

Sistema Socio Sanitario



Regione
Lombardia

ATS Brescia

Agenzia di Tutela della Salute di Brescia

Sede Legale: viale Duca degli Abruzzi, 15 – 25124 Brescia

Tel. 030.38381 Fax 030.3838233 - www.ats-brescia.it

Posta certificata: protocollo@pec.ats-brescia.it

Codice Fiscale e Partita IVA: 03775430980

DECRETO n. 291

del 18/05/2022

Cl.: 1.1.02

OGGETTO: Accordo di collaborazione (*collaboration agreement*) con il *JRC - Joint Research Centre* della Commissione europea, con Sede a Ispra (VA), ai fini dell'inclusione del Registro Tumori di ATS di Brescia nell'attività di cooperazione e ricerca in campo oncologico promossa da *JRC* e *ENCR* (*European Network of Cancer Registries*) nell'ambito del Sistema Europeo d'informazione sul Cancro (*ECIS*): presa d'atto avvenuta stipula.

**II DIRETTORE GENERALE - Dott. Claudio Vito Sileo
nominato con D.G.R. XI/1058 del 17.12.2018**

Acquisiti i **pareri** del
DIRETTORE SANITARIO
del
DIRETTORE SOCIOSANITARIO
e del
DIRETTORE AMMINISTRATIVO

Dott.ssa Laura Emilia Lanfredini

Dott.ssa Jolanda Bisceglia

Dott.ssa Sara Cagliani



IL DIRETTORE GENERALE

Premesso che:

- il *JRC (Joint Research Centre)* della Commissione Europea e l'*ENCR (European Network of Cancer Registries)* – ente istituito nel 1990 nel quadro del programma UE denominato “L’Europa contro il cancro” – promuovono l’armonizzazione e lo scambio dei dati, a livello europeo, dei vari Registri Tumori, per finalità di ricerca scientifica connessa alla valutazione delle malattie oncologiche, attraverso lo studio e il monitoraggio delle tendenze temporali e geografiche relative a incidenza, prevalenza, mortalità e sopravvivenza associate alle patologie tumorali;
- i suddetti Organismi hanno richiesto ai Registri Tumori, a livello europeo, di trasmettere i dati di incidenza tumorale a partire dall’anno 2013 (in precedenza e fino a tale anno, infatti, i dati erano già stati acquisiti);
- a tal fine, i medesimi Organismi hanno predisposto specifiche procedure per disciplinare la raccolta e la trasmissione dei dati in parola, al fine di assicurarne l’integrità e ogni necessaria tutela inerente a modalità e finalità di trattamento, nel rispetto del GDPR - Regolamento (UE) 2016/676 (Regolamento relativo alla protezione delle persone fisiche con riguardo al trattamento dei dati personali, nonché alla libera circolazione di tali dati) e delle ulteriori normative europee di settore;

Rilevato che:

- requisito essenziale per la partecipazione all’attività di ricerca sopra descritta è la sottoscrizione di un apposito accordo di collaborazione (*collaboration agreement*) con il *JRC - Joint Research Centre* della Commissione europea, con sede a Ispra (VA), Organismo responsabile dello sviluppo e della manutenzione dell'*ECIS - European Cancer Information System* (Sistema Europeo d’informazione sul Cancro), previa registrazione di ciascun Ente detentore di Registro Tumori nella banca dati europea della citata Rete *ENCR*;
- il suddetto accordo di collaborazione individua gli obiettivi del progetto e disciplina ruoli e responsabilità di ciascuna delle Parti contraenti, anche con riguardo alla tutela dei diritti di proprietà intellettuale, nonché alle necessarie garanzie di riservatezza dei dati trattati, come sopra richiamate;
- le attività condotte ai sensi di detto accordo non comportano costi aggiuntivi, essendo espressamente soggette alla disponibilità di fondi, personale e altre risorse, entro i limiti dei programmi e secondo le normative applicabili a ciascun ente aderente;

Considerato che:

- per il tramite della U.O. Epidemiologia, sono state condotte le necessarie interlocuzioni con gli Organismi coinvolti, nonché le preliminari attività istruttorie volte all’esame e all’eventuale stipulazione dell’accordo di cui trattasi;
- in ragione della manifesta rilevanza scientifica della cooperazione in parola e ad esito della valutazione dei termini e delle condizioni del testo convenzionale proposto, si è conseguentemente ritenuto di procedere alla formalizzazione dell’atto di adesione dell’Agenzia al suddetto *collaboration agreement*;

Ritenuto, pertanto, di prendere atto dell’avvenuta sottoscrizione, in data 13.05.2022 (Rep. Contr. ATS n. 256/22), dell’accordo di collaborazione in oggetto, che si allega in copia informatica al presente provvedimento (Allegato A, composto da n. 48 pagine);

Vista la proposta presentata dal Direttore del Servizio Affari Generali e Legali, Dott.ssa Lucia Branca Vergano che, anche in qualità di Responsabile del procedimento, attesta la regolarità tecnica del presente atto;

Dato atto che dal presente provvedimento non derivano oneri per l’Agenzia;



Acquisiti i pareri del Direttore Sanitario, Dott.ssa Laura Emilia Lanfredini, del Direttore Sociosanitario, Dott.ssa Jolanda Bisceglia, e del Direttore Amministrativo, Dott.ssa Sara Cagliani, che attesta, altresì, la legittimità del presente atto;

D E C R E T A

- a) di prendere atto, per le motivazioni in premessa, dell'avvenuta stipulazione, in data 13.05.2022 (Rep. Contr. ATS n. 256/22), dell'accordo di collaborazione (*collaboration agreement*) con il JRC - *Joint Research Centre* della Commissione europea, con Sede a Ispra (VA), ai fini dell'inclusione del Registro Tumori di ATS di Brescia nell'attività di cooperazione e ricerca in campo oncologico promossa da JRC e ENCR (*European Network of Cancer Registries*) nell'ambito del Sistema Europeo d'informazione sul Cancro (ECIS), accordo il cui testo si allega in copia informatica al presente provvedimento (Allegato A, composto da n. 48 pagine);
- b) di precisare che il suddetto accordo ha decorrenza dalla data di avvenuta stipulazione e non prevede limiti di durata, fatta salva la possibilità di recesso con preavviso scritto di almeno tre mesi;
- c) di dare atto che dal presente provvedimento non derivano oneri per l'Agenzia;
- d) di disporre la pubblicazione dei contenuti del presente provvedimento nella sezione "Amministrazione Trasparente" del sito web dell'Agenzia, in conformità al D.Lgs. 33/2013 e ss.mm.ii. nei tempi e con le modalità del PTPC vigente;
- e) di dare atto che il presente provvedimento è sottoposto al controllo del Collegio Sindacale, in conformità ai contenuti dell'art. 3-ter del D.Lgs. n. 502/1992 e ss.mm.ii. e dell'art. 12, comma 14, della L.R. n. 33/2009;
- f) di disporre, a cura del Servizio Affari Generali e Legali, la pubblicazione all'Albo on-line - sezione Pubblicità legale - ai sensi dell'art. 17, comma 6, della L.R. n. 33/2009, e dell'art. 32 della L. n. 69/2009, ed in conformità alle disposizioni ed ai provvedimenti nazionali e comunitari in materia di protezione dei dati personali.

Firmato digitalmente dal Direttore Generale
Dott. Claudio Vito Sileo

COLLABORATION AGREEMENT

(including AGREEMENT ON TRANSFER OF PERSONAL DATA where applicable)

The **Joint Research Centre of the European Commission**, located at Via Enrico Fermi, 2749, I-21027 Ispra (VA), Italy; represented for the purpose of signing this Agreement by Guy van den Eede, Acting Director of Directorate F – Health, Consumers and Reference Material of the Joint Research Centre, duly entitled to sign,

(hereinafter referred to as **‘the JRC’**),

and

Members of the the European Network of Cancer Registry (**‘ENCR’**):

(hereinafter referred to as **‘the Registries’**).

(The list of the Registries is contained in Annex I)

The Registries may be represented for the signature and the implementation of the present Agreement by other duly mandated bodies, such as networks of Registries at regional, national or supranational level.

Hereinafter referred to individually as **‘the Party’** or collectively as **‘the Parties’**.

PREAMBLE

WHEREAS:

- (1) The Joint Research Centre (JRC) of the European Commission is in charge of the development and maintenance of the European Cancer Information System (ECIS) in support of the European Union policies in the area of public health, and in agreement with the responsible Commission department (DG SANTE).
- (2) This activity of the JRC is in line with the objectives of the European Commission to promote cancer registration in Europe according to the following EU policy and strategy documents:
 - Treaty on the Functioning of the European Union, Title XIV (Public Health) Article 168. European Parliament resolution on policy challenges and strategies against women's cancers and related comorbidities (2018/2782)
 - Europe Against Cancer programme: proposal for a plan of action 1987-1989 including a draft Council decision concerning the information of the public and the training of members of the health professions COM(86) 717 final
 - Communication from the Commission concerning a Community action programme on health monitoring in the context of the framework for action in the field of public health (COM 95) 449 final
 - Europe Against Cancer, report from the Commission to the Council on the conclusions of the high level experts and on the state of work in progress at Community level in the fight against cancer, COM(86) 150 final
 - Europe Against Cancer, report from the Commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of the Regions on implementation of the second action plan (1990-1994 COM(95) 356 final
 - Council Recommendation of 2 December 2003 on cancer screening
 - European Parliament Resolution of 10 April 2008 on Combating Cancer in the Enlarged European Union, P6-TA(2008)0121 Council of the European Union
 - Council Conclusions on Reducing the Burden of Cancer, 2876th Employment, Social Policy, Health and Consumers Affairs Council Meeting, Luxembourg, 10 June 2008 Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on Action Against Cancer: European Partnership
 - White Paper "Together for Health: A Strategic Approach for the EU 2008-2013" (COM 2007 (0630) final).
- (3) The aim of the ECIS is to provide indicators that quantify cancer burden across Europe and ECIS builds on existing data and cooperation of cancer registries affiliated with the European Network of Cancer Registries (ENCR).

- (4) The ENCR was established 1990 within the framework of the EU's Europe Against Cancer programme initiated by the European Council Heads of State and Government, and a committee of cancer experts. By defining data coding and collection standards, the ENCR works to ensure levels of quality allowing accurate comparison of cancer-Registry data across Europe for the purpose of population-based cancer surveillance and epidemiological research. As well as contributing to the regular dissemination of information on cancer incidence and mortality in Europe, the ENCR also promotes collaboration between cancer registries, via training of cancer Registry personnel and organisation of scientific conferences. Members of the ENCR include population-based cancer registries operating in countries within the UN geographical definition of Europe plus Cyprus¹.
- (5) JRC is one of directorate-generals of the European Commission and within its scientific and technical capacity supports EU policies with independent evidence throughout the whole policy cycle.
- (6) Directorate F (Health, Consumers and Reference Materials) of the JRC via its Unit F.1 (Health in Society), which is based in Ispra, Italy, has the primary responsibility for developing and maintaining ECIS. JRC F.1 also acts as the ENCR secretariat.
- (7) The JRC and the ENCR promote harmonisation of cancer registries' data, as the input source for the assessment of cancer burden. The JRC supports the ENCR in the harmonisation of data and registration processes to strengthen the basis for monitoring the cancer burden, the JRC has developed and maintains the ECIS web site, which provides statistical indicators on temporal and geographic trends relating to cancer incidence, mortality, prevalence and survival.
- (8) The support of JRC to ENCR may involve transfer of personal data (individual cancer data), including data which have undergone pseudonymisation, from the registries to the JRC and subsequent processing by the JRC for scientific research purposes to support EU policies. In accordance with Recital 157 GDPR, by coupling information from registries, researchers can obtain new knowledge of great value with regard to widespread medical conditions such as cancer. On the basis of registries, research results can be enhanced, as they draw on a larger population. Research results obtained through registries provide solid, high-quality knowledge which can provide the basis for the formulation and implementation of knowledge-based policy, improve the quality of life for a number of people and improve the efficiency of social services. In order to facilitate research, personal data can be processed for scientific research purposes, subject to appropriate conditions and safeguards set out in Union or Member State law.
- (9) Through joint efforts of the ENCR and its member cancer registries with the JRC, new approaches can be identified and developed in the areas of harmonisation of cancer registries' data as the input source for the assessment of cancer burden, thus working to the mutual benefit of both organisations in the achievement of their objectives.
- (10) The Parties have expressed their mutual desire to co-operate in the field of cancer data harmonisation for the assessment of cancer burden at European level, and are for that

¹ <https://encr.eu/registries-network#inline-nav-3>

purpose signing this Collaboration Agreement. This Agreement constitutes at the same time an Agreement on Transfer of personal data to regulate the respective obligations of the Parties in accordance with applicable data protection legislation with regard to the processing of personal data transferred from the Registries to the JRC pursuant to it.

THE PARTIES HAVE AGREED AS FOLLOWS:

ARTICLE 1 – OBJECTIVES OF THIS COLLABORATION AGREEMENT

- 1.1** The general objective of this Collaboration Agreement is to support and contribute to the achievement of the common goal of the JRC and the ENCR Registries. This collaboration takes place in the frame of and is subsidiary to the ECIS - European Cancer Information System being developed at the JRC in agreement and close collaboration with DG SANTE.
- 1.2** This Collaboration Agreement will, in particular, have the following objectives:
 - a) To secure a sustainable solution for the continuation of the ENCR activities in support of cancer registration in Europe.
 - b) To support European-level coordination of the ENCR activities, coordinated by a newly established JRC-ENCR Management Committee.
 - c) To obtain the scientific data needed for the ECIS.
 - d) To promote mutual interest and exchange of experience in understanding and resolving issues between the Parties.
- 1.3** In order to fully achieve the objectives of this Collaboration Agreement, the Parties will take the following actions:
 - a) Joint identification of harmonisation issues to be investigated and the development of innovative and cost-effective approaches to improve harmonised computation, visualisation and dissemination of cancer burden in Europe.
 - b) Dialogue on matters of cancer registries' data harmonisation and cancer burden assessment, exploring possibilities for developing research projects of mutual interest.
 - c) Joint participation in the execution of personnel development and training programmes.
 - d) Maintenance and further development of the ECIS infrastructure to host and process population-based cancer registries' data, and compute/visualise derived cancer burden indicators.
 - e) Joint establishment of training programmes in various areas, for example, cancer registration, cancer coding, statistical analysis for cancer registries.
 - f) Support the training of scientists, engineers and technical experts, for example, through the exchange of personnel.

- g) Harmonisation of established analytical procedures and promotion of these methods to end-users internationally.
- h) Joint work aimed at implementing research projects of mutual interest.
- i) Participation in the execution of on-going programmes, projects and related activities of mutual interest to the Parties.
- j) Identification of any other action deemed appropriate to achieve the objectives of this Collaboration Agreement.

ARTICLE 2 – RESPONSIBILITIES AND ROLES OF PARTIES

2.1 Responsibilities and role of the JRC with regard to its role as ECIS manager:

- a) maintains and further develops a centralised database with cancer occurrence data according to established coding methodologies;
- b) ensures data security/safety including the process of data transmission in accordance with Annex II;
- c) manages and analyses data including data checking, standardisation, quality assessment, validation, statistical analysis and monitoring for further reporting and dissemination;
- d) communicates with the Registries and gives feedback on data-related issues and results of the monitoring;
- e) analyses data for monitoring data compliance to the required standards, giving feedback to the Registries on results of the monitoring;
- f) manages the ECIS web application - administration, maintenance, updates, development;
- g) coordinates and supports ECIS dissemination activities (cancer factsheets, scientific papers, EC technical reports and publications);
- h) manages requests for individual and aggregated cancer data access and use, in agreement with the policy decided by the JRC-ENCR Management Committee; in accordance with Annex II, Section 5.1, the transmission of individual cancer data to third parties will need to be approved by the Registry at the origin of the individual cancer data to be transmitted.
- i) establishes and maintains relations with other organisations within the remit of its role;
- j) supports actions aimed at adding value to the ENCR data through: integration into larger health information systems, dissemination of public health indicators to policy makers for decisions on primary/secondary/tertiary prevention;

- 2.2** Responsibilities and role of the JRC with regard to its role as host of the ENCR Secretariat:
- a) coordinates the activities of the Network in collaboration with the JRC-ENCR Management Committee;
 - b) processes and evaluates new applications for ENCR membership;
 - c) organises meetings of the JRC-ENCR Management Committee and meetings of ENCR-JRC working groups;
 - d) organises the ENCR Scientific Meetings and ENCR General Assemblies;
 - e) organises scientific meetings and workshops;
 - f) coordinates and supports dissemination activities of the network (ENCR website, periodic ENCR newsletters, leaflets);
 - g) offers support to the individual registries (e.g. on IT issues, on data harmonisation questions, etc.);
 - h) coordinates scientifically and technically the development of JRC-ENCR yearly training agendas, and supports the organisation of trainings;
 - i) supports and promotes the role of Registries as primary data providers;
 - j) disseminates the output of data analyses in agreement with the JRC-ENCR Management Committee;
 - k) promotes the registration of cancer across Europe.
- 2.3** Where the JRC processes personal data, in particular individual cancer data, it shall do so in full compliance with Annex II. Annex II shall not apply to the transfer to and further processing by JRC of anonymous information or aggregated cancer data.

ARTICLE 3 – RESPONSIBILITIES AND ROLE OF THE REGISTRIES

- 3.1** Each Registry undertakes to:
- a) transmit data, in the form of individual cancer data or aggregated cancer data, to the JRC following specific Calls for data issued in accordance with the established calendar for data transmission, in full compliance with applicable law, in particular data protection legislation applicable to the Registry when individual cancer data is transmitted. The Calls for data will follow detailed protocols and will define the specific purposes for the processing of individual or aggregated cancer data, as well as the processing operations to be performed.
 - b) provide feedback on the data processed by the JRC as ECIS manager and on the output of data analysis; collaborate with the JRC for data validation;

- c) contribute to the analysis and interpretation of the monitoring results and reports related to the data they provided;
- d) obtain and maintain ethical approvals if required by the applicable law at their site.

Each Registry may implement its tasks under the present Agreement as listed above directly or indirectly through other bodies duly mandated to represent the Registry for those purposes. Accordingly, networks of Registries at regional, national or supranational level may be entitled to transmit data to JRC on behalf of Registries where they have received a mandate to do so in full compliance with applicable legislation.

3.2 Further, each Registry warrants and undertakes as follows:

- a) It processes personal data relating to individuals with cancer in full compliance with applicable data protection legislation and ensures, in particular, that the data
 - Are processed lawfully;
 - Are collected for specified, explicit and legitimate purposes and not further processed in a way that is incompatible with those purposes; whereby further processing for scientific research purposes shall not be considered to be incompatible with the original purposes and shall be subject to appropriate safeguards;
- b) It will provide information to the JRC as necessary to demonstrate compliance with applicable data protection legislation.

ARTICLE 4: GENERAL COMMITMENTS OF THE PARTIES

4.1 Duty to inform and contractual loyalty:

The Parties undertake to inform each other as soon as possible of any matter or event related to the activities covered by this Agreement, which they may be aware of and which may be of interest to the other Parties and to the proper functioning of the ENCR and the ECIS activities. Communication shall take place regularly at meetings of the JRC-ENCR Management Committee.

4.2 Hosting members of staff:

Where staff members of one of the Parties are hosted at the offices of another Party in order for the Parties to collaborate on the development of the ENCR activities and ECIS:

- this shall be subject to prior written agreement between the Parties in question, on the understanding that all costs relating to the secondment shall be borne by the original employer;
- the staff members in question shall follow the internal rules and any general or specific rules in force relating to confidentiality, health and safety in the workplace and any guidelines which they may be notified of by the project manager of the hosting Party.

In any event, hosted members of staff shall remain under the hierarchical authority of their original employer who shall satisfy all legal requirements in respect of their social insurance and cover.

- 4.3** All provisions of this Collaboration Agreement apply without prejudice to the applicable law, including without limitation the law governing the right of public access to documents; as well as applicable data protection law. For the avoidance of doubt, nothing in this Agreement can be construed as an obligation for a Registry to transmit cancer data if the Registry deems this transfer to be in violation of the law applicable to that Registry. In such case, the Registry shall notify JRC thereof without undue delay and may refuse or delay the data transfer until both JRC and the Registry are satisfied that the transfer is not in violation of the law. Neither Party can claim any damages or breach of this Collaboration Agreement in cases where the other Party acts according to its obligations resulting from the applicable law.

ARTICLE 5 – LIABILITY

- 5.1** Any loss, damage or injury of non-nuclear origin suffered by one Party in connection with the performance of this Collaboration Agreement or the specific agreement shall be borne exclusively by it. If the loss, damage or injury is caused by a person invited by one Party, as described in Article 4.2, the sending Party will be liable for it.
- 5.2** Each Party shall be exclusively liable for any loss, damage or injury of non-nuclear origin caused by its personnel to third parties, arising out of the performance of this Collaboration Agreement or the specific agreement.
- 5.3** Each Party shall indemnify the other Party for all liability in respect of any action for damages brought by third parties and caused by their respective personnel in the course of the performance of this Collaboration Agreement or the specific agreement.
- 5.4** Any liability for loss, damage or injury of nuclear origin will be determined by the legislation of the state in which the installation, which is at the origin of the loss, damage or injury, is located.

ARTICLE 6 – COORDINATION

- 6.1** The Parties shall establish a JRC-ENCR Management Committee to co-ordinate the activities listed under Article 2. The JRC-ENCR Management Committee shall meet at least three times a year, in person or via videoconference.
- 6.2** The JRC-ENCR Management Committee shall consist of members of the ENCR Steering Committee, plus 2 representatives from the JRC.
- 6.3** Role of the JRC-ENCR Management Committee:
- a) Prepares and takes decisions on the JRC-ENCR activities under this Agreement, with the ultimate aim to support the ECIS.
 - b) Decides on membership criteria, including applications for membership.

- c) Facilitates the discussions between the Registries and JRC as ECIS manager concerning the execution of the activities under this Agreement.
- d) Decides on applications for additional meetings, workshops and working groups.
- e) Decides on applications for specific scientific projects and studies regarding protocol, data and authorship.
- f) Establishes policies and adopts documents related to the JRC-ENCR Management Committee.
- g) Supports and collaborates the JRC for the activities listed in Article 2.1 and 2.2.
- h) Supports and collaborates with the JRC for all other matters related to the activities under this Agreement.

Decisions of the JRC-ENCR Management Committee are taken by consensus.

- 6.4** Notifications and correspondence under this Collaboration Agreement shall be sent to the contact persons listed in Annex I. The Registries shall communicate to the JRC in writing any changes with regard to the above-mentioned contact persons. Such changes do not require signing formal amendments to the present Collaboration Agreement.

ARTICLE 7 – FUNDS

- 7.1** All activities conducted pursuant to this Collaboration Agreement or the specific agreement shall be subject to the availability of funds, personnel and other resources as well as to the applicable laws and regulations, policies and programmes of each Party.
- 7.2** Each Party shall bear the cost of any expenditure it incurs relating to the performance of its tasks under this Collaboration Agreement or the specific agreement. There will be no transfer of money between the Parties in connection with this Collaboration Agreement or the specific agreement.

ARTICLE 8 – INTELLECTUAL PROPERTY RIGHTS

- 8.1.** Intellectual Property (IP), and all rights pertaining thereto, created in and for the performance of this Collaboration Agreement shall belong to the Party whose Personnel created it. The owning Party shall have the right to use, exploit, assign or dispose of such IP at its own will and discretion, unless otherwise provided for in this Collaboration Agreement.
- 8.2.** The Parties shall put in place appropriate means to ensure their ownership of or rights in such IP to the extent necessary for the exercise of their duties and obligations under this Collaboration Agreement, subject to the maximum achievable extent under the applicable law.

8.3. Each Registry licenses to JRC any IP rights it may have on the data it transfers to the JRC under this Collaboration Agreement, on a non-exclusive, non-transferable, royalty-free, perpetual basis. JRC may use the data transferred to it by each Registry for all purposes necessary for the performance of this Collaboration Agreement. The rights licensed to JRC to use the data include the rights to reproduce, store, modify, aggregate, compile and create derivative works, notably to produce statistical indicators, reports and studies on cancer burden as well as specific scientific projects and studies referred to in Art. 6.3 (e). Whereas the applicable data protection legislation does not concern the processing of anonymous information or aggregated data, including for statistical or research purposes, JRC may disclose to third parties information on individual cancer occurrence(s) at patient level rendered anonymous in such a manner that the data subject is no longer identifiable, or aggregated cancer data, subject to the approval by the Registry at the origin of the information to be transmitted. The foregoing is without prejudice to the provisions of Article 8.4.

8.4 To the extent permitted by law, JRC acquires ownership of the IP rights on the results obtained from the activities it performs under Article 8.3. Such results may include aggregated data, reports, statistical indicators, scientific projects and studies on cancer burden.

The JRC may use the results as relevant for the performance of this Collaboration Agreement as set out in Sections 2.3/IV and 2.3/V of Annex II for processing of individual cancer data; or results obtained from similar activities performed on aggregated cancer data. Provided the results do not constitute personal data, the rights of JRC on the results include the rights to publish, display, disseminate, communicate to the public and make the results publicly available in any language, by appropriate means, including on the European Union websites.

Notwithstanding the provisions of the preceding paragraph, the JRC may publish, disseminate, make publicly available, or disclose to a third party the results it obtains from the specific scientific projects and studies referred to in Art. 6.3 (e) only with prior written consent of the Management Committee on the manner, timing and contents of such disclosure, and provided the results do not constitute personal data. Consent for the foregoing may not be unreasonably withheld.

8.5 In case the collaboration performed under this Collaboration Agreement leads to the creation of results in the form of scientific, technical or academic publications, conference proceedings, reports, and similar written work authored through the involvement of the Personnel of both Parties, the Parties undertake to respect each other's rights, moral or economic, and to duly acknowledge and reference the authors and contributors.

8.6 The provisions of this Article shall remain valid and legally enforceable for the duration of the IP rights resulting from the performance of this Collaboration Agreement.

ARTICLE 9 – CONFIDENTIALITY

9.1 The Parties undertake to keep confidential any information, documentation, data, reports referred to in Article 6 that has been declared as confidential, or any other material

communicated to them by the other Party (i) as confidential or (ii) the disclosure of which may clearly be prejudicial to the other Party, until the information legitimately becomes publicly available through other parties or through work or actions lawfully performed outside (not based on activities under this Collaboration Agreement) or has been made available to the receiving Party by another party without any confidentiality restrictions. This confidentiality obligation applies also to information communicated orally when such information shall be kept confidential, for instance in the context of information exchange through seminars and workshops.

- 9.2** Confidentiality of information exchanged orally or in writing in connection with this Collaboration Agreement shall be maintained for a period of five years after its expiry or termination. Notwithstanding the foregoing, any Party may indicate when communicating information to the other Party that the confidentiality of such information shall be maintained even after the said five-year period.

ARTICLE 10 – APPLICABLE LAW AND SETTLEMENT OF DISPUTES

- 10.1** This Agreement shall be governed and interpreted

- a) For legal aspects relating to the protection of natural persons with regard to the processing of personal data and on the free movement of such data;
 - i. With regard to processing by each Registry: data protection legislation applicable to the Registry; for Registries in the European Economic Area, such legislation is the GDPR² and national provisions of adapting the application of the GDPR in accordance with Art. 6(2) thereof.
 - ii. With regard to processing by the JRC: the EUDPR³.
- b) For other legal aspects, by the law of the European Union, complemented, where necessary, by the substantive law of Italy.

- 10.2** Parties shall seek to settle any dispute, controversy or claim arising out of or in connection with this Collaboration Agreement through amicable negotiations. Such effort shall be deemed to have failed when one of the Parties so notifies the other in writing.

- 10.3** If the Parties fail to settle their differences through amicable negotiations, each Party may initiate proceedings before the Court of Justice of the European Union in Luxembourg.

² Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (OJ L 119, 4.5.2016, p. 1).

³ Regulation (EU) 2018/1725 of the European Parliament and of the Council of 23 October 2018 on the protection of natural persons with regard to the processing of personal data by the Union institutions, bodies, offices and agencies and on the free movement of such data, and repealing Regulation (EC) No 45/2001 and Decision No 1247/2002/EC (Text with EEA relevance.) ([OJ L 295, 21.11.2018, p. 39–98](#)).

ARTICLE 11 – ENTRY INTO FORCE AND DURATION

- 11.1** This Collaboration Agreement shall enter into effect between the JRC and each Registry when it has been signed by the JRC and by that Registry. The provisions of Article 6 on Coordination and Art. 12 on Accession of a new Party shall enter into effect upon signature of the JRC and at least 7 Registries.
- 11.2** This Collaboration Agreement is concluded for a period of 4 (four) years from said date. It will be automatically extended for further periods of 4 years unless terminated or modified in accordance with the following paragraphs; or unless national legislation prevents any Registry from extending the Collaboration Agreement. In this latter case, the Registry in question shall inform the JRC accordingly at least 6 months before the expiry of the Collaboration Agreement.
- 11.3** This Collaboration Agreement may be amended only by written agreement signed by the duly authorised representatives of the Parties.
- 11.4** Each Party may terminate its participation in this Collaboration Agreement at any time upon three months prior written notice giving reasons for doing so. This shall inter alia be the case where research programmes and budget allocations are no longer compatible with the continuation of the working relationship, procedure or work programme.
- 11.5** If a Party decides to terminate this Collaboration Agreement, such termination shall be notified to the JRC who shall inform other Parties about the termination notice. At the end of the three-month period from the date of notification, this Collaboration Agreement shall cease to have legal effects between the Party which decides termination and the other Parties to this Collaboration Agreement. However, the Parties shall continue to be bound by their obligations under the Collaboration Agreement with regard to the processing of personal data transferred before that date. In particular, where a Registry terminates this Collaboration Agreement, it shall not request JRC to delete individual cancer data that the Registry had transferred before termination. Accordingly, JRC may continue to process individual cancer data previously transferred in accordance to the provisions of this Collaboration Agreement, without prejudice to obligations to erase personal data or restrict processing in accordance with applicable data protection legislation.

ARTICLE 12 – ACCESSION OF A NEW PARTY

Following the approval of the JRC-ENCR Management Committee, an entity becomes a Party to the Collaboration Agreement upon signature of the accession document (Annex III) by the new Party and the JRC. Such accession shall have effect from the date identified in the accession document.

The following Annexes shall form an integral part of this Agreement:

- Annex I: List of Registries
- Annex II: Protection of personal data transferred by the Registries to the JRC
- Annex III: Accession Document

Signed in the English language.

The Parties hereby sign the Collaboration Agreement No. 36271 (including Agreement on Transfer of Personal Data where applicable) between the Joint Research Centre of the European Commission and Members of the the European Network of Cancer Registry.

The Joint Research Centre of the European Commission

Done in Ispra on

Signature:

Qualified electronic signature by:

GUY LOUIS M VAN DEN EEDE

Date: 2022-04-02 14:25:04 +02:00

Guy van den Eede

Acting Director

Directorate F – Health, Consumers and Reference Materials

Joint Research Centre

For the _____

Done in _____ on _____

Signature: _____

Firmato da:

CLAUDIO VITO SILEO

Codice fiscale: SLICDV61P13A794E

Organizzazione: NON PRESENTE

Valido da: 03-12-2021 15:33:50 a: 03-12-2024 02:00:00

Certificato emesso da: InfoCert Qualified Electronic Signature CA 3, InfoCert S.p.A., IT

Riferimento temporale 'SigningTime': 13-05-2022 14:40:25

Motivo: Approvo il documento

ANNEX I

LIST OF REGISTRIES

1. Austria, Austrian National Cancer Registry (ENCR Registry code EUAT999AA9)
Dr. Monika Hackl
Bundesanstalt Statistik Österreich
Guglgasse 13
1110 Wien, Austria
2. Austria, Austrian Brain Tumour Registry (ENCR Registry code EUAT999BR9)
Prof. Johannes Hainfellner
Institute of Neurology, Medical University of Vienna
Waehringer Guertel 18-20
1090 Vienna, Austria
3. Austria, Carinthian Cancer Registry (ENCR Registry code EUATCARAA9)
Dr. Johann Klocker
Institut für Strahlentherapie und Radioonkologie, Klinikum - Klagenfurt am Wörthersee
Feschnigstraße 11
9020 Klagenfurt am Wörthersee, Austria
4. Austria, Landes Salzburg Tumor Registry (ENCR Registry code EUATSALAA9)
Dr. Richard Greil
Müllner Hauptstrasse 48
5020 Salzburg, Austria
5. Austria, Tyrol Cancer Registry (ENCR Registry code EUATTYRAA9)
Prof. Helmut Mühlböck
University Hospital Innsbruck
Anichstraße 35
6020 Innsbruck, Austria
6. Austria, Vorarlberg Cancer Registry (ENCR Registry code EUATVORAA9)
Dr. Alois Lang
Rheinstrasse 61
6900 Bregenz, Austria
7. Belgium, Belgian Cancer Registry (ENCR Registry code EUBE999AA9)
Dr. Liesbet Van Eycken
Koningsstraat/Rue Royale 215 Box 7
1210 Brussels, Belgium
8. Bosnia and Herzegovina, Cancer Registry Republika Srpska (ENCR Registry code TCBASRPAA9)
Prof. Zivana Gavric
Department of Social medicine

The Public Health Institute of Republika Srpska, Faculty of Medicine, University of Banja Luka
Jovan Ducic 1
78000 Banja Luka, Bosnia and Herzegovina

9. Bulgaria, Bulgarian National Cancer Registry (ENCR Registry code EUBG999AA9)
Zdravka Valerianova
National Oncological Hospital
Plovdivsko Pole Street, 6
1756 Sofia, Bulgaria
10. Croatia, Croatian National Cancer Registry (ENCR Registry code EUHR999AA9)
Dr. Mario Sekerija
Croatian National Institute of Public Health
Rockefeller street 7
10 000 Zagreb, Croatia
11. Cyprus, Cyprus Cancer Registry (ENCR Registry code EUCY999AA9)
Dr. Vasos Scoutellas
Health Monitoring Unit
Ministry of Health
1 Prodromou Street & 17 Chilonos Street
1448 Lefkosia, Cyprus
12. Cyprus, North Cyprus Cancer Registry (ENCR Registry code EUCYNCYAA9)
Dr. Mevhibe Hocaoglu
Bedreddin Demirel Squire No. 142
Nicosia, Cyprus
13. Czechia, Czech National Cancer Registry (ENCR Registry code EUCZ999AA9)
Dr. Ladislav Dušek
Institute of Health Information & Statistics of the Czech Republic
Palackého nám. 4
128 01 Praha, Czechia
14. Denmark, The Danish Cancer Registry (ENCR Registry code EUDK999AA9)
Maya Christel Milter
National Institute for Health Data and Disease Control
Artillerivej 5
Copenhagen S, DK-2300, Denmark
15. Estonia, Estonian Cancer Registry (ENCR Registry code EUEE999AA9)
Dr. Margit Mägi
National Institute for Health Development
Hiiu 42
11619 Tallinn, Estonia

16. Faroe Islands, The Faroese Cancer Registry (ENCR Registry code ACFO999AA9)
Dr. Margit Stórá
Landssjúkrahúsið
Att. Sæunn Ólavsdóttir Hansen, koordinator, Medicinsk center J. C. Svabosgøta 43
FO-100 Tórshavn, Faroe Islands
17. Finland, Finnish Cancer Registry (ENCR Registry code EUFI999AA9)
Dr. Nea Malila
Institute for Statistical and Epidemiological Cancer Research
Unioninkatu 22
00130 Helsinki, Finland
18. France, National Registry of Childhood Haematological Malignancies (ENCR Registry code EUFR999HE1)
Dr. Jacqueline Clavel
INSERM UMR-S 1018CESP - Eq 6 - Equipe d'Epidémiologie Environnementale des Cancers
Institut National de la Santé et de la Recherche Médicale
16, av. Paul Vaillant-Couturier
94807 Villejuif Cedex, France
19. France, National Registry of Mesothelioma (ENCR Registry code EUFR999ME9)
Prof. Françoise Galateau-Sallé
University Hospital - Pathology Department
CHU de Caen, Avenue Cote de Nacre
14033 CAEN cedex 9, France
20. France, Bas-Rhin Cancer Registry (ENCR Registry code EUFRBRHAA9)
Prof. Michel Velten
Laboratoire d'Epidémiologie et de Santé Publique
Université de Strasbourg, Faculté de Médecine
4 rue Kirschleger
67085 Strasbourg, France
21. France, Bourguignon Digestive Cancer Registry (ENCR Registry code EUFRBURDI9)
Dr. Anne-Marie Bouvier
7 boulevard Jeanne d'Arc
21079 Dijon cedex, France
22. France, Calvados General Cancer Registry (ENCR Registry code EUFRCALAA9)
Dr. Anne-Valérie Guizard
Centre François Baclesse
Avenue du Général Harris
14021 Caen cedex, France
23. France, Calvados Registry of Digestive Tumours (ENCR Registry code EUFRCALDI9)
Dr. Guy Launoy
Cancers et Populations ER13 INSERM
Faculté de Médecine

Avenue Côte de Nacre
14032 Caen cedex, France

24. France, Cote d'Or Breast and Gynaecologic Cancer Registry (ENCR Registry code EUFRCOTBG9)
Dr. Patrick Arveux
Centre Universitaire d'Epidémiologie de Population
Faculté de Médecine
7, Bd Jeanne d'Arc
21000 Dijon, France
25. France, Cote d'Or Hemopathy Registry (ENCR Registry code EUFRCOTHE9)
Prof. Marc Maynadié
Equipe d'Accueil 4184
Faculté de Médecine
B.P. 879007 boulevard Jeanne d'Arc
21079 Dijon CEDEX, France
26. France, Doubs and Belfort Territory Cancer Registry (ENCR Registry code EUFRDOBAA9)
Dr. Anne Sophie Woronoff
Registre des Tumeurs du Doubs et du Territoire de Belfort, CHRU Besançon
2 Place Saint Jacques
25030 Besançon Cedex, France
27. France, Finistere Registry of Digestive Tumours (ENCR Registry code EUFRFINDI9)
Prof. Michel Robaskiewicz
CHRU MORVAN
6 avenue Foch, Bât 1, 1er étage
29609 Brest, France
28. France, Gironde Cancer Registry (ENCR Registry code EUFRGIRAA9)
Dr. Gaëlle Coureau
Université Bordeaux Segalen, ISPED
146 rue Léo Saignat
33076 Bordeaux cedex, France
29. France, Haematological Malignancies Registry of Gironde (ENCR Registry code EUFRGIRHE9)
Dr. Alain Monnereau
Institut Bergonié
229 Cours de l'Argonne
33076 Bordeaux, France
30. France, Cancer registry of tumours on the nervous system in Gironde (ENCR Registry code EUFRGIRNS9)
Dr. Isabelle Baldi
Equipe Santé Travail Environnement
Centre INSERM U897, Institut de Santé Publique, d'Epidémiologie et de Développement (ISPED) - Université Victor Segalen
146, rue Léo Saignat

33076 Bordeaux, France

31. France, Herault Cancer Registry (ENCR Registry code EUFRHERAA9)
Dr. Brigitte Tretarre
Bâtiment Recherche - Parc Euromédecine, 208 rue des Apothicaires
34298 Montpellier cedex 5, France
32. France, Haut-Rhin Cancer Registry (ENCR Registry code EUFRHRHAA9)
Dr. Karima Hammas
ARER68 - GHRMSA
87 avenue d'Altkirch, BP1070
68051 Mulhouse Cedex, France
33. France, Isere Cancer Registry (ENCR Registry code EUFRISEAA9)
Dr. Marc Colonna
CHU - Pavillon E
38043 Grenoble Cedex 9, France
34. France, Lille Area Cancer Registry (ENCR Registry code EUFRLILAA9)
Dr. Sandrine Plouvier
GCS-C2RC
CHRU de Lille, Hôpital Calmette - Pavillon Breton
Boulevard du Professeur Jules Leclercq
59037 Lille CEDEX, France
35. France, Limousin Cancer Registry (ENCR Registry code EUFRLIMAA9)
Dr. Nathalie Leone
Hôpital Le Cluzeau
23 avenue Dominique Larrey
87042 Limoges cedex, France
36. France, Pays de la Loire Cancer Registry (ENCR Registry code EUFRLOIAA9)
Dr. Florence Molinié
EPIC-PL
CHU NANTES
50 route de Saint-Sébastien
44093 Nantes Cedex 1, France
37. France, Marne-Ardenne Registry of Thyroid Cancer (ENCR Registry code EUFRMADTH9)
Dr. Claire Schvartz
Institut Jean-Godinot, Centre Regional de Lutte Contre le Cancer de Reims
1 Rue de Général Koenig
51056 Reims cedex, France
38. France, Manche Cancer Registry (ENCR Registry code EUFRMANAA9)
Simona Bara
Unité Fonctionnelle No. 0323

Centre Hospitalier Public du Cotentin
46, rue du Val de Saire
50102 Cherbourg-Octeville cedex, France
s.bara@ch-cotentin.fr

39. France, Lower Normandy Hemopathy Registry (ENCR Registry code EUFRNOBHE9)
Dr. Xavier Troussard
Unité Fonctionnelle Hospitalo-Universitaire n° 0350
Centre Hospitalier Universitaire
Avenue Georges Clémenceau
14033 Caen CEDEX 9, France

40. France, Poitou-Charentes Cancer Registry (ENCR Registry code EUFRPOCAA9)
Dr. Gautier Defossez
Cancer Epidemiology Unit
Faculty of Medicine and Pharmacy at Poitiers Teaching Department
6 rue de la Milétrie BP 199
86034 POITIERS CEDEX, France

41. France, Somme Cancer Registry (ENCR Registry code EUFRSOMAA9)
Dr. Bénédicte Lapôtre-Ledoux
Registre du cancer
CHU Nord, Bât. de Santé publique
place Victor Pauchet
80054 Amiens cedex 01, France

42. France, Tarn Cancer Registry (ENCR Registry code EUFRTARAA9)
Dr. Pascale Grosclaude
81001 Albi Cedex, France

43. Germany, German Childhood Cancer Registry (ENCR Registry code EUDE999AA1)
Dr. Peter Kaatsch
Institute for Medical Biostatistics, Epidemiology and Informatics (IMBEI), University Medical Center Mainz
55101 Mainz, Germany

44. Germany, Cancer Registry of Baden-Württemberg (ENCR Registry code EUDEBADAA9)
PD Dr. Volker Arndt
Deutsches Krebsforschungszentrum (DKFZ) Heidelberg
Im Neuenheimer Feld 581
D-69120 Heidelberg, Germany

45. Germany, Population Based Cancer Registry Bavaria (ENCR Registry code EUDEBAVAA9)
Dr. Martin Meyer
Bayerisches Landesamt für Gesundheit und Lebensmittelsicherheit Sachgebiet GE5
Zentrum für Krebsfrüherkennung und Krebsregistrierung
Schweinauer Hauptstr. 80
90441 Nürnberg, Germany

46. Germany, Munich Cancer Registry (ENCR Registry code EUDEBAYAA9)
Prof. Jutta Engel
Klinikum Großhadern
Ludwig-Maximilians-Universität (LMU)
Marchioninistr. 15
81377 München, Germany
47. Germany, Common Cancer Registry of the Federal States Berlin, Brandenburg, Mecklenburg-Vorpommern, Sachsen-Anhalt and the Free States Saxony and Thuringia (ENCR Registry code EUDEBBEAA9)
Dr. Roland Stabenow
Office of Registration
Common Cancer Registry
Brodauer Str. 16/22
12621 Berlin, Germany
48. Germany, Bremen Cancer Registry (ENCR Registry code EUDEBREAA9)
Dr. Sabine Luttmann
Leibniz-Institute for Prevention Research and Epidemiology - BIPS GmbH
Achterstraße 30
28359 Bremen, Germany
49. Germany, Hamburg Cancer Registry (ENCR Registry code EUDEHAMAA9)
Dr. Stefan Hentschel
Billstraße 80,
20539 Hamburg, Germany
50. Germany, Hessen Cancer Registry (ENCR Registry code EUDEHESAA9)
Dr. Soo-Zin Kim-Wanner
Lurgiallee 10
60439 Frankfurt, Germany
51. Germany, Epidemiological Cancer Registry North Rhine-Westphalia (ENCR Registry code EUDENRWAA9)
Dr. Oliver Heidinger
Epidemiologisches Krebsregister NRW gGmbH
Robert-Koch-Str. 40
48149 Münster, Germany
52. Germany, Cancer Registry Rhineland-Palatinate (ENCR Registry code EUDERHPAA9)
Dr. Sylke Zeißig
Krebsregister Rheinland-Pfalz gGmbH
Große Bleiche 46
55116 Mainz, Germany
53. Germany, Saarland Cancer Registry (ENCR Registry code EUDESAAAA9)
Bernd Holleczer
Krebsregister Saarland

Präsident Baltz-Straße 5
66119 Saarbrücken, Germany

54. Germany, Lower Saxony Cancer Registry (ENCR Registry code EUDESALAA9)
Joachim Kieschke
Registerstelle
OFFIS CARE GmbH
Industriestr. 9
26121 Oldenburg, Germany
55. Germany, Schleswig-Holstein Cancer Registry (ENCR Registry code EUDESCHAA9)
Prof. Alexander Katalinic
Institut für Krebsepidemiologie e.V.
Ratzeburger Allee 160
23538 Lübeck, Germany
56. Greece, Hellenic Cancer Registry (ENCR Registry code EUGR999AA9)
Dr. Evangelia Tzala
Hellenic Centre for Disease Control and Prevention (KEELPNO),
3-5 Agrafon Street,
15123 Marousi, Greece
57. Greece, Nationwide Registry for Childhood Hematological Malignancies (NARECHEM) (ENCR Registry code EUGR999HE1)
Prof. Eleni Petridou
Dept.of Hygiene, Epidemiology and Medical Statistics
Medical School, University of Athens
Mikras Asias 75
11527 Athens, Greece
58. Greece, Cancer Registry of Crete (ENCR Registry code EUGRCREAA9)
Dr. Vasilios Georgoulis
Department of Social Medicine
University of Crete School of Health Sciences,
Office 4D10
Crete, Greece
59. Hungary, National Pediatric Cancer Registry of Hungary (ENCR Registry code EUHU999AA1)
Dr. Miklos Garami
2nd Department of PediatricsFaculty of MedicineSемmelweis University
Foundation for Children with Tumor & Leukaemia
Tüzoltó u. 7-9
1094 Budapest, Hungary
60. Hungary, National Cancer Registry of Hungary (ENCR Registry code EUHU999AA9)
Dr. István Kenessey
Országos Onkológiai Intézet

Budapest Pf. 21
1525, Hungary

61. Iceland, Icelandic Cancer Registry (ENCR Registry code ACIS999AA9)
Laufey Tryggvadóttir (Managing Director)
Jón Gunnlaugur Jónasson (Medical Director)
Skógarhlíð 8
105 Reykjavík, Iceland
62. Ireland, National Cancer Registry Ireland (ENCR Registry code EUIE999AA9)
Prof. Deirdre Murray
Cork Airport Business Park, Building 6800, Kinsale Road
T12 CDF7 Cork, Ireland
63. Italy, Basilicata Cancer Registry (ENCR Registry code EUITBASAA9)
Dr. Rocco Galasso
Basilicata, Italy
64. Italy, Bergamo Cancer Registry (ENCR Registry code EUITBERAA9)
Dr. Giuseppe Sampietro
Servizio Epidemiologico Aziendale, ATS di Bergamo
ASL Provincia di Bergamo, Registro Tumori di Bergamo
Via Gallicciolli, 4
Bergamo, Italy
65. Italy, Cancer Registry of ATS Brescia (old Cancer Registry of the Brescia Local Health Unit) (ENCR Registry code EUITBREAA9)
Dr. Cinzia Gasparotti
ATS Brescia
Via Duca degli Abruzzi n. 15
25124 Brescia, Italy
66. Italy, Brindisi Cancer Registry (ENCR Registry code EUITBRIAA9)
Dr. Antonino Ardizzone
Brindisi, Italy
67. Italy, Cancer Registry of Catania, Messina and Enna (ENCR Registry code EUITCAIAA9)
Prof. Margherita Ferrante
UOC Igiene Ospedaliera
Policlinico G. Rodolico San Marco di Catania
Via Santa Sofia, 87
95123 Catania, Italy
68. Italy, Childhood Cancer Registry of Campania Region (ENCR Registry code EUITCAMAA1)
Dr. Francesco Vetrano
Presidio Ospedaliero Santobono
Via Mario Fiore 6

80129 Napoli, Italy

69. Italy, Caserta Cancer Registry (ENCR Registry code EUITCASAA9)
Dr. Perillo Agostino
Caserta, Italy
70. Italy, Catanzaro Tumor Registry (ENCR Registry code EUITCATAA9)
Dr. Antonella Sutura Sardo
Azienda Sanitaria Provinciale
Via Vinicio Cortese N.25
88100 Catanzaro, Italy
71. Italy, Reggio Emilia Cancer Registry (ENCR Registry code EUITEMIAA9)
Dr. Lucia Mangone
Servizio Interaziendale di Epidemiologia
Azienda USL Reggio Emilia
Via Amendola 2, 42122
42122 Reggio Emilia, Italy
72. Italy, Cancer Registry of Vasta Emilia Centrale Area (ENCR Registry code EUITFERAA9)
Dr. Stefano Ferretti
Dipartimento di Medicina Sperimentale e Diagnostica
Ferrara University
Via Fossato di Mortara 64B
44121 Ferrara, Italy
73. Italy, North East Italy Cancer Surveillance Network (NEICSN) (ENCR Registry code EUITFVGAA9)
Dr. Diego Serraino
Direzione Centrale Salute
IRCCS Centro Riferimento Oncologico
Via F. Gallini 2
33081 Aviano, Italy
74. Italy, Ligurian Region Cancer Registry (ENCR Registry code EUITGENAA9)
Dr. Luca Boni
SS Epidemiologia Descrittiva
AOU S.Martino -IST Istituto Nazionale per la Ricerca sul Cancro
Largo R. Benzi, 10
16132 Genoa, Italy
75. Italy, Cancer Registry of ATS dell'Insubria (ENCR Registry code EUITINSAA9)
Dr. Maria Gambino
ATS dell' Insubria
Varese, Italy
76. Italy, Latina Province Cancer Registry (ENCR Registry code EUITLATAA9)
Dr. Silvia Iacovacci

Azienda USL Latina Centro Direzionale Latina Fiori
Registro Tumori Latina
viale P. Nervi Torre 2 Girasoli
4100 Latina, Italy

77. Italy, Liguria Mesothelioma Registry (ENCR Registry code EUITLIGME9)
Dr. Valerio Gennaro
UO Clinical Epidemiology (IST Nord - CBA)
IRCCS Az. Ospedale Università San Martino, Istituto Nazionale per la Ricerca sul Cancro (IST)
National Cancer Research Institute
Largo Rosanna Benzi 10
13132 Genova, Italy
78. Italy, Cancer Registry of South Lombardy (ENCR Registry code EUITLODAA9)
Dr. Giovanni Marazza
Medicina Preventiva nelle Comunità
Local Health Authority of Lodi province, Local Health Authority of Pavia province
Piazza Ospitale, 10
Lodi, Italy
79. Italy, Mesothelioma Registry of Lombardy (ENCR Registry code EUITLOMME9)
Dr. Carolina Mensi
Milan, Italy
80. Italy, Macerata Province Tumor Registry (ENCR Registry code EUITMACAA9)
Dr. Susanna Vitarelli
Scuola di Scienze Mediche Veterinarie
Università di Camerino
Via Gentile III da Varano
62032 Camerino (MC), Italy
81. Italy, Childhood and Adolescents Cancer Registry Marche Region (ENCR Registry code EUITMARAA1)
Dr. Iolanda Grappasonni
Via Gentile III da Varano 26,
62032 Camerino (MC), Italy
82. Italy, Cancer Registry of Monza-Brianza-Lecco (ENCR Registry code EUITMBLA9)
Dr. Luca Cavaliere d'Oro
Servizio Epidemiologia, U.O. Epidemiologia - Registro Tumori
ASL Monza e Brianza, Dip. Programmazione, Acquisto e Controllo
Viale Elvezia, 2
20900 Monza, Italy
83. Italy, Cancer Registry of Metropolitan City of Milan (ENCR Registry code EUITMILAA9)
Dr. Antonio Giampiero Russo
SC Epidemiologia
Agency for Health Protection of Milan

Via Conca del Naviglio, 45
20123 Milan, Italy

84. Italy, Modena Cancer Registry (ENCR Registry code EUITMODAA9)
Dr. Gianbattista Spagnoli
Centro Oncologico Modenese
Policlinico,
via del pozzo, 71
41124 Modena, Italy
85. Italy, Modena Colorectal Tumor Registry (ENCR Registry code EUITMODCR9)
Dr Bonetti Luca Reggiani
Dipartimento di Medicine e Specialità Mediche
Struttura Complessa di Medicina I
Ingresso 1, Piano 5°, Policlinico, Via del Pozzo 71
41100 Modena, Italy
86. Italy, Naples 1 Cancer Registry (ENCR Registry code EUITNA1AA9)
Dr. Rosanna Ortolani
Dipartimento di Prevenzione
UOC Epidemiologia, Prevenzione e Registro Tumori
Via Comunale del Principe 13/a (NA)
80145 Napoli, Italy
87. Italy, Naples 2 Cancer Registry (ENCR Registry code EUITNA2AA9)
Dr. Giancarlo D'Orsi
Naples, Italy
88. Italy, Cancer Registry of the Campania Region (ENCR Registry code EUITNAPAA9)
Dr. Mario Fusco
Registro tumori di popolazione, Regione Campania
c/o Azienda Sanitaria Napoli 3 Sud
Piazza San Giovanni
80031 80031 Brusciano (NA), Italy
89. Italy, Nuoro Cancer Registry (ENCR Registry code EUITNUOAA9)
Dr. Pasquala Pinna
Registro tumori di Nuoro
Servizio Igiene e Sanità Pubblica, ASL Nuoro
Via Trieste 80
8100 Nuoro, Italy
90. Italy, Palermo Province Cancer Registry (PPCR) (ENCR Registry code EUITPALAA9)
Prof. Francesco Vitale
Department of Sciences for the Health Promotion
AUOP "P. Giaccone" di Palermo, Palermo District Health Agency

Via del Vespro 133
90127 90127 Palermo, Italy

91. Italy, Cancer Registry of Parma (ENCR Registry code EUITPARAA9)
Dr. Maria Michiara
Parma, Italy

92. Italy, Cancer Registry Province of Pavia (ENCR Registry code EUITPAVAA9)
Dr. Lorenza Boschetti
U.O.C. Osservatorio Epidemiologico per il Governo della Domanda
Public Health Agency of Pavia
ATS di Pavia - V.le Indipendenza, 3
Pavia, Italy

93. Italy, Piacenza Cancer Registry (ENCR Registry code EUITPIAAA9)
Dr. Giorgio Chiaranda
Piacenza, Italy

94. Italy, Childhood Cancer Registry of Piedmont (ENCR Registry code EUITPIEAA1)
Dr. Carlotta Sacerdote
Centro di riferimento per l'epidemiologia e la prevenzione oncologica in Piemonte
SCDU Epidemiologia dei tumori
via Santena 7
10126 Torino, Italy

95. Italy, Puglia Cancer Registry (ENCR Registry code EUITPUGAA9)
Dr. Lucia Bisceglia
AReSS Puglia - Epidemiology and Care Intelligence Area
Lungomare Nazario Sauro, 33
70121 Bari, Italy

96. Italy, Ragusa and Caltanissetta Cancer Registry (formerly Ragusa Cancer Registry) (ENCR Registry code EUITRAGAA9)
Dr. Giuseppe Cascone
Dipartimento di prevenzione medica
Azienda Sanitaria Provinciale (ASP) Ragusa
Piazza Igea No 1
97100 97100 Ragusa, Italy

97. Italy, Emilia-Romagna Cancer Registry (formerly Romagna Tumor Registry) (ENCR Registry code EUITROMAA9)
Dr. Fabio Falcini
IRCCS Istituto Romagnolo per lo Studio dei Tumori "Dino Amadori" IRST
via Piero Maroncelli, 42
47014 Meldola (FC), Italy

98. Italy, Salerno Province Tumor Registry (ENCR Registry code EUITSALAA9)
Dr. Anna Luisa Caiazzo

Via Vincenzo Loria n. 24
84129 Salerno, Italy

99. Italy, Sassari Province Tumor Registry (ENCR Registry code EUITASAA9)
Dr. Daniela Piras
Servizio epidemiologia
ASL 1 Sassari
via Tempio 5
7100 Sassari, Italy
100. Italy, Cancer Registry of ATS della Montagna (ENCR Registry code EUITSONAA9)
Dr. Anna Clara Fanetti
Epidemiologia
ATS della Montagna (Province of Sondrio; Valcamonica; Alto Lario)
Via N. sauro 38
23100 Sondrio, Italy
101. Italy, South Tyrol Cancer Registry (ENCR Registry code EUITSTYAA9)
Dr. Guido Mazzoleni
Corso Italia 13/M
39100 Alto Adige, Italy
102. Italy, Siracusa Cancer Registry (ENCR Registry code EUITSYRAA9)
Prof. Anselmo Madeddu
Registro Territoriale di Patologia
Health Unit of Siracusa
Corso Gelone, 17
96100 Siracusa, Italy
103. Italy, Trento or Trento Province Cancer Registry (ENCR Registry code EUITTREAA9)
Dr. Roberto Vito Rizzello
Epidemiology Department
Azienda Provinciale per i Servizi Sanitari - Provincia Autonoma di Trento
Viale Verona
38123 Trento, Italy
104. Italy, Trapani-Agrigento Cancer Registry (ENCR Registry code EUITTRPAA9)
Dr. Giuseppina Candela
Viale della Provincia
91016 Erice, Italy
105. Italy, Piedmont Cancer Registry (ENCR Registry code EUITTURAA9)
Dr. Enrica Migliore
Centro di Prevenzione Oncologica Piemonte, SC epidemiologia dei tumori
AOU San Giovanni Battista, Molinette
Via San Francesco da Paola, 31
10123 Torino, Italy

106. Italy, Tuscany Region Tumor Registry (ENCR Registry code EUITTUSAA9)
Dr. Adele Caldarella
UO Epidemiologia clinica e descrittiva
Istituto per lo studio e la prevenzione oncologica - ISPO
Via Elle Oblate n.2, Palazzina 28/A
50141 Firenze, Italy
107. Italy, Umbrian Tumor Registry (ENCR Registry code EUITUMBAA9)
Prof. Fabrizio Stracci
Dipartimento di Specialità Medico-Chirurgiche e Sanità Pubblica
Università di Perugia
Via del Giochetto
6100 Perugia, Italy
108. Italy, Aosta Valley Cancer Registry (ENCR Registry code EUITVALAA9)
Dr. Maurizio Castelli
Aosta Valley , Italy
109. Italy, Val Padana Cancer Registry (ENCR Registry code EUITVAPAA9)
Dr. Marco Villa
ATS VAL PADANA,
Via dei Toscani 1,
46100 Mantova, Italy
110. Italy, Veneto Cancer Registry (ENCR Registry code EUITVENAA9)
Prof. Massimo Rugge
Registro Tumori del Veneto
Azienda Zero - Regione del Veneto
Via J Avanzo 35
Padova, Italy
111. Italy, Viterbo Province cancer Registry (ENCR Registry code EUITVITAA9)
Dr. Angelita Brustolin
U.O.S.D. Epidemiologia e Registro Tumori Dipartimento di Prevenzione ASL Viterbo
Cittadella della Salute (6° piano) Via Enrico Fermi
15 01100 Viterbo, Italy
112. Latvia, Latvian Cancer Register (ENCR Registry code EULV999AA9)
Dr. Elina Liepina
Registers Supervision Unit
The Centre for Disease Prevention and Control
Duntes street 22
LV-1012 Riga, Latvia
113. Liechtenstein, Cancer Registry Liechtenstein (ENCR Registry code TCLI999AA9)
Dr. Mohsen Mousavi

114. Lithuania, Lithuanian Cancer Registry (ENCR Registry code EULT999AA9)
Dr. Giedre Smailyte
Cancer Control and Prevention Centre
Institute of Oncology, Vilnius University
P.Baublio g. 3B
LT-08406 Vilnius, Lithuania
115. Luxembourg, Morphological Tumour Registry (ENCR Registry code EULU998AA9)
Dr. Gaël Hammer
Registre Morphologique des Tumeurs (RMT)
Laboratoire national de santé (LNS) E.P.
1, rue Louis Rech L-3555 Dudelange
L-3401 Dudelange, Luxembourg
116. Luxembourg, Cancer Registry of Luxembourg (ENCR Registry code EULU999AA9)
Dr. Sophie Couffignal, operational director / Michel UNTEREINER, scientific director
Registre National du Cancer
Luxembourg Institute of Health (L.I.H.)
1A-1B rue Thomas Edison
L1445 Strassen, Luxembourg
117. Malta, Malta National Cancer Register (ENCR Registry code EUMT999AA9)
Dr. Miriam Azzopardi
Malta National Cancer Registry
Department of Health Information and Research
95 Guardamangia Hill
PTA1313 G"Mangia, Malta
118. Montenegro, Registry of Malignant Neoplasms of Montenegro (ENCR Registry code ACME999AA9)
Dr. Rajko Strahinja
Institute of Public Health in Montenegro
Montenegro
119. Netherlands, Netherlands Cancer Registry (ENCR Registry code EUNL999AA9)
Dr. Otto Visser
Netherlands Comprehensive Cancer Organisation (IKNL)
Utrecht, Netherlands
120. Norway, Cancer Registry of Norway (ENCR Registry code ACNO999AA9)
Dr. Giske Ursin
Kreftregisteret
Institute of Population-based Cancer Research
Majorstuen
N-0304 Oslo, Norway

121. Poland, Polish National Cancer Registry (ENCR Registry code EUPL999AA9)
Dr. Joanna Didkowska
Dept. of Epidemiology & Cancer Prevention
Maria Skłodowska-Curie National Research Institute of Oncology
ul. Wawelska 15
02-034 Warsaw, Poland
122. Poland, Greater Poland Cancer Registry (ENCR Registry code EUPLGRPAA9)
Dr. Maciej Trojanowski
Wielkopolskie Biuro Rejestracji Nowotworów
Wielkopolskie Centrum Onkologii im. Marii Skłodowskiej-Curie, Greater Poland Cancer Center, named after Marie Skłodowska-Curie
ul. Garbary 15
61- 866 Poznań, Poland
123. Poland, Holy Cross Regional Cancer Registry (ENCR Registry code EUPLHOLAA9)
Dr. Pawel Macek
Department of Cancer Control & Epidemiology
Swietokrzyskie Cancer Centre
Artwinskiego 3
25-734 Kielce, Poland
124. Poland, (ENCR Registry code EUPLKIEAA9)
Dr. Pawel Macek
Swietokrzyskie Cancer Centre
Artwinskiego 3
25-734 Kielce, Poland
125. Poland, Cracow Cancer Registry (ENCR Registry code EUPILLEPAA9)
Dr. Jadwiga Rachtan
Unit of Epidemiology
Maria Skłodowska-Curie Memorial Institute
Garncarska 11
31-115 Kraków, Poland
126. Poland, Lodz Regional Cancer Registry (ENCR Registry code EUPLLODAA9)
Dr. Agnieszka Rosinska
Poland
127. Poland, Lower Silesian Regional Cancer Registry (ENCR Registry code EUPLLSIAA9)
Dr. Jerzy Blaszczyk
Lower Silesian Oncology Center in Wroclaw
pl. Hirszfelda 12
53-413 Wroclaw, Poland
128. Poland, Lublin Regional Cancer Registry (ENCR Registry code EUPLLUBAA9)
Dr. Beata Koscianska

Wojewodski Rejestr Nowotworow
Centrum Onkologii Ziemi
ul. Jaczewskiego 7
20-090 Lublin, Poland

129. Poland, Masovian Regional Cancer Registry (ENCR Registry code EUPLMASAA9)

Dr. Maria Zwierko
Independent Unit
Cancer Center and Institute of Oncology, The Maria Skłodowska-Curie Memorial
ul. W.K. Roentgena 5,
02-781 Warsaw, Poland

130. Poland, Subcarpathian Regional Cancer Registry (ENCR Registry code EUPLSUCAA9)

Dr. Monika Gradalska-Lampart
Department of Epidemiology and Cancer Registry
Podkarpacki Subcarpathian Cancer Center Regional Hospital
35-055 Rzeszów, Poland

131. Poland, West Pomeranian Regional Cancer Registry (ENCR Registry code EUPLWEPA9)

Dr. Karolina Sikorska
Zachodniopomorskie Centrum Onkologii
Sekcja Koordynacji Badań i Promocji Zdrowia -, Wojewódzkie Biuro Rejestracji Nowotworów
ul. Strzałowska 22
71-730 Szczecin, Poland

132. Portugal, ROPP (Portuguese Pediatric Oncologic Registry) (ENCR Registry code EUPT999AA1)

Dr. Filomena Pereira
Portugal

133. Portugal, Azores Cancer Registry (ENCR Registry code EUPTAZOAA9)

Dr. Raul Rego
Centro de Oncologia dos Azores Prof Doutor José Conde,
Rua da Rocha 38,
9700-169 Angra do Heroísmo, Portugal

134. Portugal, Central Portugal Cancer Registry (ENCR Registry code EUPTCOIAA9)

Dr. Manuel António Silva
Instituto Português de Oncologia de Coimbra, Francisco Gentil, EPE
Avenida Bissaya Barreto 98,
3000-075 Coimbra, Portugal

135. Portugal, North Region Cancer Registry of Portugal (ENCR Registry code EUPTNOPAA9)

Dr. José Laranja Pontes
Inst. Português de Oncologia do Porto
Rua António Bernardino da Almeida
4200-072 Porto, Portugal

136. Portugal, ROR-SUL (South Regional Cancer Registry) (ENCR Registry code EUPTSOLAA9)

Dr. Ana Miranda

Instituto Português de Oncologia de Francisco Gentil, Centro Regional de Lisboa

Rua Professor Lima Basto

1099-023 Lisboa, Portugal

137. Romania, Romanian Childhood Cancer Registry (ENCR Registry code EURO999AA1)

Prof. Dr. Monica Dragomir

Societatea Romana de Onco-Hematologie Pediatrica

153 Ion I.C. Brătianu Street, Balotești, Ilfov County

Romania

138. Romania, Cancer registry Bucharest-Ilfov (ENCR Registry code EUROBCHAA9)

Dr. Bogdan Georgescu

Romania

139. Romania, Cluj Regional Cancer Registry (ENCR Registry code EUROCLUAA9)

Dr. Daniela Coza

Dept. of Epidemiology & Medical Biostatistics

Oncological Institute 'Ion Chiricuta'

Republicii Street no. 34-36

400015 Cluj Napoca, Romania

140. Romania, Centre Regional Cancer Registry - TARGU-MURES (ENCR Registry code EUROTAMAA9)

Dr. Edith Fekete

Romania

141. Romania, Timisoara Regional Cancer Registry (ENCR Registry code EUROTIMAA9)

Dr. Camelia Nicoleta Claici

Department of Health Promotion and Evaluation

Institutul National de Sanatate Publica

16 Victor Babes Street

300226 Timisoara, Romania

142. Serbia, Central Serbia Cancer Registry (ENCR Registry code ACRSCSEAA9)

Dr. Dragan Miljus

Department for prevention and control of non communicable diseases, NCD Registry Unit

Institute of Public Health of Serbia

5, Dr Subotica St.

11000 Belgrade, Serbia

143. Slovakia, National Cancer Registry of Slovakia (ENCR Registry code EUSK999AA9)

Dr. Chakameh Safaei Diba

National Health Information Center (NCZI)

Lazaretska 26

81109 Bratislava, Slovakia

- 144.Slovenia, Cancer Registry of Republic of Slovenia (ENCR Registry code EUSI999AA9)
Dr. Vesna Zadnik
Institute of Oncology Ljubljana
Zaloska cesta 2
1000 Ljubljana, Slovenia
- 145.Spain, Spanish National Registry of Childhood Tumours (RNTI-SEHOP) (ENCR Registry code EUES999AA1)
Prof. Rafael Peris-Bonet
Faculty of Medicine
University of Valencia
Avda. V. Blasco Ibañez, 15
46010 Valencia, Spain
- 146.Spain, Albacete Cancer Registry - Castille La Mancha (ENCR Registry code EUESALBAA9)
Dr. Enrique Almar Marqués
Seccion de Epidemiología
Consejería de Sanidad y Asuntos Sociales, Junta Comunidades de Castilla-La Mancha
Avda de la Guardia Civil, 5
2005 Albacete, Spain
- 147.Spain, Asturias Cancer Registry (ENCR Registry code EUESASTAA9)
Dr. José Ramón Quirós García
Sección de Información Sanitaria
Dirección General de Salud Pública, Consejería de Sanidad
C/Ciriaco Miguel Vigil N° 9
33006 Oviedo, Spain
- 148.Spain, Mallorca Cancer Registry (ENCR Registry code EUESBALAA9)
Dr. Carmen Sánchez-Contador Escudero
Coordinación Estrategia de Càncer
Direcció General de Salut Pública i Participació. Conselleria de Salut i Consum. Illes Balears
Calle Jesús nº 40,
7010 Palma, Spain
- 149.Spain, Basque Cancer Registry (ENCR Registry code EUESBASAA9)
Dr. Arantza Lopez De Munain Marques
Servicio de Registros e Informacion Sanitaria
Departamento de Salud del Gobierno Vasco
01010Donostia-San Sebastian, 1
1010 Vitoria-Gasteiz, Spain
- 150.Spain, Registro poblacional de Tumores Infantiles de Castilla y León (ENCR Registry code EUESCALAA1)
The Director General for Public Health in Castile and Leon
Spain
- 151.Spain, Registro Poblacional de Cáncer de Castilla y León (ENCR Registry code EUESCALAA9)
The Director General for Public Health in Castilla y León

Junta de Castilla y León
Paseo de Zorrilla, 1
47007 Valladolid, Spain

152.Spain, Canary Islands Cancer Registry (ENCR Registry code EUESCANA9)

Director General de Salud
Dirección General de Salud Pública Gobierno de Canarias
Rambla de santa Cruz Nº 53
38006 Santa Cruz de Tenerife, Spain

153.Spain, Castellon Cancer Registry (ENCR Registry code EUESCASAA9)

Dr. Carmen Alberich Martí
Spain

154.Spain, Ceuta Cancer Registry (ENCR Registry code EUESCEUA9)

Ana Isabel Rivas Perez
Spain

155.Spain, Cancer Registry of Ciudad Real (RCCR) (ENCR Registry code EUESCIUA9)

Dr. Matilde Chico
Spain

156.Spain, Cancer Registry of Cuenca (ENCR Registry code EUESCUEAA9)

Dr. Ana Isabel Marcos Navarro
Spain

157.Spain, Girona Cancer Registry (ENCR Registry code EUESGIRAA9)

Dr. Rafael Marcos-Gragera
Catalan Institute of Oncology
Carrer del Sol, 15 1era planta
17004 Girona, Spain

158.Spain, Granada Cancer Registry (ENCR Registry code EUESGRAAA9)

Dr. Maria-Jose Sanchez-Perez
Spain

159.Spain, Registro Poblacional de Cáncer en la Infancia y Adolescencia de la Comunidad de Madrid (ENCR Registry code EUESMADAA1)

Dr. General Director of Public Health. Community of Madrid. Spain.
Madrid Health Department
Public Health Division,
C/San Martín de Porres 6 (1st floor),
28035 Madrid, Spain

160.Spain, Murcia Cancer Registry (ENCR Registry code EUESMURAA9)

Dr. Maria Dolores Chirlaque
Spain

- 161.Spain, Navarra Cancer Registry (ENCR Registry code EUESNAVAA9)
Dr. Eva Ardanaz Aicua
Spain
- 162.Spain, La Rioja cancer registry (ENCR Registry code EUESRIOAA9)
Dr. Josefina Perucha González
Spain
- 163.Spain, Tarragona Cancer Registry (ENCR Registry code EUESTARAA9)
Dr. Jaume Galceran
Hospital Universitari Sant Joan de Reus
Av. Josep Laporte, 2
Spain
- 164.Spain, Comunitat Valenciana Childhood Cancer Registry (ENCR Registry code EUESVALAA1)
Dr. Francesc Botella Quijal
Public Health Directorate General. Health Department, Comunitat Valenciana
Direcció General Salut Pública i Adiccions
46020 València, Spain
- 165.Sweden, Swedish Cancer Registry (ENCR Registry code EUSE999AA9)
Dr. David (old was: Staffan) Pettersson (old was: Khan)
Department of Registers and Statistics, Unit of statistics
National Board of Health and Welfare
Rålambsvägen 3
106 30 Stockholm, Sweden
- 166.Switzerland, National Institute for Cancer Epidemiology and Registration (NICER) (ENCR Registry code ACCH111AA9)
Dr. Ulrich Wagner
National Agency for Cancer Registration (NACR)
Hirschengraben 82,
CH-8001 Zürich, Switzerland
- 167.Switzerland, Swiss Childhood Cancer Registry (SCCR) (ENCR Registry code ACCH999AA1)
Prof. Claudia Kuehni
Institute for Social- and Preventive Medicine
University of Bern
Mittelstr. 43
3012 Bern, Switzerland
- 168.Switzerland, Aargau Cancer Registry (ENCR Registry code ACCHAGAAA9)
Dr. Martin Adam & Dr. Ivan Curjuric
Switzerland
- 169.Switzerland, Basel Cancer Registry (ENCR Registry code ACCHBASAA9)
Dr. med. Katharina Staehelin
Basel Cancer Registry

Gesundheitsdienste, Cantonal Department of Health
Gerbergasse 13
4001 Basel, Switzerland

170. Switzerland, Bern Solothurn Cancer Registry (ENCR Registry code ACCHBERAA9)

Prof. Dr. Aurel Perren
University of Bern
Murtenstrasse 31
3008 Bern, Switzerland

171. Switzerland, Fribourg Tumor Registry (ENCR Registry code ACCHFRIAA9)

Dr. Bertrand Camey
Registre Fribourgeois des Tumeurs
Rte St-Nicolas-de-Flue 2
1705 Fribourg, Switzerland

172. Switzerland, Geneva Cancer Registry (ENCR Registry code ACCHGENAA9)

Prof. Christine Bouchardy
Institute for social and preventive medicine - IMSP
University of Geneva
55 boulevard de la Cluse
1205 Geneva, Switzerland

173. Switzerland, Graubünden and Glarus Cancer Registry (ENCR Registry code ACCHGGGLAA9)

Dr. S. Mohsen Mousavi
Kantonsspital Graubünden
Lürlibadstrasse 118
7000 Chur, Switzerland

174. Switzerland, Neuchatel Cancer Registry (ENCR Registry code ACCHNEUAA9)

Prof. Murielle Bochud
Public Health Department
Rue du Plan 30
2000 Neuchatel, Switzerland

175. Switzerland, East Switzerland Cancer Registry (ENCR Registry code ACCHSGAAA9)

Dr. S. Mohsen Mousavi
East Switzerland Cancer League
Flurhofstr. 7
9000 St Gallen, Switzerland

176. Switzerland, Thurgau Cancer Registry (ENCR Registry code ACCHTHUAA9)

Dr. Anne Schmidt
Krebsregister Thurgau
Unterseestrasse 47
8280 Kreuzlingen, Switzerland

177. Switzerland, Ticino Cancer Registry (ENCR Registry code ACCHTICAA9)
Dr. Andrea Bordoni
Registro Tumori del Canton Ticino
Istituto Cantonale di Patologia,
Via in Selva 24,
6601 Locarno, Switzerland
178. Switzerland, Valais Cancer Registry (ENCR Registry code ACCHVALAA9)
Dr. Isabelle Konzelmann
Observatoire valaisan de la santé
Av. Grand-Champsec 86
1950 Sion, Switzerland
179. Switzerland, Vaud Cancer Registry (ENCR Registry code ACCHVAUAA9)
Dr. Patrick Arveux & Jean-Lux Bulliard
CHUV
Center for Primary Care and Public Health (Unisanté), University of Lausanne
route de la Corniche 10
1010 Lausanne, Switzerland
180. Switzerland, Central Switzerland Cancer Registry (ENCR Registry code ACCHZENAA9)
Prof. Dr. med. Joachim Diebold
Zentralschweizer Krebsregister
Luzerner Kantonsspital, Haus 40
Spitalstrasse
6000 Luzern 16, Switzerland
181. Switzerland, Cancer Registry Zurich and Zug (ENCR Registry code ACCHZURAA9)
Dr. Sabine Rohrmann
Institute of Surgical Pathology
Institute of Social and Preventive Medicine, University Hospital Zürich
Vogelsangstrasse 10
8091 Zurich, Switzerland
182. Ukraine, National Cancer Registry of Ukraine (ENCR Registry code OTUA999AA9)
Dr. Zoya Fedorenko
National Institute of Cancer
Lomonosova Street, 33/43
3022 Kiyv, Ukraine
183. United Kingdom, Northern Region Young Persons' Malignant Disease Registry (ENCR Registry code ACUKENRAA1)
Dr. Richard McNally
Institute of Health and Society
Newcastle University
Sir James Spence Institute, Royal Victoria Infirmary
NE1 4LP Newcastle upon Tyne, United Kingdom

184. United Kingdom, National Cancer Registration and Analysis Service (NCRAS) (ENCR Registry code ACUKERSAA9)
Dr. Jem Rashbass
National Cancer Registration and Analysis Service (NCRAS)
NHS Digital
Unit C, Magog Court Shelford Bottom
CB22 3AD Cambridge, United Kingdom
185. United Kingdom, West Midlands Regional Children's Tumour Registry (ENCR Registry code ACUKEWMAA1)
Dr. Helen Jenkinson
Oncology Research Dept
Children's Hospital
Steelhouse Lane
B4 6HN Birmingham, United Kingdom
186. United Kingdom, Northern Ireland Cancer Registry (ENCR Registry code ACUKNIRAA9)
Dr. Anna T. Gavin
Dept. of Epidemiology & Public Health, Queen's University
Inst. of Clinical Science
Mulhouse Bldg, Grosvenor Road
BT12 6BJ Belfast, United Kingdom
187. United Kingdom, Scottish Cancer Registry (ENCR Registry code ACUKSCOA9)
Dr. David Morrison
Information Services Division
Public Health Scotland
Area 159A, Gyle Square, 1 South Gyle Crescent
EH12 9EB Edinburgh, United Kingdom
188. United Kingdom, Welsh Cancer Intelligence and Surveillance Unit (ENCR Registry code ACUKWALAA9)
Dr. Dyfed Wyn Huws
Welsh Cancer Intelligence & Surveillance Unit (W.C.I.S.U.)
Public Health Wales (NHS Trust), Cardiff University
13th Floor Brunel House, 2 Firzalan Road
CF24 0HA Cardiff, United Kingdom

ANNEX II

PROTECTION OF PERSONAL DATA TRANSFERRED BY THE REGISTRIES TO THE JRC

SECTION 1 - SCOPE OF THE RULES IN THE PRESENT ANNEX II

The rules in the present Annex II apply exclusively to the processing of personal data by the JRC; whereby ‘personal data’ shall have the same meaning as in the GDPR and EUDPR.

In particular, these rules apply to the processing of individual cancer data transferred by the registries to and further processed by the JRC; whereby ‘individual cancer data’ means personal data on individual cancer occurrence(s) at patient level transferred by population-based cancer registries affiliated to ENCR to the JRC pursuant to the present Agreement.

They do not apply to the processing of anonymous information or to aggregated cancer data transferred by the registries to and further processed by the JRC.

SECTION 2 - CORE PRINCIPLES OF PROCESSING OF PERSONAL DATA BY THE JRC

- 2.1** Without prejudice to the commitments and undertakings of the JRC under the present Agreement, the JRC determines alone the purposes and means of further processing. In accordance with Art. 3(8) EUDPR, the JRC is therefore to be considered as a new controller. In accordance with Art. 5 EUDPR, the JRC alone shall be responsible for the compliance of its own processing with applicable data protection legislation.
- 2.2** The JRC, as part of the Commission as subsequent controller for the further processing of the personal data transferred by the registries, is subject to the EUDPR. As stated in Recital 4 and 5 thereof, the EUDPR results from the adaptation of the data protection rules applicable to the EU institutions to the principles and rules of the GDPR. The scheme of the EUDPR is understood as equivalent to the scheme of the GDPR and those two sets of provisions should be interpreted homogeneously.
- 2.3** The JRC shall process the personal data transferred as described below and has the legal authority to give the warranties and fulfil the undertakings set out in this Agreement. The JRC will provide information to the Registries as necessary to demonstrate compliance with applicable data protection legislation.

I. Data subjects

“Individual cancer data” are personal data on individual cancer occurrence(s) at patient level provided by population-based cancer registries affiliated to ENCR. Data subjects are patients of cancer occurrences.

II. Categories of data

Individual cancer data may include the following categories of data:

- Information about the area of residence of the patient (such as region or subregion);

- Medically relevant data on the patient (such as month of birth, year of birth, gender and age at diagnosis);
- Clinical data about the cancer (such as tumour identifier, month of incidence, year of incidence, topography, morphology, stage at diagnosis, type of treatment received and other clinically relevant information);
- Variables related to follow up (such as vital status, duration of survival, and cause of death).

III. Purposes for processing of individual cancer data

The JRC, as new controller, shall process individual cancer data exclusively for scientific research purposes in support of public health policies, within the JRC mission to provide Union policies with independent scientific evidence and technical support throughout the policy cycle. In accordance with Recital 159 GRPR, scientific research purposes should also include studies conducted in the public interest in the area of public health.

In particular, such scientific research purposes are the following:

- gaining a better understanding of cancer epidemiology, aetiology, clinics, therapy and care, genetics, and correlations with socio-economic aspects;
- providing a scientific basis for the evaluation and design of EU and national public health policies aimed at improving prevention, diagnosis, treatment and care of cancer;
- supporting research by national and international bodies in the fields of cancer epidemiology, clinical medicine, basic and translational research, pharmacology prevention, diagnosis and treatment.

Within the scientific research purposes set out above, the Call for data shall define in detail the specific purposes for the processing of individual cancer data. The JRC shall process individual cancer data exclusively for the specific purposes defined in the Call for Data and in full compliance with the EUDPR, in particular Art. 1 (b) thereof (purpose limitation principle).

IV. Processing Activities and Storage Period – Regular operation of the ECIS

Within the scientific research purposes set out in part III above and specified in detail in the Call for Data, the JRC will process individual cancer data for the regular operation of the ECIS. The JRC processing activities on individual cancer data, include, in particular, the following:

- Facilitating submission of individual cancer data by registries and exchange of information through a dedicated secure online portal;
- Conducting quality control and standardising individual cancer data provided by registries, in order to ensure the reliability of the results and information produced. Such quality control shall be carried out in accordance with agreed scientific standards;

- Where JRC detects potential inaccuracies or incompleteness of individual cancer data, JRC shall draw attention on the specific occurrence to the respective registries that provided the data, so that the registries can take appropriate action in accordance with its applicable legislation, in particular rectification of inaccurate data or completing incomplete data;
- Producing statistical indicators on the cancer burden, in particular relating to incidence, mortality, prevalence and survival, and information resulting from scientific research on cancer epidemiology, etiology, clinics, therapy and care, genetics and correlations with socio-economic aspects;
- Ensuring that statistical indicators aimed at dissemination to the public do not constitute personal data, namely that they cannot be attributed to a natural person who is identifiable taking into account all the means reasonably likely to be used to identify the natural person directly or indirectly. The precise methodology to ensure statistical confidentiality shall be specified in detail in the Call for data. Where a statistical indicator includes fewer than 3 individuals for a given statistical unit, the JRC and the Registry at the origin of the individual cancer data will agree on the modalities for dissemination of that statistical indicator.
- Provided that statistical indicators do not constitute personal data, disseminating statistical indicators on the cancer burden, in particular relating to incidence, mortality, prevalence and survival, and information resulting from scientific research on cancer epidemiology, etiology, clinics, therapy and care, genetics and correlations with socio-economic aspects, including through publication on the ECIS website, freely accessible to the public.
- Using and releasing the statistical indicators on cancer burden for support to EU and national public health policies.

Storage Period

Cancer data shall be kept for a maximum total storage period of 10 years from the moment of submission by the registries. After that maximum total storage period, the cancer data will be destroyed

Cancer data shall be kept for the purposes of carrying out the processing activities described above for a maximum period of 5 years.

Subsequently, cancer data will be kept for archiving purposes in order to perform data verification and audits in case inaccuracies, inconsistencies or incompleteness are detected. The additional storage period for such secondary, compatible purposes will be for a maximum of 5 years from the moment of publication of the statistical indicators, or until a new set of statistical indicators produced on the basis of a new set of cancer data submitted by national registries is published, whichever date comes first.

V. Processing Activities and Storage Period - Specific Scientific Projects and Studies

Within the scientific research purposes set out in part III above, the JRC will process individual cancer data for specific scientific projects and studies referred to in Art. 6.3 (e). The details of the processing of individual cancer data necessary for each specific scientific research project or study, including the storage period, will be defined in the specific data request to the registries, and the request will be approved by the Management Committee in accordance with Art. 6.3 of the Collaboration Agreement. The JRC will process individual cancer data in accordance with the conditions set out in the data request and in full compliance with the EUDPR.

The publication of results of specific scientific projects and studies will take place in accordance with the conditions set out in the data request. In the absence of specific conditions,

- where such results do not constitute personal data, it will take place in accordance with the provisions of Article 8.4, third paragraph of the present Collaboration Agreement.
- Where such result constitute personal data, it will take place in accordance with the provisions of Section 4 of the present Annex II ('DISCLOSURE OF DATA AND ONWARDS TRANSFERS') and in full compliance with the EUDPR.

2.4 In accordance with Art. 4(1)(b) EUDPR, the processing of individual cancer data by JRC for scientific research purposes, including scientific research to support public policies, is not considered to be incompatible with the initial purposes for which the data were collected. In accordance with Recital 25 EUDPR further processing for scientific research purposes should be considered to be compatible lawful processing operations.

2.5 In accordance with Art. 5(1) EUDPR, processing by the JRC is lawful.

In accordance with Recital 25 EUDPR, where the processing is compatible with the purposes for which the personal data were initially collected, no legal basis separate from that which allowed the collection of personal data is required.

In addition to it, the applicable legal basis referred to in Art. 5(1) EUDPR for the processing is the following:

a) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the Union institution or body, on the basis of Union law.

In accordance with Article 2.3 of the present Annex II, the JRC will provide information to the Registries on the applicable Union law.

2.6 Processing involves personal data concerning health, which are considered special categories of data.

In accordance with Art. 10 EUDPR, processing by the JRC is lawful. The applicable legal basis referred to in Art. 10 EUDPR for the processing of special categories of data is the following:

j) the processing is necessary for scientific research purposes based on Union law which shall be proportionate to the aim pursued, respect the essence of the right to data protection

and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

In accordance with Article 2.3 of the present Annex II, the JRC will provide information to the Registries on the applicable Union law.

SECTION 3 - SAFEGUARDS, SECURITY MEASURES AND CONFIDENTIALITY

- 3.1** In accordance with Art. 13 EUDPR, the JRC will make processing of personal data subject to appropriate safeguards to ensure that technical and organisational measures are in place in particular in order to ensure respect for the principle of data minimisation.

Accordingly, the JRC declares that, at the moment of signing the present Agreement, it implements the following measures to safeguard the rights and freedoms of data subjects:

Pseudonymisation

Individual cancer data are received and further processed by JRC as pseudonymised data. Individual cancer data shall be linked to a code and not to a name of a specific person. The key of the pseudonymisation is held by the registries and is not exchanged with the JRC. Cancer registries may delete the pseudonymisation key after agreement with the JRC that the quality control of their data has been completed.

Where the Registry providing the individual cancer data has additional information which is not relevant for scientific research purposes, and which would allow JRC to attribute the individual cancer data to a specific data subject, such additional information shall be kept by the Registry separately and shall not be made accessible to the JRC. The JRC shall not request the cancer Registry to provide such additional information.

Information to data subject on their rights

Privacy notices prepared by JRC will be provided to all the ENCR registries contributing with data. Registries will be asked to make reference to these privacy notices in their privacy statements and make available the information to the data subjects. A link to the privacy notices prepared by JRC is available also on the ENCR website.

These measures are described for information purposes only. The JRC may unilaterally decide at any time to adopt different measures to comply with the requirements set out in the EUDPR.

- 3.2** In accordance with Art. 33 EUDPR, the JRC will implement appropriate technical and organisational measures to ensure a level of security appropriate to the risk, taking into account the state of the art, the costs of implementation and the nature, scope, context and purposes of processing as well as the risks of varying likelihood and severity for the rights and freedoms of natural persons.

Accordingly, the JRC declares that, at the moment of signing the present Agreement, it implements the following technical and organisational measures:

Professional secrecy

JRC staff processing individual cancer data is subject to a duty of professional secrecy.

Access limitation and staff awareness

Access to individual cancer data within JRC is limited to selected staff having been formally authorised by the JRC management. JRC puts in place regular awareness-raising measures among authorised staff on their duties with regard to the level of security to be ensured.

Other technical and organisational measures

- The processing of individual cancer data by JRC is subject to the requirements set out in Commission Decision COM (2017)/46⁴ and its implementing rules⁵ on the security of communication and information systems in the European Commission. Compliance with these rules provide appropriate safeguards in regard to personal data in full compliance with the data protection rules applicable to the Commission.
- In particular, the following measures are adopted:
 - standard mandatory measures for access control and authentication, IT asset management, backups, business continuity, compliance, control against malicious code;
 - information security and risk management;
 - encryption, logging and monitoring of access, management of vulnerabilities from removable media, physical and environmental security, secure systems development, IT vulnerability and remediation management, web applications security standards;
 - The system compliance is checked by a risk management process followed by the Local Informatics Security Officer (LISO).

These measures are described for information purposes only. The JRC may unilaterally decide at any time to adopt different measures to comply with the requirements set out in the EUDPR.

- 3.3** In accordance with Art. 30 and 33 EUDPR, the JRC's processor, if appointed, and any person acting under the authority of the JRC or of the processor, who has access to personal data, will not process those data except on instructions from the controller, unless required to do so by Union or Member State law.

SECTION 4 - RIGHTS OF THE DATA SUBJECT AND TRANSPARENCY

⁴ Commission Decision (EU, Euratom) 2017/46 of 10 January 2017 on the security of communication and information systems in the European Commission, C/2016/8998, OJ L 6, 11.1.2017, p. 40–51

⁵ Commission Decision (EU, Euratom) 2018/559 of 6 April 2018 laying down implementing rules for Article 6 of Decision (EU, Euratom) 2017/46 on the security of communication and information systems in the European Commission, C/2018/1726, OJ L 93, 11.4.2018, p. 4–10

- 4.1** The JRC will take the necessary measures to ensure the exercise of the rights of the data subjects in accordance with Chapter III EUDPR, including the right to information, access to personal data, rectification and erasure, right to object and rights relating to automated individual decision-making, including profiling, without prejudice to restrictions in accordance with Art. 25 EUDPR.

In the implementation of the relevant provisions of the EUDPR, account will be taken of the following:

- (a) With regard to Art. 12 and 14(2) EUDPR, the JRC processes individual cancer data only in a form that does not or no longer require the identification of the data subject.
- (b) With regard to Art. 16 EUDPR, the JRC has obtained individual cancer data from the Registries pursuant to this Agreement, and not from the data subject.
- (c) With regard to Art. 16(5) EUDPR, the JRC processes individual cancer data subject to pseudonymisation for scientific research purposes, is not in a position to identify the data subject, and therefore the provision of information on the processing by the JRC to the data subject would prove impossible or would involve a disproportionate effort.

- 4.2** In accordance with Art. 31 EUDPR, the JRC will maintain a record of processing activities under its responsibility, including the processing activities performed on individual cancer data received by the importer under the present Agreement. The record will be kept in a central register, which is publicly available.

Accordingly, the JRC declares that, at the moment of signing Amendment 1 to the present Agreement, it provides information on the processing of personal data as follows:

- Data subjects can access the register at the following link: <http://ec.europa.eu/dpo-register>.
- The specific processing activities covered by the present Agreement have been notified to the Data Protection Officer of the European Commission with the following reference: DPR-EC-01972.2. The privacy statement is joined to the record included in the public register

These measures are described for information purposes only. The JRC may unilaterally decide at any time to adopt different measures to comply with the requirements set out in the EUDPR.

SECTION 5 - DISCLOSURE OF DATA AND ONWARDS TRANSFERS

- 5.1** In accordance with Art. 9 EUDPR, the JRC will only transmit individual cancer data to recipients other than Union institutions and bodies if:

- (a) the recipient establishes that the data are necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the recipient; or
- (b) the recipient establishes that it is necessary to have the data transmitted for a specific purpose in the public interest and the JRC, where there is any reason to assume that the data subject's legitimate interests might be prejudiced, establishes that it is

proportionate to transmit the individual cancer data for that specific purpose after having demonstrably weighed the various competing interests.

Where the JRC initiates the transmission under this Article, it will demonstrate that the transmission of individual cancer data is necessary for and proportionate to the purposes of the transmission by applying the criteria laid down in points (a) or (b) above.

In addition to the requirements set out above, the transmission of individual cancer data to third parties will need to be approved by the Registry at the origin of the individual cancer data to be transmitted. The Registry will notify JRC its approval once it is satisfied that the envisaged transfer complies with applicable national legislation, including with requirements imposed on the recipient.

- 5.2** In the framework of access to document requests, personal data may be transmitted by the JRC to recipients in compliance with Union law, which reconciles the right to the protection of personal data with the right of access to documents.
- 5.3** In accordance with Art. 46 EUDPR, any disclosure or transfer of individual cancer data by the JRC to a recipient located outside the European Economic Area (EEA) or to an international organisation may take place only subject to the provisions of Chapter V EUDPR to ensure that the level of protection of natural persons guaranteed by the EUDPR is not undermined.

SECTION 6 - INDEPENDENT SUPERVISION

In accordance with Art. 58 EUDPR, the JRC declares that it is subject to the investigative powers of the European Data Protection Supervisor, including the power to order the controller to provide any information; the power to carry out investigations in the form of data protection audits; the power to notify the controller of alleged infringements; and the power to obtain access to all personal data and to all information necessary, as well and access to any premises of the controller and any data processing equipment in accordance with Union law. In accordance with Art. 61 EUDPR, the European Data Protection Supervisor shall cooperate with national supervisory authorities to the extent necessary for the performance of their respective duties.

ANNEX III- ACCESSION DOCUMENT

ACCESSION

of a new Party to the Collaboration Agreement No. [to be added] between the Joint Research Centre of the European Commission and the members of the European Network of Cancer Registries (ENCR) for the public health surveillance of cancer.

[OFFICIAL NAME OF THE NEW PARTY]

hereby consents to become a Party to the Collaboration Agreement identified above and accepts all the rights and obligations of a Party.

The Joint Research Centre of the European Commission acting as ECIS manager hereby certifies that the JRC-ENCR Management Committee has accepted in the meeting held on [date] the accession of

[the name of the new Party] to the Agreement.

The accession of [the name of the new Party] to the Collaboration Agreement shall become effective on the date of the signature by the last Party of this Accession document.

Signed in two originals in the English language.

[Date and Place]

[INSERT NAME OF THE NEW PARTY]

Signature(s)

Name(s)

Title(s)

[Date and Place]

Joint Research Centre of the European Commission

Signature(s)

Name(s)

Title(s)