



Co-funded by the Health Programme of the European Union

Innovative Partnership for Action Against Cancer (iPAAC) Joint Action

Final layman report February 2022

www.ipaac.eu

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Foreword

Cancer control poses several challenges to the entire community of stakeholders involved in addressing cancer. Not all of them can be tackled within a single project or a programme but many can be discussed, assessed, and comprehensively addressed. The overarching aim is always the same - improving cancer care and cancer control for the benefit of all cancer patients, their carers, professionals, and our entire societies.

The innovative Partnership for Action Against Cancer (iPAAC) is the third Joint Action (JA) in row, dedicated to cancer control on the

initiative of the European Commission (EC) and the Member States (MSs). Its two main objectives were to address some of the current, burning issues in cancer control in the EU and, to propose a synthesis of the policy actions in cancer control across all MSs and across the three JAs. The fulfilment of these two objectives resulted in the final deliverable - the Roadmap on Implementation and Sustainability of Cancer Control Actions (https://www.ipaac.eu/roadmap).

iPAAC was funded under the 2017 call of the Third European Health Programme of the EU 2014–2020. The iPAAC JA consortium was composed of 44 partners (between Competent Authorities, which are public institutions nominated by the respective Ministries of Health (MoHs) and Affiliated Entities, which are institutions linked to the former) from 24 European countries. Out of those 21 were EU MSs and also Moldova, Norway and Serbia participated. The coordination was carried out by the National Institute of Public Health of Slovenia (NIJZ). JA iPAAC was running for three years and nine months between April 2018 and December 2021.

This report summarises nearly four years of work by the iPAAC JA Consortium. It includes results and deliverables prepared by the five specific work packages as well as the development of the Roadmap. Until

March 2020 the work of the project was running according to plan. Similarly, as all our other activities, the work of the JA was affected by the COVID-19 pandemic. All presential meetings, discussions, workshops, and conferences had to be replaced by virtual events. No event was cancelled, and we estimate that the reach of most of our open online events was even greater than in the pre-pandemic times. Obviously, some of our activities were delayed but, with the support of the EC and HaDEA, we managed to complete all our deliverables and activities during the nine-month extension. The report brings details of the deliverables and activities that were running under each of the work packages and have contributed to the different actions, which have already been launched. We estimate that several of our actions and deliverables will importantly contribute to the implementation of the Europe's Beating Cancer Plan.

We would like to thank all the partners of the Consortium, our very special thanks go to the work-package leaders, who have done a lot of the groundwork in their respective specialised areas represented by the work packages. We could not have achieved this much without the strong commitment, dedicated work, and efforts of all partners in the consortium in reaching our joint objectives and completing our deliverables.



Estimates of cancer mortality in EU countries in 2020 (European age-standardised rates per 100,000 population, all sites but non-melanoma skin). Source: European Cancer Information System, https://ecis.jrc.ec.europa.eu/

Executive summary

The Joint Action Innovative Partnership for Action Against Cancer (iPAAC – www.ipaac.eu) was a project financed jointly by the European Commission's Agency HaDEA and the governments of the participating Member States (MSs). It joined partners from 24 MSs as well as Moldova, Norway, and Serbia in developing its work around two interconnected pillars: several topics addressing current challenges in cancer control in Europe and the development of the Roadmap on Implementation and Sustainability of Cancer Control Actions (www.ipaac.eu/roadmap).

The topical work of the JA evolved around three core themes: health promotion and cancer prevention (including early detection) combined with the extension of

- cancer population registries' datasets;
- **cancer genomics** and immunotherapy for cancer;
- NCCPs, accreditation and certification of networks, patient pathways as well as PREMs and PROMs.

Each of these activities produced a series of deliverables, which are further elaborated in this abbreviated final report. This project showed continuity in tackling new issues in cancer screening as this had been one of the key topical areas of all three cancer JAs and a structured elaboration of new evidence on existing recommended screening programmes and on the potential new ones, thus feeding into the forthcoming proposal of new EC Recommendations on screening. Importantly, the implementation of the **European Code Against Cancer** (ECAC) has been dealt with as a key topic in promoting simple and easily understandable measures in reducing future burden of cancer where participation of IARC has proved to be extremely valuable. Cancer registries are one of the cornerstones of both the successful measurement of cancer burden as well as of assessing the advances in cancer treatment and control. We proposed an additional set of indicators to get a better grasp of the impact of social inequalities and cancer and the way social determinants impact on outcomes as well as how to monitor the challenges posed by survivorship. Understanding cancer genomics is important from the point of view of prevention as from the treatment alternatives development in cancer control.

A previously developed policy paper in the frame of the CanCon cancer JA was now upgraded and coupled with the activities on new reimbursement models for immunotherapy, which are the most rapidly developing area in cancer treatment and present many challenges in terms of costs. Also, a proposal for reimbursement in radiation oncology and complex cancer surgery with focus on how to tackle innovation in this model was develop. The approaches developed in iPAAC JA will help MSs tackle them in a more structured and innovative way.

Cancer care is facing many challenges ranging from the need for better and more transparent clinical regulations to addressing cancers, which have not yet been successfully managed. We have provided for sets of standards of care, which have been prepared and agreed with the OECI. Furthermore, we have successfully carried out the certification of two Comprehensive Cancer Control Networks (CCCNs), one in the Charité Cancer Center in Berlin and one in the Lower Silesian Cancer Center in Wrocław. Two patient pathways have been developed for **colorectal** and for **pancreatic cancer**. The latter was an important focus of activities in the field of cancer care (development of Bratislava Statement on pancreatic cancer). Palliative care was another challenge considered with a focus in its integration in the oncology care. An early access to specialized palliative care from diagnosis to end-of-life should be the objective in a high quality care. In addition, an assessment of the prevalence of pain in EU found that more than half of advanced cancer patients suffer from pain and how to deal with it should be included in medical education and clinical guidelines. We stress that experiences of patients and patient-relevant outcome measures need to become central to all interventions concerning cancer care and control.





specific challenges in cancer care combined with the regulatory instruments - sets of standards.



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The central activity of the iPAAC JA was in ensuring that the summarised deliverables and actions of the three cancer JAs and the important policy actions raised in the MSs would be streamlined into a **Roadmap**. This is based on three important sets of inputs:

- results and recommendations of the three JAs;
- Cancer Control Policy Interview Survey (CCPIS) report on visits dedicated to key cancer control **policymakers** in all 24 participating countries;
- one-pagers produced by the countries as examples of their successfully introduced elements of cancer policy.

This is the most important legacy of the cancer control JAs and offers the possibility to be used as a link between the initiatives put forward by the Europe's Beating Cancer Plan (EBCP) and the existing body of work and results of the different actions, which have already been implemented across the EU.

iPAAC has raised and elaborated several issues that have become cornerstones and flagships of the **EBCP**. This is a **significant milestone** and testament to the importance and relevance of the work and results provided by all three JAs on cancer control, launching Joint Action outputs into tangible outcomes and action in this practical instrument able to **impact the entirety of the EU**.

Target groups



Policy- and

involved in healthcare

decision-makers



Professional and scientific organisations involved in cancer care and research





Cancer patients

and patient organisations

Results and outputs

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Roadmap on Implementation and Sustainability of Cancer Control Actions



The main output is the Roadmap on Implementation and Sustainability of Cancer Control Actions – an online tool that can be described in a simplified way as an overview of possible approaches, activities and recommendations on different aspects of cancer control that either have already been implemented in some European countries or will be implemented soon. In one place, it is possible to find out how different countries approach primary or secondary prevention, how they organise treatment for cancer patients, or how they provide care for cancer survivors.

The Roadmap is a web-based application that allows users to browse and search for individual projects according to the domain of the cancer programmes they address or the country they come from. The development of the web application, which is available at <u>www.ipaac.eu/roadmap</u>, was carried out by IHIS CR in close cooperation with the Belgian health institute Sciensano, whose team was responsible for identifying suitable projects and collecting information about them. Each of these projects is described in a unified and structured way by means of a one-pager; it is really a one-page information containing relevant background information, identifying potential problems and presenting the most important results and experience, but also providing links to detailed materials and contact details of the responsible.







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Cancer prevention and early diagnosis

https://www.ipaac.eu/en/work-packages/wp5/

There have been considerable developments during the last 15 years in the implementation of populationbased screening programmes for cancer within the European Union Member States. European countries have a lot of potential to advance cancer prevention and health promotion. Prevention is the most cost-effective long-term strategy for cancer control. About 4 in 10 cancer cases can be preventable.



We looked for social innovations and tools for implementation in three screening programmes recommended by the EU Council (breast, colorectal and cervical cancer). One key area is reducing inequality through cancer screening programmes. The challenges with social inequalities in health are an important focus area also for the so-called risk-stratified screening concepts. With the aim of identifying successful approaches to cancer prevention in terms of equity, we organised a Contest of Best Practices tackling social inequalities in cancer prevention.

We also prepared recommendations for the sustainability and monitoring of the future 5th edition of the European Code Against Cancer, an initiative of the European Commission to inform people about actions they can take for themselves or their families to reduce their risk of cancer.

Genomics in cancer control and care

https://www.ipaac.eu/en/work-packages/wp6/

Cancer pathology is strongly driven by genetic modifications in the genome DNA. A new era in science has emerged in the last decade, the so-called 'genomics' study field wherein we try to better understand health through integrating broad information on the genome with data on the impact of environmental factors such as nutrition, physical fitness but also disease. A societal debate on ethical, legal and privacy issues on the use of genome information in healthcare is needed.

Our research has revealed remaining conflicts of values among citizens, mainly regarding a conception of the genome as an individual property or a common good. The attitude of contributors towards the societal use of genomic information aligns with a soft precautionary approach, in which prudence and the weighing of different values should result in protective measures against potential risks and harms. Further societal implementation of genomics should include these values and concerns.

A distance training on oncogenomics addressed to physicians and biologists has been developed. The course is aimed at improving knowledge, attitude and practice of health professionals on the fundamental principles of genetics and on the main clinical applications of current genomic technologies in oncology.

Cancer information and registries

https://www.ipaac.eu/en/work-packages/wp7/

Cancer registries provide accurate and representative information on cancer patients, real-world data, without any selection due to age, socio-economic or co-morbid condition, granting by design longitudinal follow up, even in the long term. They are not only essential in cancer epidemiology, but they have the potential to support quality improvement in cancer care and provide multidimensional information on cancer survivorship. Despite their potential, cancer registries data are under-utilised.

We conducted a survey on available electronic data sources for individual linkage among 27 population-based European cancer registries from 14 different countries. We performed pilot projects on feasibility of linking population-based cancer registries datasets with administrative and health data







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sources to describe the complete pathway of cancer patients from diagnosis to rehabilitation or terminal care, to assess the adherence of the administered treatments to standard clinical guidelines, and to produce indicators on costs directly related to diagnostic, care and follow-up pathways. A comprehensive ICT model integrating multiple data sources has been developed and piloted.

We also focused on young cancer survivors (15–39 years at cancer diagnosis) to estimate the burden of late effects and to compare late effect indicators. And since cancer survivors are a growing and heterogenous population with varying health care needs through the whole disease journey, we also addressed cancer prevalence as an important indicator derived from population-based cancer registries datasets.



Challenges in cancer care

https://www.ipaac.eu/en/work-packages/wp8/

While cancer care has evolved, showing better organisation and specificity with regards to treating different cancer diseases, cross-cutting and disease-based challenges remain.

We reviewed and assessed the situation for neglected cancers with a special focus on pancreatic cancer, highlighting the challenges and opportunities for improving detection, diagnosis and access to expert clinicians in order to increase the quality of care and outcomes, and raising awareness within the EU Policy and Research agenda. We defined 22-step consensus recommendations that health care systems can rapidly implement to address the issues of pancreatic cancer and to provide high-quality care for patients while maximising the value of health care resources. We also created a list of neglected cancers and quantified the health impact of these cancers.

We also reviewed different reimbursement models for cancer surgery and radiation oncology. This initiative resulted in a set of recommendations to be taken into consideration when developing or updating a reimbursement system for radiation and surgical oncology in order to support and promote a comprehensive perspective, avoid fragmentation, and support valuable innovation.

We further focused on multidisciplinary teams (MDT) and the use of modern information and communication technologies in their work. We identified 10 instruments or functionalities that were related to MDT activities, with implications for transforming the way professionals obtain information, communicate and make decisions.

Innovative therapies in cancer

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https://www.ipaac.eu/en/work-packages/wp9/

The panel of anticancer drugs available has strongly evolved over the past few years. The most recent arrival of specific immunotherapies (therapies that stimulate the patient's immune system to attack cancer cells) has affected the landscape of cancer drugs.

We mapped and reviewed existing clinical practice guidelines placing innovative immunotherapies in the cancer treatment strategy (with a focus on checkpoint inhibitors and CAR-T cells). We also focused on reimbursement of these therapies, early access programmes for unapproved indications, and reimbursement of immunotherapies in European countries with their potential restrictions of uses as well as existing frameworks enabling early access. Recommendations aiming to reduce inequities in terms of access to innovative immunotherapies and for control rising prices have been given.

We reviewed the main existing horizon scanning systems (HSS, tools that predict the availability of new medicines and their main impacts) and related networks in Europe to characterize the methodological specificities needed to enable a better anticipation of anticancer drugs, gene and cells therapies, biomarkers, and paediatric indications. A retrospective analysis of the efficiency of HSS was conducted in order to identify strengths of existing HSS as well as difficulties encountered in the oncology field.

We monitored existing initiatives for the real-life monitoring of patients treated with CAR-T cells and also presented the remaining challenges and notably the gaps that would need further European coordinated approach.







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Governance of integrated and comprehensive cancer care

https://www.ipaac.eu/en/work-packages/wp10/

To coordinate cancer care on the national level and to increase access to quality cancer care, the implementation of Comprehensive Cancer Care Networks (CCCNs) is recommended by the European Guide on Quality Improvement in Comprehensive Cancer Control (CanCon Guide). The quality of care is made transparent through quality indicators (QI), which are used for a continuous quality improvement process. In addition to the QI, patient-reported outcomes, as a central parameter of outcome quality, are another instrument with which the quality in the CCCN as a whole and at the level of the care providers can be measured, compared and improved.

A method for the development of patient pathways was designed and tested with the development of patient pathway templates for pancreatic and colorectal cancer. They have been tested and implemented in two pilot sites in Poland and Germany.

We developed the "iPAAC evaluation tool for QI" (iET-QI) to assess guality indicators identified within our previous review that have been used by European guality assurance institutions in oncology.

Following the literature review, a framework for implementation of Patient Reported Outcome Measures (PROMS) in routine cancer care was developed to enable providers to better serve individual patients (e. g., treatment of impaired quality of life) and to enable cancer centres to compare their own patient reported outcomes data with that of others (benchmarking).

A tumour-specific and a generic set of standards for CCCNs were developed. The overall concept was successfully implemented in pilot CCCNs in two member states (Poland and Germany).



iPAAC Associated Partners

- Slovenia (coordinator): National Institute of Public Health of the Republic of Slovenia
- Belgium: Sciensano
- Bulgaria: National Center of Public Health and Analyses
- Croatia: Croatian Institute of Public Health
- **Cyprus**: Ministry of Health of the Republic of Cyprus
- Czech Republic: Institute of Health Information and Statistics of the Czech Republic
- Finland: National Institute for Health and Welfare France: French National Cancer Institute
- Germany: Federal Ministry of Health
- Greece: 7th Health Region of Crete
- Hungary: National Institute of Oncology
- Ireland: Department of Health
- Italy: National Institute of Health
- Lithuania: Ministry of Health of the Republic of Lithuania
- Malta: Ministry for Health Government of Malta
- Moldova: Institute of Oncology of the Republic of Moldova
- Netherlands: National Institute for Public Health and the Environment
- Norway: Oslo University Hospital
- Poland: National Institute of Public Health National Institute of Hygiene
- Portugal: Ministry of Health of Portugal
- Romania: National Institute of Public Health
- Serbia: Institute of Public Health of Serbia "Dr Milan Jovanović Batut"
- Slovakia: Biomedical Research Center of the Slovak Academy of Sciences
- Spain: Catalan Institute of Oncology







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