bias in the Kannari-2 study. This study will be the subject of a separate formality with the Commission. Authorizes, in accordance with this deliberation, the National Public Health Agency to implement the aforementioned processing. President Marie -Laure DENIS