Directorate-General for Internal Policies of the Union
Directorate for Economic and Scientific Policies
Secretariat of the Special Committee on Beating Cancer

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BACKGROUND NOTE ON SHARED KNOWLEDGE IN CANCER CARE AND RESEARCH

Though public health is the competence of the Member States and EU actions are complementary to national policies, sharing knowledge and pooling expertise in the field of cancer treatment, research and training is the strength of the Union. Thanks to the cross-border healthcare directive, cancer patients can have access to treatment abroad, and via the European Reference Networks their doctor can refer complex cases for virtual consultation amongst specialists. The Europe-wide and international network of cancer registries, the eHealth platform and the electronic health records and the upcoming European Health Data Space are the contributions of the EU for making large amount of health data available for secondary use. Data will drive next-generation cancer research and treatment; technical and interoperability standards and clarity about the legal framework for the use of data will be key in this regard.
"Sharing is caring", for the benefit of the cancer patients and for the advancement of treatment and care. This message clearly projects through Europe's Beating Cancer Plan as well, which plans to step up cooperation and incentives in several areas.

In this note:

I. The data driving cancer treatment, research and policy-making

I.1. Cancer registries and networks[1,2]

Cancer registries are **systems for data collection, storage, validation and analysis**, which allow for **extracting and disseminating information on cancer incidence, mortality, survival, and prevalence rates, time trends, and projections** in the populations covered. On a more advanced plan, cancer registries can give information on the stage at diagnosis, diagnostic and treatment delay, type of treatment, medical equipment use, and compliance with clinical care guidelines.

[1] A-M Forsea: Cancer registries in Europe - going forward is the only option; *eCancer*, 2016
https://ecancer.org/en/journal/article/641-cancer-registries-in-europe-going-forward-is-the-only-option
[2] JRC technical reports: The European Cancer Information System (ECIS) web application
https://www.encr.eu/sites/default/files/JRC113106_ecis_wa_guide_11_sept_2018_print-.pdf

Cancer registries have a key role in:

- epidemiologic research, for monitoring the trends of cancer incidence, survival, and prevalence rates in geographical areas, social groups, or time periods;
- investigation of aetiological factors for cancer, by supporting the analysis of the impact of different social or environmental factors on cancer risk;
- public health policy measures:
    - planning of cancer control measures, helping to prioritise different actions according to the current and projected cancer burden;
    - assessment and monitoring of the effectiveness of cancer control measures such as primary prevention, screening programmes, treatment patterns, and health care quality;
    - assessment of the impact of differences in access to diagnosis and treatment between geographical areas or social groups, in order to create programmes for reducing health inequalities; and
- clinical and translational cancer research.

The **completeness and validity of data, and data quality** is key for cancer registries for assuming their roles. Screening programmes are one of the important data sources for cancer registries, as it was highlighted during the previous BECA hearing in March 2021[3,4]. As the roll-out and coverage of screening programmes differ substantially across the EU and even across the regions in some Member States, this affects the completeness of data included in cancer registries. Aiming for quality-controlled nation-wide screening programmes with sufficient coverage is crucial for cancer prevention, and it remains the primary purpose; and, as improved screening programmes provide more complete and better data, the data feed into the cancer registries also improves.

There are **some 200 population-based cancer registries in Europe**, including national, regional and local ones. At international level, countries have been cooperating under the aegis of the **International Association of Cancer Registries (IARC)**. At EU-level, it is the **European Network of Cancer Registries** (ENCR), operational since 1990, that promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on cancer incidence and mortality in Europe. ENCR is also affiliated to the International Association of Cancer Registries, and it currently comprises178 individual registries across Europe (including non-EU countries).

The **ENCR** aims at improving the quality, comparability and availability of cancer incidence data; creating a basis for monitoring cancer incidence and mortality in the EU; providing regular information on the burden of cancer in Europe; and promoting the use of cancer registries in cancer control, health-care planning and research.

[3] BECA hearing of 18 March 2021: "Saving lives and improving patient outcomes: Why screening and early detection of cancer matter"
https://www.europarl.europa.eu/committees/en/hearing-why-screening-and-early-detectio/product-details/20210309CHE08442

[4] Summary of the BECA hearing of 18 March 2021 on "Saving lives and improving patient outcomes: Why screening and early detection of cancer matter"
https://www.europarl.europa.eu/cmsdata/231399/Summary_BECA%20meeting_18%20March%202021.pdf

Its full membership is open (upon the fulfilment of other, well-defined criteria) for population-based cancer registries, i.e. registries that collect data on all new cases of cancer occurring in a specified population in a defined geographical area.

General cancer registries in Europe with ENCR membership

Fed by data from the cancer registries, as well as from UN, WHO and Eurostat sources, the **European Cancer Information System** (ECIS) provides the latest information on indicators related to the cancer burden across Europe. The web-based tool thus supports research and decision making in public health policy in the field of cancer and serves as a point of reference and information for European citizens. ECIS allows for monitoring cancer burden, its trends and future evolution (over time, and across Europe and its geographical regions); and assessing the magnitude of the cancer burden and its likely future evolution. It provides data to illustrate the effects of health policy interventions; establishes a reference base for cancer epidemiological research; and provides information for further research on possible underlying causes of cancer as well as best practices for prevention, treatment, and follow-up. Its web-based application for data visualisation was launched in 2018. The ECIS is managed by the European Commission's science and knowledge service, the Joint Research Centre (JRC), which supports EU policies with independent scientific evidence throughout the whole policy cycle.

Under **Europe's Beating Cancer Plan** (COM(2021)44[5]), **ECIS will be expanded** to understand cancer more, and tackle it better. New indicators detailed also by cancer staging, a new section on childhood cancers, and more detailed data at sub-national level will facilitate linkages with environmental and socioeconomic data.

I.2. Electronic health records

Electronic health records (EHRs) are collections of longitudinal medical records or similar documentation of a patient, in digital form. In order to achieve secure, interoperable, cross-border exchange and access to electronic health data in the EU, Commission Recommendation (EU) 2019/243 sets out the framework for the development of a European EHR exchange format. In addition to the governing principles on access and exchange, the recommendation also includes common technical specifications.

Electronic health records can improve healthcare and patient outcomes in a number of situations:

[5] Communication from the Commission: Europe's Beating Cancer Plan
https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52021DC0044&qid=1617800220487

- *Cross-border healthcare:* There are over two million recorded instances a year where a citizen living in one Member State has sought healthcare in another. Secure access and sharing of health records across borders facilitate citizens' life in cross-border situations; e.g. citizens having moved within the EU can have access to health records between the Member States in which they have been resident; and quality of care is improved when medical treatment is required while travelling in the EU, or as part of a cross-border agreement. The Recommendation also mentions the link, in the future, between EHRs and EU initiatives in the field of social security coordination.

- *Telemedicine:* A system that allows a citizen secure access to their own health data combined with digital solutions linked to health applications or wearable devices, also enable patients with chronic conditions such as cancer to monitor their own symptoms at home and share them quickly with their clinical teams. This not only reduces the number of visits to a health facility for monitoring, but also helps to detect early a need for a change in treatment, resulting in fewer hospitalisations due to complications.

- *Sharing clinical information between treating doctors:* Europe's Beating Cancer Plan forecasts that electronic health records will become crucial tools in cancer prevention and care. They will ensure that oncologists, radiologists and surgeons can share clinical information efficiently with each other, enhancing the patients' treatment and survival chances. EHRs can also give a clearer picture on the experiences and outcomes of oncology patients than clinical trials. Combining health records with other data sets (in compliance with data protection rules), such as genomics, can provide even better insights into the efficacy of treatments and their optimisation.

The **Beating Cancer Plan** underscores the importance of EHRs in the European Health Data Space (more on this in the next section), and commits the Commission to work with Member States on a common exchange format for EHRs taking into account data security, privacy and interoperability.

I.3. eHealth systems and the European Health Data Space

The development and deployment of eHealth solutions in healthcare systems is a national competence, but the EU has been supporting Member States' efforts through funding and collaboration platforms for almost a decade now. Certain areas like interoperability and quality standards are addressed at European level, through coordinated action and digital alignment.

Several structures provide a platform for collaboration and cooperation[6]:

- Set up under Directive 2011/24/EU on cross-border healthcare, the **eHealth Network** is a voluntary network connecting national authorities responsible for eHealth. The network helps shape policy on eHealth

[6] https://ec.europa.eu/health/ehealth/cooperation_en

interoperability and standardisation, and can give direction to eHealth developments in Europe.

- eHAction, the **Joint Action supporting the eHealth Network**, was launched in 2018 to support the eHealth Network with technical and scientific advice, facilitate cross-border healthcare and provide the necessary policy support to the **eHealth Digital Service infrastructure** (eHDSI). eHAction develops strategic recommendations and instruments to support the political discussions between the eHealth Network, Member States and the Commission on certain priority areas, which are based on the eHealth Network Multiannual Work Programme.
  The roll-out of the **eHealth Digital Services Infrastructure** was supported by the Connecting Europe Facility (CEF) Programme.

- The **eHealth stakeholder group** (eHSG) is composed of altogether 30 members, who are representatives of European umbrella organisations and associations, and organisations with a European outreach in the fields of research, industry, standardisation and associations representing users (patients, professionals, providers etcetera) active in the eHealth sector. It was established in 2012, and its mandate ends in 2022.

- The **Joint Action for the European Health Data Space**, TEHDAS (Towards the European Health Data Space) was launched in February 2021, bringing together 25 European countries, including 21 Member States. It supports the Commission's work on the European Health Data Space by bringing together relevant actors on the secondary use of patient data; collecting best practices across the EU on the secondary use of data; and developing 'concepts' and 'options' for efficient secondary use of health data on governance, data quality, infrastructure and the empowerment of citizens.

The 2018 Communication from the Commission on the **digital transformation of health and care** (COM(2018)233)[7] gave a new impetus to the eHealth sector. It builds on the digitisation of the health and care sectors around three axes:

- **Secure data access and sharing**, via the establishment of the **eHealth Digital Service Infrastructure**, in which all Member States would participate by 2025. It allows the exchange of e-prescriptions and patient summaries between healthcare providers; the first cross-border exchanges started in 2019. Work is also underway to establish a European EHR exchange format that is accessible to all EU citizens.

- **Connecting and sharing health data for research, faster diagnosis and improved health**. Digitising health records and enabling their exchange for secondary use supports the creation of large health data structure. Combined with the use of new technologies, such as big data analytics and artificial intelligence, it supports the search for new scientific discoveries and improves prevention, diagnosis, treatments, drugs and medical devices. This is reflected in the TEHDAS Joint Action, mentioned above.

[7] Communication from the Commission on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society (COM(2018)233) https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2018:233:FIN

- **Strengthening citizens' empowerment and individual care**. Digital services help citizens to be more in charge of their own health. By using those services, citizens can more easily follow prevention guidelines, find motivation to lead healthier lifestyles, manage chronic conditions and provide feedback to healthcare providers. The use of telehealth and eHealth also helps to ease the stress on the health care system, derived from the rise of chronic conditions and an ageing European population, and help with the transformation towards integrated and personalised care systems.

The creation of a European Data Space, including a common **European Health Data Space** (EHDS), is one of the priorities of the Von der Leyen-Commission. It will allow better exchange and access to different types of health data (EHRs, genomics data, data from patient registries etcetera), both for primary and secondary use. From the patients' point of view, it will enable them to securely access and share their health data in an integrated format in the EHRs between healthcare providers and across borders in the EU; this way, health and care delivery happens along the entire patient pathway. For secondary data use, it will connect with the Knowledge Centre on Cancer that will be launched in 2021 as one of the Flagship initiatives of Europe's Beating Cancer Plan, to ensure that learnings are shared efficiently.

The legislative proposal on the European Health Data Space is expected later in 2021 and will be built on three main pillars: (i) a strong system of data governance and rules for data exchange; (ii) data quality; and (iii) strong infrastructure and interoperability. The new Joint Action, TEHDAS, has already been set up, as mentioned above.

I.4. Data protection rules[8]

As it is clear from the above, health data can be used for different purposes: the primary use of data is for direct patient care; and secondary data use consists of supporting the safe and efficient functioning of healthcare systems, and driving health research and innovation. Data protection rules play a key role in ensuring safe data flow.

The EU's **General Data Protection Regulation** (Regulation (EU) 2016/679, GDPR), applicable since 2018, is part of the EU data protection reform package. The regulation modernises and unifies rules, allowing businesses to reduce red tape and to benefit from greater consumer trust, and citizens to better control their personal data. Its relevance for cancer research and cancer registries is that the regulation recognises the principle of *one-time consent* for retrospective research and biobanking, and the principle of *no consent* for population-based registries.

Article 7 of the GDPR regulates consent, and some key recitals elaborate on the secondary use of data. With regard to **one-time consent for retrospective research and biobanking**, **Recital 33 of the GDPR** acknowledges that it is often not possible to fully identify the purpose of personal data processing for scientific research purposes at the time of data collection, i.e. the subject of future research may be unknown at the time when a patient gives his/her consent on the use of clinical data for scientific purposes. The recital also explains that patients should be allowed to give their consent (withdrawable any time) to certain areas of scientific research, or certain areas of research or parts of research projects.

[8] P.G.Casali: Data protection and research in the European Union: a major step forward, with a step back; *Annals of Oncology*, 2020
https://www.annalsofoncology.org/article/S0923-7534(20)42964-3/fulltext

The new **Clinical Trials Regulation** (Regulation (EU) No 536/2014, CTR, not yet applicable) specifically acknowledges the notion of one-time consent with regard to clinical trials. CTR specifies that in order to collect data from clinical trials to be used for future scientific research, it is necessary that the trial subject gives consent (withdrawable any time) to the use of his/her data outside the trial protocol. In this case, the one-time consent is given to use data retrospectively beyond the end and scope of a clinical trial. CTR is very clear on that all this should comply with the framework of the GDPR.

Concerning **epidemiological research**, **Recital 157 of the GDPR** underlines that researchers can obtain new knowledge on widespread medical conditions such as cancer by coupling information from registries. Provided that safeguards set by EU law or national law for the protection of privacy are complied with, registries should be allowed to process data even without patient consent.

A recent study[9], prepared for the Commission, has assessed **Member States' rules on health data in light of the GDPR**. As the interpretation of the GDPR varies across Member States and national legislation linked to its implementation has created a fragmented approach, it has negatively affected cross-border cooperation for providing healthcare, healthcare system administration and research. During previous BECA hearings in November 2020[10,11] and February 2021[12,13,] experts highlighted the unfortunate consequences of the GDPR on medical research, pointing to issues concerning comparability of the data needed for proper research. The GDPR left a margin of manoeuver for Member States to further specify the application of the regulation in the area of health and Article 168 the Treaty on the Functioning of the European Union, therefore a fully harmonised approach to the rules on processing of data in the area of healthcare provision, administration or research across the EU has not been achieved. Furthermore, the interpretation of the law is complex for researchers at national level, and patients do not always find it easy to exercise the rights granted by the GDPR. The study has concluded that there is **support for actions at EU level to promote health data access and sharing**; such measures may include a combination of soft law, e.g. via a code of conduct, with other non-legislative and legislative actions. A code of conduct is considered desirable to explain concepts from the GDPR and to ensure a consistent approach to health data exchange at a more practical level, e.g. defining formats for data exchange.

[9] J. Hansen, P. Wilson, E. Verhoeven, M. Kroneman, M. Kirwan, R. Verheij, E-B. van Veen: Assessment of the EU Member States' rules on health data in the light of GDPR
https://ec.europa.eu/health/sites/health/files/ehealth/docs/ms_rules_health-data_en.pdf
[10] BECA hearing of 12 November 2020: "Supporting research on cancer - New mission on cancer within Horizon Europe"
https://www.europarl.europa.eu/committees/en/supporting-research-on-cancer-new-missio/product-details/20201103CHE07721
[11] Summary of the BECA hearing on "Supporting research on cancer - New mission on cancer within Horizon Europe"
https://www.europarl.europa.eu/cmsdata/215331/BECA%20hearing_research_12.11.20_Summary.pdf
[12] BECA hearing of 23 February 2021: "From lab to life: transforming childhood, adolescent and rare cancer care"
https://www.europarl.europa.eu/committees/en/hearing-from-lab-to-life-transforming-ch/product-details/20210216CHE08322
[13] Summary of the BECA hearing on "From lab to life: transforming childhood, adolescent and rare cancer care"
https://www.europarl.europa.eu/cmsdata/230434/Summary%20BECA%20Hearing%20Paediatric%20adolescent%20and%20rare%20cancers%2020210223.pdf

II. Sharing expertise and thriving for the highest standards

II.1. European Reference Networks[14]

The EU plays a central role in improving collaboration across countries in respect to cancer. Launched in 2017 in connection to the Cross-Border Healthcare Directive, several European Reference Networks (ERNs) were constructed and have been operational since then.

Four of these networks are specifically devoted to cancers:

- European Reference Networks on Rare Adult Solid Cancers (EURACAN)
- European Reference Network on Rare Haematological Diseases (EuroBloodNet)
- European Reference Network on Paediatric Cancers (ERN PaedCan)
- European Reference Network on Genetic Tumour Risk Syndromes (ERN GENTURIS)

To be recognised by the Commission, an ERN must fulfil the following requirements[15]:

- ✓ have at least ten healthcare providers from at least eight different EU countries;
- ✓ each healthcare provider be endorsed by their respective EU country;
- ✓ all members of a network have common expertise in a specific field, treatments, diseases or health conditions;
- ✓ a proposal is submitted, once the Commission has launched the call for ERN;
- ✓ meet the criteria for networks and its members, as provided in the Commission delegated decision on ERNs (Commission Delegated Decision 2014/286/EU); and
- ✓ gain the approval for membership, which is granted by the Board of Member States based on the independent technical assessment of the proposal.

ERNs pool **knowledge and resources via virtual networks of healthcare providers across Europe**, to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment. The management of rare and complex cancers poses significant diagnostic challenges, sometimes with major consequences for patients' quality of life and outcome. Inappropriate management of these patients may result in an increased risk of relapse, and risk of death. ERNs are opening new possibilities for improving cancer treatment and care by sharing clinical cases; rationalisation of patient referral; and improved rare cancer management in small countries.

In concrete terms, to review a patient's diagnosis and treatment, ERN coordinators and other network leaders convene **'virtual' advisory boards of medical specialists** across different disciplines, using a dedicated IT platform and telemedicine tools. Consultations are carried out through the Clinical Patient Management System (CPMS), which is a dedicated web-based

[14] https://ec.europa.eu/health/ern_en
[15] https://ec.europa.eu/health/ern/implementation/faq_en

clinical software application that allows healthcare providers to work together virtually to diagnose and treat patients. ERNs are not directly accessible to individual patients; it is their healthcare provider who refers the patient's information to the competent ERN member, with the patient's consent and in accordance with the rules of their national health system. Spreading information amongst oncology professionals and cancer patients about cross-border treatment options and the possibility for virtual consultation via the ERNs is key for exploiting the full potential of these networks for the benefit of the patients.

ERNs collaborate beyond diagnosis and treatment. They develop guidelines, provide training and foster knowledge exchange; facilitate large clinical studies to improve understanding of diseases; support the development of drugs and medical devices through gathering patient data; and contribute to the development of new care models, eHealth solutions and tools.

Europe's Beating Cancer Plan has announced the establishment of an **EU Network** by 2025, linking recognised National Comprehensive Cancer Centres in every Member State. This cross-border collaboration will improve patients' access to high-quality diagnostics and care and the latest innovative treatments, and help with patient mobility. The existing four rare-cancer focused ERNs and **a group of newly-created ERNs for specific, challenging cancer conditions** will support the Network. The new ERNs will deal with complex cancer cases such as metastatic diseases, co-morbidities in cancer care, complex cancers with poor prognosis, paediatric cancers and specific conditions related to genomics in cancer care, palliative care and survivorship.

The Cancer Plan aims to ensure that 90% of eligible patients have access to Comprehensive Cancer Centres by 2030. The **EU Cancer Treatment Capacity and Capability Mapping** project will help to map and share the different capabilities and expertise available across the EU.

II.2. Partnerships and joint actions, Commission initiatives

Through its Health Programme , the EU has been supporting partnerships in the field of cancer for more than a decade, with each project building on the results of the previous ones.
The **European Partnership for Action against Cancer** (EPAAC) delivered documents on a broad range of topics, including the European Guide for Quality National Cancer Control Programmes.

The main deliverable of the **Joint Action on Comprehensive Cancer Control** (CANCON) was the European Guide on Quality Improvement in Comprehensive Cancer Control in 2017, the result of the work of hundreds of cancer experts, in 25 countries and 126 partner organisations. CANCON also published policy papers and briefs.

The **Innovative Partnership for Action against Cancer** (iPAAC), the current Joint Action brings together 24 associated partners and 20 affiliated entities across Europe whose main objectives are to build upon deliverables of the CANCON Joint Action and to implement innovative approaches to cancer control. Its main product will be a Roadmap on Implementation and Sustainability of Cancer Control Actions; an impressive set of work package documents is already available.

European Commission Initiative on Breast Cancer (ECIBC) is a multidisciplinary platform, bringing together healthcare professionals, researchers and patient advocates. The initiative aims at reviewing, developing and facilitating the implementation of European guidelines addressing the entire care pathway for breast cancer, including screening programmes.[16]

The Joint Research Centre has launched the call for experts and patients to form a working group for the development of evidence-based guidelines and a quality assurance scheme for the **new European Commission Initiative on Colorectal Cancer** (ECICC).[17]

II.3. Knowledge Centre

Europe's Beating Cancer Plan announced the launch of **a new Knowledge Centre on Cancer within the Joint Research Centre** in 2021, as one of the flagships of the Plan. It will diffuse best practice implementation, issue guidelines to feed the design and roll-out of new actions under the EBCP, and help coordinating scientific and technical cancer-related initiatives at EU level. E.g., it will contribute to the European Cancer Imaging Initiative, the European Health Data Space and research carried out under the Cancer Mission.

III. Keeping up with excellence: continuing training of oncology professionals

Given the rapid pace of advancement and innovation in oncology, continuing medical education (CME) and continuing professional development (CPD) of oncology professionals is crucial. Their commitment for life-long learning is for the benefit of the patients and the society at large; it is not only a professional requirement or a legal obligation in many Member States, but an ethical obligation as well which for many doctors is deeply rooted in their professional philosophy.

'Training' is to be understood broadly, as it includes meetings for the presentation of pioneering clinical data and the latest educational updates, multidisciplinary congresses or conferences, as well as e-learning. There is no centralised continuing training path for medical professions and for oncology professionals in particular. However, only the completion of accredited trainings/events earn CME/CPD credits and count into the learning history.

A comprehensive study[18], prepared for the Commission, evaluated the **state of play of lifelong learning for medical professions in general**. It concluded that for physicians, CPD was mandatory in the majority of Member States, with the trend of moving away from voluntary schemes. Most of the national regulatory bodies of health professions developed standards and guidelines on the use of CME/CPD, and set the minimum number of credits/hours doctors should gain/spend on CME/CPD on an annual basis in order to meet requirements. However, the consequences for non-compliance of mandatory CME/CPD vary and range in severity, and it is unclear as to whether more serious sanctions are enacted; where CME/CPD is mandatory, it is sometimes linked to financial and status benefits; and in a number of countries it is linked to revalidation, re-certification and -registration. In a few countries, regulatory bodies

[16] https://healthcare-quality.jrc.ec.europa.eu/ ; https://healthcare-quality.jrc.ec.europa.eu/discover-ecibc

[17] https://healthcare-quality.jrc.ec.europa.eu/ecicc

[18] Review and mapping of continuous professional development and lifelong learning for health professionals in the EU, 2013
https://ec.europa.eu/health//sites/health/files/workforce/docs/cpd_mapping_annex3b_en.pdf

determine the subject matters for CME/CPD or the type of CME/CPD that must be undertaken (e.g. formal programmes).

Accreditation of CME/CPD activities and providers is extensive and undertaken by a variety of actors, including regulatory bodies, medical chambers, medical associations, medical/professional societies, etc..

For high quality cancer care, the **European Guide for Quality National Cancer Control Programmes**[19] (produced by the EPAAC Joint Action) requires several provisions to be in place to ensure that oncology professionals are well-prepared:

- licensing and certification systems;
- degree programmes for high-priority medical specialties, including one or more university or departmental chairs;
- continuing education programmes related to oncological care, for both general and specialist physicians, nurses and medical support staff;
- inclusion of integrated care principles within medical curricula; and
- specific requirement for a module on patient communication for all staff working with cancer patients, in addition to clinical coursework.

In the field of oncology, professional medical societies, e.g. national/specialist colleges/cancer societies deliver CME/CPD schemes. At EU-level, cancer associations and organisations organise high-quality events, and so do the ERNs. On some occasions, they team up with universities and learning institutions. The Accreditation Council of Oncology in Europe (ACOE) runs accreditation to CME providers. By participation in accredited programmes, delegates earn CME credits in recognition of the high quality of the education received. In addition to CME/CPD accredited training, the European Institute of Innovation and Technology, the Marie Skłodowska-Curie Actions and the Erasmus+ programme offer training for oncology medical professionals.

Europe's Beating Cancer Plan has announced the launch of an **Inter-specialty cancer training programme** in 2021. The programme builds on cross-border training and information-sharing in the fields of oncology, surgery and radiology; it will also focus on patients' quality of life and well-being, including mental, psychosocial and nutritional support, along with patient empowerment. The training programme fits into the framework of the **Pact for Skills** large-scale partnership in the health sector, which was announced in the Skills Agenda for sustainable competitiveness, social fairness and resilience[20].

IV. Educating cancer patients and the general public, improving health literacy

Education to the general public focuses mostly on **prevention and early detection of cancer**. Given that 40% of cancers are preventable, and that downstaging saves lives and considerably improves patient outcomes, the importance of health education cannot be underestimated. Spreading information by credible sources, in an accessible language, adapted to various ethnic, cultural and social backgrounds is key for success. **Early education of schoolchildren** with age-appropriate materials, reinforcing good lifestyle habits and

19 https://cancercontrol.eu/archived/uploads/images/European_Guide_for_Quality_National_Cancer_Control_Programmes_web.pdf

20 https://ec.europa.eu/social/main.jsp?catId=1223&langId=en

preventing/combatting bad ones at an early age is paramount; it is an investment into a healthier new generation.

The different types of education programmes include increasing the public's awareness of cancer; changing specific risk behaviour; learning self-examination skills; and promoting early cancer detection.

Health education and health promotion campaigns should be part of the **National Cancer Control Programmes** (NCCPs), which should describe the use of those campaigns, health education in schools and other activities, which target different generations in society. International organisations' initiatives such as the **IARC**'s European Code against Cancer[21], and awareness raising campaigns by **patient organisations** contribute greatly to the education of the public.

Europe's Beating Cancer Plan has introduced a series of initiatives to **improve health literacy** to be implemented in 2021-2015. It includes:

- promoting cooperation between health and social services and the community, involving social workers, teachers and nurses to educate the public on healthy behaviour, and patients on how to live well after cancer treatment;
- **updating the European Code against Cancer**, based on the latest scientific developments and completed by new evidence-based recommendations to improve health literacy, and ensuring that by 2025 at least 80% of the EU population will be aware of the Code;
- deploying an **EU Mobile App for Cancer Prevention**, to be funded under the EU4Health programme, that will reinforce the Code by offering individuals information on how to reduce their cancer risks and how to benefit from new developments in personalised cancer risk-assessment; and
- launching a new project on **Health Literacy for Cancer Prevention and Care** to develop and share best practice to strengthen health literacy in cancer prevention and care programmes, with a focus on disadvantaged groups.

Access to accurate information for cancer patients and their family is crucial throughout the whole cancer journey: at the time of receiving the cancer diagnosis, during treatment, and in remission and end-of-life care as well. Learning about the particular cancer, treatment options including treatment abroad, and possible outcomes enable patients to take informed decisions about their care. It is an integral part of patient empowerment and patient-centred cancer care.

[21] https://cancer-code-europe.iarc.fr/index.php/en/