iPAAC JA_WP4_Sustainability & Implementation Report

Sustainability & Implementation of Cancer Control Actions

in EU Member States:

Challenges and Opportunities

Author(s):	Belgian Cancer Center, Sciensano, Brussels National Institute of Public Health, Slovenia Régine Kiasuwa Mbengi, Marie Delnord, Anna Francesconi, Marjetka Jelenc, Laure Bakker and Marc van den Bulcke
Version:	1.0
Date:	01. 12. 2021

Contents

Abbreviations

AYAs	Adolescents and young adults
CanCon	Cancer Control
CAR	Chimeric Antigen Receptors
CCCN	Comprehensive Cancer Care Networks
CCPIS	Cancer Control Policy Interview Survey
CHAFEA	Consumers, Health, Agriculture and Food Executive Agency
EBCP	Europe's Beating Cancer Plan
ECAC	European Code Against Cancer
EC	European Commission
EPAAC	European Partnership for the Action Against Cancer
ERNs	European Reference Networks
ERQCC	European Cancer Organisation Essential Requirements for Quality Cancer Care
EU	European Union
GP	General practitioner
Guide	European Guide for Quality National Cancer Control Programmes
HCS	Health Care System
HPV	Human Papillomavirus
INCA	French National Cancer Institute
iPAAC	Innovative Partnership for Action Against Cancer
JA	Joint Action
MDTs	Multidisciplinary teams
MSs	Member States
PCPs	Primary care professionals
PROMS	Patient Reported Outcome Measures
Roadmap	Roadmap on Implementation and Sustainability of Cancer Control Actions
QI	Quality Indicators
WP	Work Package

Executive summary

Cancer continues to present one of the key public health challenges in the European Union (EU). Over the last 8 years, we have seen an intensification of the activities at the level of the EU in order to tackle cancer from different aspects. Still, a number of important outstanding issues in cancer control remain unaddressed. The Innovative Partnership for Action Against Cancer Joint Action (iPAAC JA), which has been selected for funding under the Third Health Programme 2014–2020, aims to build upon the outcomes of previous EPAAC and CanCon Joint Actions.

The general objective of the iPAAC JA was to develop innovative approaches to advances in cancer control. The innovation that is covered within the JA consists of further development of cancer prevention, comprehensive approaches to the use of genomics in cancer control, cancer information and registries, improvements and challenges in cancer care, mapping of innovative cancer treatments and governance of integrated cancer control, including a new analysis of National Cancer Control Programmes (NCCPs). The key focus of the JA was on implementation, reflected in the key deliverable: the Roadmap on Implementation and Sustainability of Cancer Control Actions (Roadmap), which will support Member States (MSs) in implementation of iPAAC JA and CanCon JA recommendations. The content of the iPAAC JA innovative tool Roadmap as well as a concrete example of its use are presented.

This report aims at describing the results of different joint actions and matching them with the challenges reported by EU countries during the Cancer control policy interview survey (CCPIS).

1 THE iPAAC JOINT ACTION: MAIN RESULTS

1.1 EPAAC JA and CanCon JA legacies

EPAAC JA

The general objective of the European Partnership for Action Against Cancer Joint Action (**EPAAC JA**) (2011-2014), which was the first of three consecutive JA projects in the field of cancer was to contribute to the reduction of cancer burden in the European Union (EU) by supporting Member States (MSs) in the development of their National Cancer Control Programmes (NCCPs). EPAAC JA (Figure 1) provided a framework for identifying and sharing information, capacity and expertise in cancer prevention and control. As demonstrated by the existing stark differences and inequalities in cancer incidence and mortality throughout the European Community, there was considerable added value in working together at EU level to prevent and control cancer more effectively.

Figure 1. The logo of EPAAC JA.

The objective of the Commission Communication on Action Against Cancer: European Partnership (COM (2009) 291 final) was that by the end of the Partnership, all MSs should have integrated cancer plans. The more long-term aim was to reduce cancer incidence by 15% by 2020.

In total, EPAAC JA provided with a wide range of deliverables[1], of which the most important are highlighted below:

---

[1] http://www.epaac.eu/final-deliverables

- Primary prevention: the European Week Against Cancer Conferences and the Youth Competition,
- Cancer screening: the European School of Screening Management,
- Healthcare: the multidisciplinary cancer care network approach; the standardization of symptoms in palliative cancer care; information about the inequalities in development and implementation of clinical guidelines; pilot workshop for psychosocial and communication skills among health care providers,
- Research: pilot projects on coordination of cancer research funding,
- Information and data: proposal for a European Cancer Information Society,
- NCCPs: the European Guide for Quality National Cancer Control Programmes (Guide)[2].

All these findings are presented and extensively described in the final overall EPAAC JA deliverable, the publication: "Boosting Innovation and Cooperation in European Cancer Control. Key findings from the European Partnership for Action Against Cancer"[3] (Figure 2).

Figure 2. The frontcovers of the publications European Guide for Quality National Cancer Control Programmes and Boosting Innovation and Cooperation in European Cancer Control.

---

[2] https://webgate.ec.europa.eu/chafea_pdb/assets/files/pdb/20102202/20102202_d10-00_en_ps_european_guide_on_quality_national_cancer_control_programmes.pdf
[3] http://www.epaac.eu/images/OF_Ljubljana/Cancer_book_web_version.pdf

CanCon JA

The goal of the Comprehensive Cancer Control Joint Action (**CanCon JA**) (2014-2017) was to contribute in reducing the cancer burden in the EU mainly by bringing improvements in cancer control strategies. It provided an extensive publication – the European Guide on Quality Improvement in Comprehensive Cancer Control (CanCon Guide) - that MSs can use in cancer control strategies at a national level. This CanCon Guide is addressed to governments, policymakers, health care providers, funders, and cancer care professionals. The main addressed challenge was to shift actions from „how long" people live after diagnosis to „how well" people live from diagnosis onward (Figure 3).

Figure 3. The logo of CanCon JA.

The core chapters of the CanCon Guide adresses the following themes[4]:
- Integrated cancer control, exploring a model of integrated cancer control that reconciles the expertise of high-volume specialized referral centres with the greater accessibility of general hospitals, other health care institutions (e.g. imaging centres, community care centres) and primary care professionals (PCPs), e.g. general practitiones (GPs), home nurses and others),
- Community-level cancer care, focussing on the organization of after-care and supportive care for patients, predominantly outside of specialized oncological care,
- Survivorship and rehabilitation, providing policy recommendations for the content, format, management and implementation of survivorship care plans in EU MSs,
- Cancer screening, providing advice and guidance for the development and implementation of cancer screening in the EU MSs in accordance with the EU Council recommendation and the current European quality assurance guidelines (Figure 4).

---

[4] https://cancercontrol.eu/archived/guide-landing-page.html

Figure 4. The frontcover of the publication European Guide on Quality Improvement in Comprehensive Cancer Control.

In the frame of the work of the CanCon JA another important publication, entitled Cancer Control Joint Action Policy Papers was prepared (Figure 5). The publication covers five Policy Papers that position cancer control into planning processes of the EU MSs. The five topics of the Cancer Control JA Policy Papers that were suggested by the MSs are:

1. A public health genomics approach to "omics" in oncology,
2. Common European objectives for National Cancer Control Programmes,
3. Enhancing value of cancer care through a more appropriate use of health care interventions,
4. An impact evaluation system to assess prevention outcomes, and
5. An equity mainstreaming in the cancer control in Europe.

The frontcover of the publication is presented on Picture 5.

Figure 5. The frontcover of the publication Cancer Control Joint Action Policy Papers.

Building on this knowledge, the expertise and experience acquired by the consortium of these two consecutive policy projects, the third JA on cancer control, Innovative Partnership for Action Against Cancer (iPAAC)[5], aimed at conciliating the provided recommendations with the concrete needs and challenges faced while trying to implement them.

1.2 Examples and experience in EU countries

In order to ensure having concrete insights on the difficulties faced by EU countries while implementing cancer control programs, the iPAAC JA Work Package 4 (WP4), led by the Belgian Cancer Centre of Sciensano, has visited 28 European countries to collect examples of innovative approaches for implementing cancer control policies (cancer control policy implementation survey). These examples of innovative implementation approaches are shared in the so called iPAAC JA tool the *Roadmap on Implementation and Sustainability of Cancer Control Actions* (Roadmap).

> The objective of the Roadmap is to facilitate mutual learning and experience exchange among EU countries.

Semi-structured interviews were conducted with the aim to identify those initiatives that were considered of interest for sharing with other countries by the local stakeholders (i.e., health

---

[5] www.ipaac.eu

advisers, healthcare providers, scientists, civil society representatives and healthcare providers). Five domains were prioritized for the discussion:

- Health promotion and prevention,
- Cancer screening,
- Diagnostics and treatment (innovative therapies),
- Cancer care (including rehabilitation and end of life care) and
- Cancer information systems.

During these discussions, planned and ongoing innovative cancer control initiatives and encountered challenges and the levers used while implementing these initiatives were identified.

The results of this exercise are described in the Cancer Control Policy Interview Survey (CCPIS) Report[6], which can be considered as a summary description of the discussions.

> The CCPIS Report provides an overview of the common and country specific implementation issues reported by MS's, the main organizations models in the six cancer control domains, and the innovative approaches and levers to overcome encountered implementation barriers.

Importantly, the CCPIS does not present an evaluation, benchmarking or a state of play of cancer control policies among the EU countries. The report could represent the basis for the development of propositions for further cancer control actions on EU level.

---

[6] https://www.ipaac.eu/res/file/outputs/wp4/ccpis-report.pdf

1.3 iPAAC JA recommendations supporting cancer control implementation

1.3.1 Effective and sustainable cancer prevention

The iPAAC JA WP5 (Cancer Prevention)[7] aimed at :

- Updating, build awareness and strengthen implementation of the European Code Against Cancer (ECAC) in MSs[8],
- Plan a sustainable monitoring system with a follow-up structure for ECAC[9],
- Target vulnerable populations to reduce inequalities and foster health promotion (building upon the CanCon JA policy papers and the Guide)[10],
- Reinforce cancer prevention via population-based screening programs, further developing the principles of the 2003 EU recommendations on screening,
- Identify data collaboration partners and to describe the process leading to better implementation of screening[11],
- Strengthen screening practices with quality criteria and to remove obstacles of early detection of cancer[12].

1.3.2 Use and implement genomics in cancer care

The iPAAC JA WP6 (Genomics in Cancer Control and Care) aimed at developing practical guidance for MSs on five important aspects in successful integrating genomics in the health care system:

- Societal debate on ethical, legal and privacy issues on the use of genome information in healthcare[13,14],
- Stratified screening by genetic testing of high-risk cancer patients,

---

[7] https://www.ipaac.eu/en/work-packages/wp5/
[8] https://www.ipaac.eu/res/file/outputs/wp5/recommendations-monitoring-sustainability-european-code-againts-cancer.pdf
[9] https://www.sciencedirect.com/science/article/pii/S1877782121000503?via%3Dihub
[10] https://www.ipaac.eu/res/file/outputs/wp5/insight-effectiveness-early-diagnosis.pdf#page=18
[11] https://www.ipaac.eu/news-detail/en/51-wp5-cancer-screening-webinar/
[12] https://www.ipaac.eu/news-detail/en/15-early-diagnosis-of-cancer-5-things-you-need-to-know-registration-open/
[13] https://www.ipaac.eu/res/file/outputs/wp6/belgian-dna-debate.pdf
[14] https://www.ipaac.eu/res/file/outputs/wp6/citizens-conceptions-genome.pdf

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Co-funded by
the Health Programme
of the European Union

- Precision genomics in medical care[15],

- 'Direct to Consumer' testing,

- Education and training on genomics of health professionals, policy makers and the citizens is a key element to full success of this new paradigm in healthcare[16]

1.3.3 Advanced cancer information and registration

The goal of the iPAAC JA WP7 (Cancer Information and Registries) was to advance population-based cancer registries information to better support evidence-based cancer surveillance and care. Two main directions were used.

First, by expanding the current registries data by piloting the linkage with administrative data to derive key additional indicators at population level (data re-use). Three pilots were conducted:

- Integrating cancer registry data on quality of care[17],

- Piloting the integration of data on cancer costs[18],

- Piloting registries data integration to assess long-term cancer survivorship in adolescents and young adults (AYAs) cancer survivors[19].

Second, by better exploiting the current registries data by promoting systematic delivery of cancer prevalence indicators[20] at MSs level in Europe[21].

---

[15] https://www.ipaac.eu/res/file/outputs/wp6/genetic-passport-for-all.pdf
[16] https://www.ipaac.eu/res/file/outputs/wp6/oncogenomics-training.pdf
[17] https://www.ipaac.eu/res/file/outputs/wp7/integrating-cancer-registry-data-quality-of-care.pdf
[18] https://www.ipaac.eu/res/file/outputs/wp7/piloting-integration-data-cancer-costs.pdf
[19]   https://www.ipaac.eu/res/file/outputs/wp7/piloting-registries-data-integration-cancer-survivorship-adolescents-young-adults.pdf
[20] https://www.ipaac.eu/res/file/outputs/wp7/training-prevalence.pdf
[21] https://academic.oup.com/ije/article/49/5/1517/5912108

1.3.4 Tackling cancer care challenges

The iPAAC JA WP8 (Challenges in Cancer Care) has led five specific taks in order to define strategies to improve the quality of cancer care by optimising the use of healthcare resources and promoting realistic and evidence-based responses to existing needs.

The main outputs are the following:

- The Bratislava Statement: consensus recommendations for improving pancreatic cancer care[22],

- Tackling reimbursement for radiation oncology and cancer surgery: challenges and options[23],

- Literature review for definition of neglected cancers and list of variables to study pancreatic cancer[24],

- Multidisciplinary teams (MDTs) and the potential impact of new technologies and systems for improving integrated cancer care[25],

- European Cancer Organisation Essential Requirements for Quality Cancer Care (ERQCC): Pancreatic Cancer[26],

- Literature review on pain prevalence in cancer patients and Recommendations[27],

- Integration between oncology and palliative care[28].

---

[22] https://www.ipaac.eu/res/file/outputs/wp8/bratislava-consensus-statement-pancreatic-cancer.pdf

[23] https://www.ipaac.eu/res/file/outputs/wp8/reimbursement-radiation-oncology-cancer-surgery.pdf

[24] https://www.ipaac.eu/res/file/outputs/wp8/neglected-cancers-definition-literature-review.pdf

[25] https://www.ipaac.eu/res/file/outputs/wp8/multidisciplinary-teams-impact-new-technologies-systems-improvement-integrated-cancer-care.pdf

[26] https://www.ipaac.eu/res/file/outputs/wp8/european-cancer-organisation-essential-requirements-quality-cancer-care-pancreatic-cancer.pdf

[27] https://www.ipaac.eu/res/file/outputs/wp8/pain-prevalence-cancer-patients-literature-review-recommendations.pdf

[28] https://www.ipaac.eu/res/file/outputs/wp8/integration-oncology-palliative-care.pdf

1.3.5 Managing innovative therapies

The iPAAC JA WP9 (Innovative Therapies in Cancer)[29] focussed on immunotherapies and mapped all the existing guidelines and created a database accessible for professionals. In this framework, four main outputs can be mentioned:

- Innovative cancer therapies in clinical practice guidelines[30],
- Reference frameworks linked with the access to innovative therapies[31],
- Horizon scanning systems applied for cancer control in Europe[32]
- Real-life monitoring of innovative immunotherapies[33]

1.3.6 Integrated and comprehensive cancer care

The goal of iPAAC JA WP 10 (Governance of Integrated and Comprehensive Cancer Care) was to further develop practical instruments ensuring a standardized integrated and comprehensive oncological care in all European MSs that is tumour-specific and delivers all-encompassing high-quality care to all patients.

Six main tasks and outputs can be mentioned:

- Report on the basis of the analysis of data from the survey on National Cancer Control Programmes/Cancer documents in EU[34],
- Report on the basis of the literature review and terminological assessment of the terms „Governance/Stewardship in/of Cancer Care"[35],
- Definition and methodical support for patient pathways in Comprehensive Cancer Care Networks (CCCNs)[36],
- Systematic review of the Quality Indicators (QIs) to evaluate the CCCN approach in the management of oncologic patients[37],

---

[29] https://www.ipaac.eu/en/work-packages/wp9/
[30] https://www.ipaac.eu/res/file/outputs/wp9/innovative-cancer-therapies-clinical-practice-guidelines.pdf
[31] https://www.ipaac.eu/res/file/outputs/wp9/reference-frameworks-access-innovative-immunotherapies.pdf
[32] https://www.ipaac.eu/res/file/outputs/wp9/horizon-scanning-systems-cancer-control-europe.pdf
[33] https://www.ipaac.eu/res/file/outputs/wp9/innovative-immunotherapies-real-life-monitoring.pdf
[34] https://www.ipaac.eu/res/file/outputs/wp10/national-cancer-control-plans-survey.pdf
[35] https://www.ipaac.eu/res/file/outputs/wp10/governance-stewardship-cancer-care-literature-review.pdf
[36] https://www.ipaac.eu/news-detail/en/59-patient-pathways-for-comprehensive-cancer-care-networks/
[37] https://www.ipaac.eu/res/file/outputs/wp10/quality-indicators-systematic-review-evaluation-comprehensive-cancer-care-network.pdf

- Methodology for defining quality indicators (QI) in order to monitor and improve oncological care within a CCCN – the iPAAC JA Evaluation Tool for QIs in oncology[38],
- Quality Indicators for Colorectal and Pancreatic Cancer to monitor and improve oncological care within CCCNs[39],
- Implementation of patient-reported outcome assessment in routine cancer care – a systematic review of multicentric programs in Europe[40],
- Framework for the implementation of Patient Reported Outcome Measures (PROMs) in routine cancer care[41],
- Implementation of CCCNs[42].

1.4 The iPAAC JA innovative tool Roadmap

The iPAAC JA WP4 (Integration in National Policies and Sustainability) had the role of gathering all the results from the three JAs into a comprehensive and coherent output, the iPAAC JA Roadmap on Implementation and Sustainability of Cancer Control Policies.

In order to ensure the development of a useful tool and find a consensus among the scientific community and (healthcare) administrators, a Governmental Board has been set up[43].

During almost two years, discussions were led in order to define the objetive, format and content of the iPAAC JA Roadmap. The following requirements were collected:

➢ Present the achievements of the 3 JAs,
➢ Searcheable repository,
➢ Web-based tool, allowing for printing,
➢ Information provided needs to be brief but allows for further investigation if any interest,
➢ Main target group: those in charge of cancer implementation (not the policy development or decision-making process),

---

[38]   https://www.ipaac.eu/res/file/outputs/wp10/quality-indicators-methodology-comprehensive-cancer-care-network.pdf
[39] https://www.ipaac.eu/res/file/outputs/wp10/quality-indicators-colorectal-pancreatic-cancer-care.pdf
[40]   https://www.ipaac.eu/res/file/outputs/wp10/patient-reported-outcome-measure-cancer-care-review.pdf
[41]   https://www.ipaac.eu/res/file/outputs/wp10/patient-reported-outcome-measure-cancer-care-implementation-framework.pdf
[42] https://www.ipaac.eu/res/file/outputs/wp10/cccn-standard.pdf
[43] https://www.ipaac.eu/en/work-packages/wp4/

- ➢ Clear understanding of the 'level' of the information provided (country's examples vs. evidence-based recommendations),
- ➢ Information provided towards implementation (concrete and practical insights + contacts),
- ➢ Tool supporting cancer control implementation/mutual learning/experience exchange.

1.4.1 Format and content of the iPAAC JA Roadmap

In the framework of the third JA on cancer control, iPAAC, the innovative tool Roadmap was developed.

> The Roadmap is intended to facilitate the implementation of cancer control actions in EU MSs.

Many EU MSs face similar implementation challenges and some have developed innovative approaches to overcome these barriers. An organized and facilitated mutual learning is needed to gather knowledge and experience, leading to the improvement of cancer control among EU MS. It allows the identification of remaining gaps, providing with key information on additional efforts needed at the EU level, especially in terms of research.

The Roadmap draws on the practical implementation experience in the field of prevention, screening, diagnose and treatment, organisation of care and cancer information systems and key contextual features of the country (legal framework, healthcare systems, etc.).

The web-based tool is presented as a searchable repository of examples of implemented actions. The Roadmap gathers all results from three EU JAs on cancer control as well as the evidence, background documents and legal frameworks related to the implementation of the examples provided.

The primary target group of the Roadmap are EU-level policymakers and decision makers at national, regional and local level. All of the innovative actions covered by the JA in 'One pagers' will be made available. To ensure knowledge exchange and uptake in national policies, will rely on continued engagement with policymakers at MS level.

1.4.2 How to use the iPAAC JA Roadmap: the case study on cognitive impairments

The iPAAC JA Roadmap represents the concrete and practical result of the iPAAC JA, drawing together the information generated and collected during the last 10 years by the EU Cancer control consortiums[44]. The iPAAC JA Roadmap makes this knowledge and experience available to those who are looking for innovative approaches in the fight against cancer. In order to better capture the opportunities brought by the Roadmap, the idea emerged of putting the Roadmap into use for the first time in order to practically show how it might work.

As a reminder, the iPAAC JA Roadmap presents a sample of examples of the experience gained by different European countries in cancer control actions implementation (e.g. program piloted; studies; campaigns; policy measures; legal frameworks; etc.) but also, the results from the search and gathering of the best available knowledge, reviewed by European experts.

> The most important added value of the iPAAC JA Roadmap is that it represents a unique source of information based on concrete examples or options, which have been applied in EU countries, to overcome specific cancer control implementation problems.

These examples present preferential ways or options for those looking for actions, and interested in replicating similar initiative.

The aim of this chapter is to provide a concrete example of the sustainability of the iPAAC JA project, showing how its results may be utilized by MSs that need to develop, implement or recommend specific cancer control actions.

Context of the case study

In January 2021 France launched a ten-year strategy (634 million of euros for the first 5 years) for the fight against cancer, by which it also wants to act as a driving force at the European and international level by consolidating and deepening the partnership that are essential for the success of the cancer program.

---

[44] EPAAC partners: http://www.epaac.eu/about-us
CanCon associated partners: https://cancercontrol.eu/archived/who-we-are/associated-partners.html
iPAAC partners: https://www.ipaac.eu/en/partners/collaboration/

The National Cancer Institute (INCA) was given the task of leading the development of the strategy and launched a large number of calls for projects, 78 in total, including the involvement of various partners who are considered crucial to the success of the projects.

The French strategy is based on four main pillars: improving prevention; reducing the consequences of cancer and its treatment to improve the quality of life of survivors; and fighting also against cancers with the worst prognoses and ensuring that the progress made will be available to everyone.

In the context of the second pillar '*reducing the consequences of cancer and anti-cancer therapies*', France aims to reduce by 1/3 the number of patients suffering from cancer sequelae. It is for this purpose that INCA has launched a "study on European best practice in the management of the neurological and psychosocial sequelae of cancer treatment". The rationale is that there is the lack of cognitive care among cancer patients, especially survivors although it has a significant impact on their quality of life as e.g. the return to employment.

As iPAAC JA partner, INCA contacted the Belgian Cancer Center of Sciensano, to get support for the use of iPAAC JA results (but also CanCon JA results) and more specifically the results obtained by the WP4 during the Cancer Control Policy Interview Survey (https://www.ipaac.eu/en/work-packages/wp4/).

This section will provide a detailed description of the interaction and use of the iPAAC JA results by France, in order to develop recommendations and action plan to tackle the cognitive impairments among cancer survivors.

Methods

Step 1: INCA defines scope and framework

Following the evaluation of French national cancer plan, one of the main points was to limit sequelae and improve the quality of life of cancer patients. Cognitive difficulties were chosen as one of the sequelae for which there was a need to develop actions as it involves most patients after cancer therapy and not much has been done until now. (*Stratégie décennale de lutte contre les cancers 2021-2030 Feuille de route 2021-2025 fiche action II.1*)[45]

---

[45] https://solidarites-sante.gouv.fr/IMG/pdf/feuille_de_route_-_strategie_decennale_de_lutte_contre_les_cancers.pdf

In March 2021, a call for projects has been launched to improve the knowledge and the capacity to reduce the sequelae due to the cancer disease and its treatment. (Appel à projets 2021 Recherches multithématiques et pluridisciplinaires pour Limiter les séquelles et améliorer la qualité de vie)[46].

The objective was to organize the cooperation between different stakeholders in order to identify what already exists for the management of cognitive difficulties in cancer patients, promote mutual learning and implement new solutions. A document was published with all the technical details of the projects in terms of working hours, number of meetings and expected results, in order to identify possible partners (*Cahier des clauses techniques particulières – CCTP*)[47].

In the framework of the iPAAC JA WP 4, the Belgian Cancer Center of Sciensano has interviewed public health institutions from 28 different states, and gathered a significant database regarding ongoing innovative approaches to cancer control (*WP4 Integration in national policy and sustainability – Report of the CCPIS*)[48].

The screening of answers to the call resulted in the choice of a proposal submitted by ANTARES, a medical consulting agency, proposed as the leader of the project (i.e. responsible for data collection) and UNICANER, as the source of experts that were included in the project for the scientific support at different stage of the project.

Step2: Identify programs or actions and underlying challenges

In order to broaden the field of inquiry INCA and ANTARES decided to adopt a *multivocal* approach. A multivocal literature review is a form of Systematic Literature Review that includes both the formal published literature (articles, review, conference papers) and the grey literature such as white papers and blog posts. This methodology provides insights in both the state-of-the art and practice of a given area.

In parallel, the Belgian Cancer Center screened the CCPIS report and database to look for practical information regarding implemented actions, but also to identify experts in EU countries involved within administrative and medical institutions for the management of cancer-related sequelae. The results were transmitted to ANTARES.

---

[46] https://www.canceropole-idf.fr/appel-projet/inca-2021-sequelles-et-qualite-de-vie/
[47] https://www.canceropole-idf.fr/wp-content/uploads/2021/04/aap2021-inca-sequelles-texte.pdf
[48] https://www.ipaac.eu/res/file/outputs/wp4/ccpis-report.pdf

The INCA, Sciensano and the consortium ANTARES-UNICANCER regularly came together to discuss the results and plan the next steps. Rapidly, researchers faced a lack of literature regarding implemented and structural programs or interventions. The INCA and Sciensano therefore suggested to have a broader approach while choosing the key-words list, but also the sources of information, integrating also results from screening of local health institutes, administrations, etc.

Step 3: Find applicable models

The outcome of the search was a state of the art on what currently exists, in Europe and internationally, to address cognitive difficulties in cancer patients. The Prisma methodology was chosen for presenting the results and for identifying, among hundreds of different data, the most valid examples that could be applied at the French level. The primary goal of identifying effective models was also to reach key responsables to conduct an interview. The Delphy methodology was chosen for conducting the interviews, being conducted in sequence.

Again, INCA and Sciensano advised the researchers to maintain a broad and transnational approach not only to the choice of keywords but also to the selection of the key persons to be interviewed. In that framework, Sciensano suggested useful contacts of stakeholders (people or institutions) active in the field of ‚survivorship care'.

While dealing with implementation expertise and experiences are important, but institutional prerogatives are also considerably significant, as providing the resources and legal frameworks for healthcare.

Step 4: Draw conclusions and recommendation

Results were gathered, interpreted, and presented in a report (Guide) organised in three main chapters: introduction (explaining the context of the study), methodology (how literature search and interviews were conducted) and recommendations. The latter included 6 main recommendations each presenting results, challenges and other more specific recommendations, structured around the subject. The report was submitted for expert evaluation in preparation for the workshop. Constructive discussion within the group took place to present the most interesting and applicable models. Invitations were sent within Europe and internationally to four main working areas: Public Authorities, Clinical experts and researchers (oncologists, psychiatrists, neurologists), representatives of associations and projects.

While dealing with a great amount of information, the way of presenting the results is a key aspect for both understanding and drawing conclusions from it. Experience in the field of European projects and implementation brings concreteness to the presentation of data. Steps to be followed in the process of formulating recommendations and how to present them was the main role played by Sciensano at this level.

Step 5 : Workshop

The online workshop was organized as to be interactive and communicative, making use of voting and discussion. In the first part of the workshop the context and the methodology of the study was presented. In the second part, recommendations were presented, each introduced by an explanation in which main results were highlighted. The participants were invited to vote in favour or not for the recommendations and to motivate their vote. Out of the 29 invited experts, there were 20 participants from different European and non-European countries, with sufficiently varied work expertise to allow a comprehensive analysis of the issue from a wide range of experience. The table presents the participants with their country of origin, field of expertise and institution. The workshop was divided into 6 main sessions each referring to a chapter of the report and recommendation.

Steering Committee members moderated each session, explaining how and why the recommendations were made, but also leading the discussion. The workshop has been an opportunity to describe the findings and recommendations to experts who may or may not support them and can then justify their position. The selected list of participants was a fundamental step in organising the workshop to create a solid group of professionals who could analyse the problem from various points of view and propose concrete solutions at all levels: clinical, social, occupational and personal. The resulting discussion reflected the concrete needs of the medical and social environments and was an additional source of information that was added to the study report and used to finalise the dissemination event.

	Country	Working Role	Institution	Working Domain
				Table showing Work-shop participants
1.	France	Expert	Maison rose - Paris	Psychologue clinicien spécialisé en neuropsychologie
2	France	Expert	Oncogite	Neuropsychologue - Fondatrice oncogite Institut
3	France	Expert	CHU - Lyon	Médecin MPR - Chercheur
4.	France	Usager	Clinique Tivoli-ducos - Bordeaux	Ancienne patiente - Orthophoniste -
5.	France	Expert	Enfant - CHU St Etienne	Oncologue
6.	France	Usager	Patiente	Ancienne patiente, impliquée dans différentes organismes et sociétés savantes comme l'AFSOS, membre du conseil d'administration Europa donna, co-fondatrice de Patients & Web
7.	France	Pouvoir public	Réseau Régional de Cancérologie OncoPaca-Corse	Chef de Projet - Soins de Support Ville Hôpital -
8.	France	Association	Ligue contre le cancer	Ligue contre le cancer - Psychologue du travail
9.	France	Association	Ligue contre le cancer	Ligue contre le cancer - Chargée de mission accompagnement social et socio-professionnel
10.	France	Société savante	AFSOS	Directeur AFSOS - Oncologue
11.	France	Pouvoir public France	ARS - Corse	ARS - gastro-entérologue – PACA
12.	Danemark	Association - institut de cancer	Danish Cancer Society	Responsable Documentation et Développement
13.	Portugal	association de patient	ECL	ECL representative of the Liga Portuguesa Contra o Cancro
14.	Pologne	Institut oncologie	Maria Sklodowska-Curie National Research Institute of Oncology	Head of Department of Soft Tissue/Bone Sarcoma and Melanoma Warsaw Poland Deputy Director for National Oncological Strategy and Clinical Trials
15.	Denmark	Research	Aarhus university	Researcher
16.	Belgium	Research	KU Leuven	Researcher
17.	Belgium	Research	KU Leuven	Researcher
18.	Belgium	Research	CHU Brugmann	Researcher – Psychiatrist
19.	Italy	Expert	Italian National Cancer Institute - Milan	Pediatric oncologist
20.	Spain	Expert	Bellvitge University Hospital	Neurologist
21.	Luxembourg	Expert	La Croix Rouge Château de Colpach	Directeur général chez Centre de rehabilitation

Table 1. List of participants to the workshop

Step 6: Dissemination

For the online dissemination event 135 invitations were sent, as shown in the table below, to different stakeholders around Europe (public authorities, clinical experts and members of the iPAAC Governmental Board) and finally 50 participants registered for the event. During the whole duration of the iPAAC JA, the GB members have been actively participating in building up the Roadmap and the dissemination event represented a first practical demonstration of how the Roadmap could be used once available online. Firstly, the specificity of the Roadmap, of the case study and of problems related to cognitive impairments where presented in details. Results were presented with the main recommendations. For each recommendation a concrete example was proposed as an example and a model „to" or „not-to" be followed.

While presenting the results of the study it was important to focus the attention of the participants on three main points: the study subject, the utility of the iPAAC Roadmap and the sustainability of the results. Regarding the study area it has been clearly demonstrated that cancer patient are significantly concerned with cognitive impairments and something has to be done in order to implement interventions in this domain and give concrete solutions for their management. The Roadmap has been presented as a useful tool which has been associated to literature search to provide practical and technical information in terms of initiatives already implemented and key persons that could be interviewed.

#	Organisation/institution
1	German cancer Research center DKFZ
1	SIOPE- European Society of Paediatric Oncology
2	Institut National du Cancer -Luxembourg
1	ECL
1	Bellvitge University Hospital (Spain)
1	European Regional and Local Health Authorities
1	Joint Research Centre
2	National Institute of Public Health NIH - National Research Institute (POLAND)
2	Sciensano
1	Institute of Public Health of Serbia
1	Centre de rehabilitation du chateau de colpach (Luxembourg)
1	Cancer Care Pathways Directorate Malta
1	CHU Brugmann (Belgium)
1	Oncogite
1	Generalitat Valenciana
1	Member of Cancer Mission Board
1	Réseau Régional de Cancérologie OncoPaca-Corse
1	DG Research & Innovation6 European Commission

| 2 | Unicancer | |
| 1 | Nijz (Slovenia) | |

Table2. List of organisations/institutions present at the dissemination event

Budget (EUR)		
	Study conduction	**50 000**
	Expert Workshop	**5 300**
	Dissemination event	**11 300**
Duration (months)		
	Study conduction	**7**
	Expert Workshop	**1**
	Dissemination event	**0,5 (2 weeks)**
On-line meetings (number)		
	Study conduction	**14 (2/month)**
	Expert Workshop	**4 (1/week)**
	Dissemination event	**2 (1/week)**
Produced documents		
	Study conduction	**Report (Guide) PPT-results and minutes each meeting**
	Expert Workshop	**PPT presentation voting analysis**
	Dissemination event	**PPT presentation on-line recording**
Contacted persons/institutions (number)		
	Study conduction	**72(30 interviwed)**
	Expert Workshop	**29 (20 attended)**
	Dissemination event	**135 (50 attended)**

Table 3. Summary table of the case-study
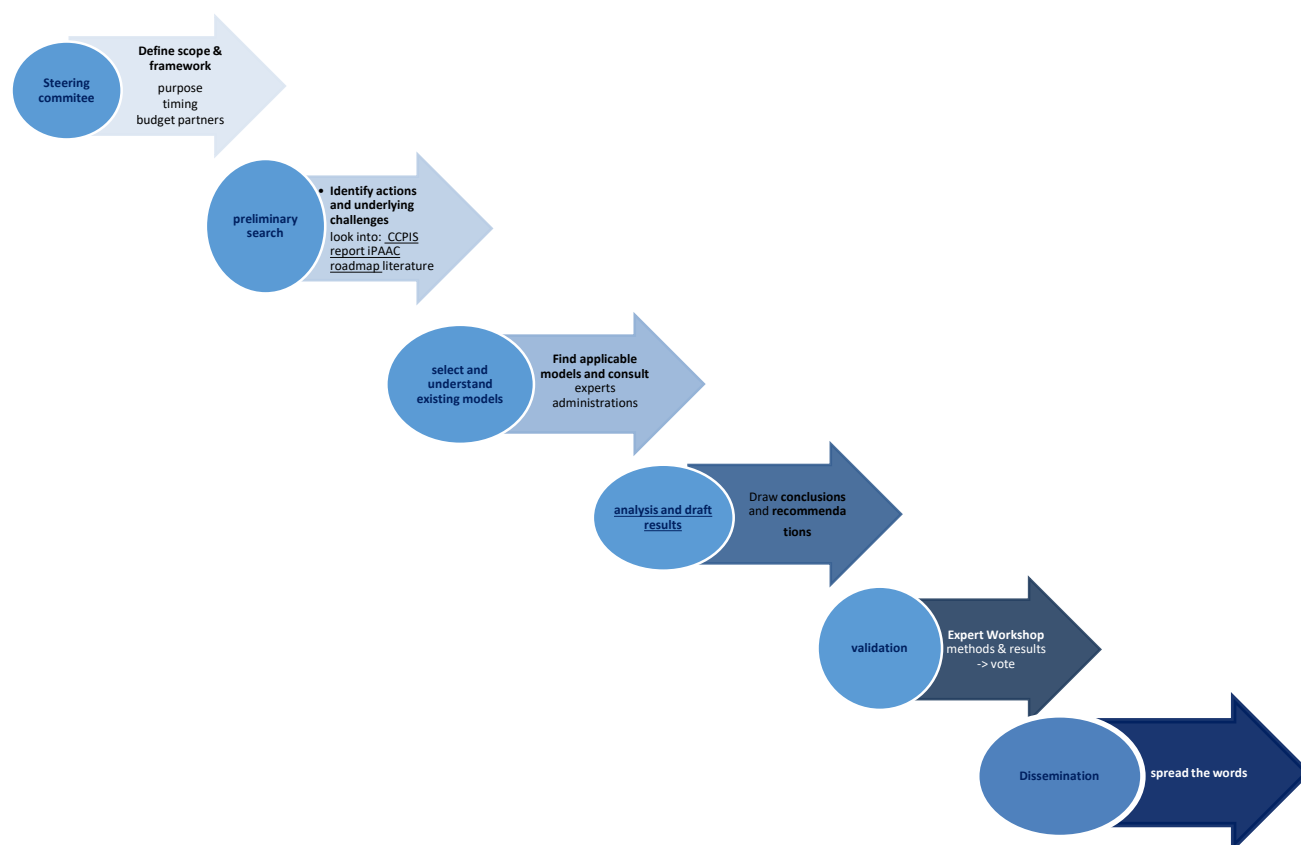
Figure . The stepwise approach followed to derive recommendations for the management of cognitive difficulties after cancer treatment.

LESSONS LEARNED AND FUTURE STEPS

Problem of low level of evidence filled in by expert's opinions. Considering the exercise that has been performed, one of the main challenges was the low level of evidence available regarding the selected topic. Indeed, this represented also one of the main reasons why that specific topic was selected. This gap was mainly filled by the experts opinion which came out particularly during the workshop. Indeed the work-shop was probably the most significant moment of the group's work, as it allowed the analysis of the results and at the same time gave the possibility to discuss them with concrete territorial experiences. The presentation and voting of recommendations helped to direct the discussion to existing problems and possible

solutions in a rapid and concrete manner. Proposals and suggestions of the participants were included in the presentation of the dissemination event, offering additional incentive to the participants.

Problem of low level of correspondence filled in by iPAAC contacts. After scientific and grey literature searches, key persons from facilities and initiatives were identified and contacted in order to conduct the interview. Lack of response and willingness to participate in the interview not only indicated a lack of interest, but was an obstacle to the progress of the study. Previously established working contacts within the iPAAC working group have been of great help. Willingness is always the result of personal interest but also of trust in the kind of work being done. The dissemination event represented the first moment of interaction with a large audience of public authorities, decisive not only for the presentation of the work done and the resulting recommendations, but also for starting a new type of co-working relationships that will necessarily have to be consolidated and developed over time.

CONCLUSION

European projects represent a new way of working and in the future almost everyone will be involved in one or more projects. Within a consortium, a large number of experts, representing a wide range of fields of work, have the opportunity to share ideas and build projects that are likely to be realised. In this context, the Road Map represents a unique source of information and contacts that can help not only to create new professional relationships, but also to benefit from the experience of others to further solve specific problems more quickly and efficiently.

2 CANCER CONTROL IMPLEMENTATION CHALLENGES

2.1 From recommendations to implementation

The last decade has seen great improvements in cancer care and prevention. The iPAAC JA, which has been selected for funding under the Third Health Programme 2014–2020, aims to build upon the outcomes of previous EPAAC and CanCon JAs. In both JAs, policy and practice recommendations were also developed such as the European Guide for Quality National Cancer Control Programmes (Guide) (2015). However, recommendations do not allow to solve practical implementation issues. Many policy recommendations in the field of cancer control have been developed at the EU level, but insights on the practical implementation are lacking.

In-depth interviews with national policy makers, administrators and experts of 28 EU MSs were carried out as part of iPAAC JA WP4. The CCPIS Report provides a summary of the challenges encountered also focusing on solutions from the field.

In the CCPIS, two types of examples of experiences came up:
- Firstly, implementation plans or frameworks and
- Secondly, practical solutions to implementation challenges.

These last relate to different barriers encountered: the industry lobbies; stakeholder's involvement; avoid and tackle social inequalities; evaluation of programs; introduction and financing of innovations, digitalization, organization of the health care system, etc. The results also include a series of reported challenges for which further policy support or knowledge is needed.

Similar challenges exist and are solved in different EU countries. Through translating the examples of implementation experience into 'One Pagers', countries can learn from each other and develop the strategies that can support optimized implementation.

2.1.1 Health promotion and prevention

When it comes to primary prevention, all countries reported having pursued innovative approaches to better inform and communicate with key stakeholders, especially related to children, adolescents and young adults (AYAs) and lower socio-economic groups. A recurrent issue concerns the sustainability of primary prevention actions. A vicious circle exists due to the difficulty in measuring short-term impacts, which in turn, does not provide support for the provision of structural budgets.

Register-based collection of structured and validated data of lifestyles and interventions from electronic data sources in health care would be a key to evaluation and to generate evidence-based recommendations.

A second important challenge relates to the interference of the corporate giants of the tobacco, alcohol and food industries. Regulatory actions as well as inter-ministerial and inter-sectorial platforms have proven their efficacy to mitigate the influence of these corporate interests and promote the pursuit and maintenance of healthy lifestyles.

The Table 1 presents the list of challenges reported during the CCPIS , with a cross-overview of the related existing material provide by the three joint actions on cancer control, and the

flagships and actions of the Europe's Beating Cancer Plan (EBCP) and the recommendations of the EU Mission on Cancer.

In health promotion and prevention, commercial determinants play a major role and should not be ignored. Although few countries made references to EU regulations and legislation, it should be mentioned that several EU-level regulations are the rationale for national policies.

Indeed, cancer is a major health issue as referred in Article 168 TFEU, which gives the EU the competence to support, coordinate or supplement the actions of the Member States for the protection and improvement of human health.

The most known and used are probably the *Tobacco products directive* and the *Tobacco tax directive*, explaining the wide implementation at national levels of tobacco products legislation. When it comes to labelling, as from December 2016, the *Regulation (EU) No 1169/2011* requires the vast majority of pre-packed foods to bear a nutrition declaration.

Some products are regulated by EU-level measures, for instance ban on snus within EU, with exemption of Sweden.

Regarding e-cigarette and the difficulty expressed by some countries in regulating it, it should be mentioned that some countries regulate it similarly as cigarettes[31], because there is no evidence supporting the claims that these products do not damage health[32]. For instance, Finland has a goal of not letting children to be dependent on toxic nicotine products and for this reason has strictly regulated the use of e-cigarettes and prohibited flavors in liquids for e-cigarettes.

In cancer prevention, avoiding premature deaths, saving health care costs and human suffering are also drivers for action. Although not reported during the interviews, importantly, one of the main drivers for cancer prevention is that risk reduction has the potential to prevent around half of all cancers, especially if implemented with evidence-informed policies like the ECAC is recommending. The iPAAC JA WP5 also emphasizes that communication campaigns and information should be part of comprehensive programs to be effective. Communication alone is not enough to change behaviors. A specific task of iPAAC JA WP5 is to plan sustainability to 12 evidence-based strategies of cancer prevention, the 4th edition of the ECAC.

In the framework of research, monitoring and evaluation, it should be also noted that the health surveys can be used in evaluation of impacts of the health interventions and in fact, taking into account that there are interviews performed already over decades the overall data size is substantially large and enables with linkage studies to assess also the achievements up to

mortality or disease endpoints. Furthermore, during 2000s there is a growing interest to combine biobanking in the population health surveys.

Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of primary prevention programs or actions and …..
Are presented in Table 1.

THEMES	Challenges	JAs' material	EBCP actions & cancer mission recommendations	
Risk factors & young people	Increased tobacco use among youngsters	EPAAC: The European Week Against Cancer (EWAC) Youth Competition iPAAC Roadmap	Update the Council Recommendation on Smoke-free environments; extend "track and trace system"; support Member States in implementing the Framework Convention on Tobacco Control	the creation of a Policy Support Facility, for example to enhance knowledge sharing to support the implementation of cancer-related education tools in children and young citizens promote a whole-of-government approach to achieving a major breakthrough in cancer prevention.
	Increased obesity among young children	iPAAC Roadmap	Evaluate the 2014-2020 EU Action Plan on Childhood obesity and propose follow up actions	
	Binge drinking among young people during the weekend	iPAAC Roadmap	Protect young people, reduce online marketing and advertising of these products, implementation of evidence-based brief interventions	
	Reaching young people through classical channels		Update the European Code on Cancer; add new evidence-based recommendations, improve access & understanding of information	
	Lack of time in school curriculum for physical activity	iPAAC Roadmap	"Healthystyle4all" political commitment in 2021, involving key sectors in promoting sport, physical activity and healthy diet	
Resources	Differences in resources among regions		Local implementation of the Health promotion and prevention strategy	
	Lack of structural funding for health promotion activities			
Policy, Regulation & Industry interference	Promotion of new tobacco products		Review of the Tobacco Products Directive, the Tobacco taxation directive and the legal framework on cross border purchase;	

			extend taxation to novel tobacco products, tackling advertising promotion and sponsorship, on internet and the social media, for e-cigarettes and heated tobacco products; strengthen smoke free environment	
	Income from local tobacco and alcohol production/selling			
	Effective application of the tobacco control law			
	Regulation of e-cigarets		extend taxation to novel tobacco products, tackling advertising promotion and sponsorship, on internet and the social media, for e-cigarettes and heated tobacco products;	
	Industry questioning the (evidence-based) association between tobacco, alcohol and cancer			
	GDPR and data protection regulation makes it more difficult to directly target and address people regarding prevention		Legal framework for the collection, analysis and dissemination of health information in accordance with the GDPR	
	How to avoid exposition to environmental pollution and decrease environmental pollution		Expanded EU cancer information system with new cancer data indicators (stage, outcome, age), linking of cancer incidence across regions with exposure to environmental pollutants	

	Implementing sugar and salt regulation in the context of the free-market		Exploring tax incentives with Member States	
	Support from EC regarding implementation of HiAP approach		"Health Literacy for Cancer Prevention and Care: develop and share best practices with a focus on vulnerable groups	
Inequity & Health literacy	Awareness of the link between risk factors and cancer	CanCon Policy paper: https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/Policy_Paper_4_Tackling.pdf CanCon Policy Brief#4: https://cancercontrol.eu/archived/uploads/images/PolicyBriefs/CanconPolicyBrief04.pdf	improve health literacy on cancer risk by updating the European Code against Cancer; Healthy Lifestyle4All political commitment	Raise awareness of cancer and its risks but correct perception of cancer as deadly, as it undermines health-related behaviour and screening participation.
Research & monitoring	Lack of indicators to monitor prevention programmes	iPAAC Task 5.3: Report iPAAC 5.3 Article	Create a Knowledge Cancer Centre to facilitate the coordination of scientific and technical cancer-related initiatives at EU level	
Others	Guidelines and incentives for GPs in including primary prevention activities in their consultation		Update and explore expansion of the Council Recommendation on cancer screening	
	Communicate about the availability of services without stigmatization		Promote cooperation between health, social & community services to educate the public	

	Anti-vaccine movement influencing public opinion		Council recommendation on vaccine preventable cancers; Ensure better access to first line medicines and vaccines; Sustain member state for systemic vaccination against HPV	
	Operationalize the shift from treatment to prevention		EU digital passport for cancer prevention to reduce cancer risk	

Table 4. Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of primary prevention programs or actions.

2.1.2 Cancer screening

Regarding cancer screening, the extent of implementation of screening programs varies widely among EU MS The most often reported challenges concern test selection, non-appropriate governance and/or legal frameworks and the effectiveness of population-based screening programs. Some countries, as well as the scientific community, are investigating the possibility of shifting to high-risk stratified screening programme. Some groups have been found to have systematically lower compliance to organized screening programs. Special attention should be given to the means of reaching, informing and inviting these specific populations.

The involvement of community health professionals (pharmacists or nurses) and the training of community lay workers have been reported by several countries to better inform the population and raise the participation of target groups to screening.

When it comes to legal framework, an appropriate list of aspects that legal frameworks on cancer screening programs should cover has been presented in the CanCon Guide[46] (Chapter 4), where it has been indicated that the available national legal frameworks are often inappropriate to support screening organization and coordination, and quality assurance.

While many countries reported issues regarding the choice of tests and the effectiveness of population-based screening programs, it should be mentioned that cancer screening is by definition a public health measure targeting asymptomatic population and a chain on measures, not merely a test.

Some countries reported to explore the possibility to shift to high-risk group stratified screening. However, all screening programs with evidence target high-risk groups, are defined by age or results in screening tests (for example positive Human Papillomavirus (HPV) test or precancerous change in pap-smears). Some high-risk groups cannot be defined from population reliably, for example smokers for lung cancer screening and in some screening trials (prostate cancer) harms have exceeded benefits despite of mortality reduction. Some groups have been found to systematically escape from the organized programs. Special attention should be given to the means of reaching, informing and inviting them.

Moreover, countries need to have appropriate governance developed, taking care e.g. of the required evaluation, and policy-making criteria. In the policy-making criteria one important aspect would be health economic assessments (although indicated in CanCon that it is often lacking) and also the required threshold values have often not been developed in the MSs.

The examples provided in this report do not present a comprehensive state of play on cancer control policy of EU MSs, but they rather identify themes and topics of interest to be included in the mutual learning platform foreseen, i.e., Roadmap. However, in order to be added to EU platforms, all measures identified should be tested and based on science.

THEMES	Challenges	JA's material	EBCP flagships or actions	Cancer mission recommendations
Ressources	Lack of specialists to perform screening exams (e.g. colonoscopy)			
	Planning and availability of infrastructures for screening	CanCon Guide, chapter 4		Generate evidence on the optimization of existing population-based cancer screening programs
Health care system	Lack of organized follow-up	CanCon Guide, chapter 4	Review, update and explore expansion of the Council Recommendation on cancer screening.	
	Involvement of GPs in invitation and follow-up		Review, update and explore expansion of the Council Recommendation on cancer screening.	Primary care physicians should play a bigger role in informing and motivating patients to participate in screening
	Introduction of the HPV testing: which test?; for whom?; who analyze the results?	X one pagers in the iPAAC Roadmap	Review, update and explore expansion of the Council Recommendation on cancer screening.	Develop novel approaches for screening and early detection

Uptake and participation	Public-private difference in payment screening tests			
	Information on opportunistic screening (who, when, results)		Review, update and explore expansion of the Council Recommendation on cancer screening.	
	Lack of awareness of screening progammes	iPAAC Roadmap	Update the European Cancer Information system	Raise awareness of cancer and its risks but correct perception of cancer as deadly, as it undermines health-related behavior and screening participation.
	Difficult-to-reach groups: elderlies, migrants, romas, lower socio-economic groups	Find nurse responsible to follow up the non-responders and to inform about colorectal cancer screening (HR)	Develop a new EU Cancer Screening Scheme to ensure that by 2025, 90% of the target population is offered breast, cervical and colorectal cancer screening – 2021-2025.	

Registries, research and monitoring	Update and implementation of EU guidelines	CanCon guide, chapter 4	Develop and update guidelines and quality insurance shceme	
	HTA regarding new tests (including cost-effectiveness studies)	iPAAC Roadmap		
	Up-to-date evidence regarding new screening programmes		Update the European Cancer Information System to monitor and assess cancer screening programmes – 2021-2022.	

Table 5. Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of cancer screening.

2.1.3 Cancer diagnostic and treatment

Cancer diagnostics and treatment are of high importance for both quality and equity. Most countries struggle with controlling the rise of the costs of innovation that put the sustainability of their systems at risk. Also, the rapid pace of some innovations can require regular adjustments in reimbursement schemes and decision-making processes. EU cooperation on these two matters is highly sought and needed.

Several challenges related to the integration of innovative therapies into clinical practice guidelines have been highlighted through WP9 and are addressed in the deliverable entitled "Innovative cancer therapies in clinical practice guidelines".

The iPAAC WP9 work revealed a divergence of opinions regarding the acceptability of providing recommendations for off-label indications. Several experts interrogated by the WP9 agree to say that there are situations for which off-label recommendations could be tolerated in a clinical practice guideline, especially for small groups of patients, specific biomarker expression, paediatric population, or when there is no other therapeutic alternative.

Furthermore, the low visibility of European clinical practice guidelines in oncology was pointed out during the stakeholder consultations.

> Therefore, iPAAC WP9 recommends strengthening the collaboration of clinical guidelines providers in Europe with the implementation of a central platform/repository of guidelines to facilitate awareness and use.

Inequities across European countries have been observed regarding access to innovative immunotherapies, such as check point inhibitors and Chimeric Antigen Receptors (CAR)-T cells (CAR-T therapy is an innovative type of blood cancer treatment that programs a patient's own altered white blood cells to destroy cancer cells). The WP9 deliverable "Reference frameworks linked with the access to innovative immunotherapies" addresses challenges related to reimbursement restrictions as well as early access programs for unapproved indications.

Increasing and framing the use of real-life data to further assess new treatments arriving on the market could help providing early and secured access to innovative therapy. To facilitate

the implementation of such programs, two main aspects stood out from the work conducted by the WP9:

- The need to have clearly defined pathways and

- The need to have strong discussion among the different stakeholders involved (see details in the deliverable: Reference frameworks linked with the access to innovative therapies).

THEMES	Challenges	JA's material	EBCP flagships and actions	Cancer mission recommendations
Manage innovations	Affordability of new drugs and new tests	iPAAC Roadmap		Advance and implement personalised medicine approaches for all cancer patients in Europe

Accelerate innovation and implementation of new technologies and create Oncology-focused Living Labs to conquer cancer |
| | Contradiction of rapid innovations and slowness and heaviness of new drug introduction in healthcare systems | iPAAC WP9 results | 'Cancer Diagnostic and Treatment for All' initiative

Regulation on Health Technology Assessment (HTA) | |
| | Expectations of EU collaboration on : HTA, cost-effectiveness studies, horizon scanning, price negotiation, informed consent | the iPAAC Roadmap | A permanent framework for EU cooperation on HTA | |
| **Stakeholder involvement** | (New) Role of healthcare professionals in facilitating the introduction or opposing | | | |

Table 6. Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of diagnostic and treatment-related initiatives.

2.1.4 Cancer care and organization

Cancer care provision and organization is at the heart of action in most EU countries. It regulates the ,what and how' for cancer patients and their families. Waiting times, lack of cancer care professionals, cultural habits and quality control are recurrent challenges reported by EU countries. In addition, the lack of knowledge and the persistent need to identify best practices, especially for long-term care have been raised.

> Comprehensive cancer care networks, patient pathways and coordinated activities have been reported as the current ways to improve and ensure quality and equity in the provision of cancer care.

More efforts are needed to investigate (evidence-based) improvements that focus on a more patient-centred provision of care, especially for rehabilitation and palliative care. Rare cancers are specific priorities for these networks, especially in relation to European Reference Networks (ERNs).

THEMES	Challenges	JA's material	EBCP flagships and actions	Cancer mission recommendations
Palliative care	Including palliative care in cancer care pathways	the iPAAC Roadmap		
	Lack of possible specialty training			Furthermore, it is recommended that national and EU-wide capacity building be developed and supported in order to adapt the skills and competences of all stakeholders in the changing field of cancer. This includes training all stakeholders and education programmes/campaigns
	Problematic transition from hospital acute care to palliative care institutions or home care	the iPAAC Roadmap		high-quality research to limit the (late) side-effects of cancer treatments, to relieve pain and improve palliative care, home care therapy models as well as interventions in other sectors, such as regulatory and social interventions.
Survivorship	Survivorship care best practices and guidelines development			Develop an EU-wide research programme and policy support to improve the quality of

				life of cancer patients and survivors, family members and carers, and all persons with an increased risk of cancer Create a European Cancer Patient Digital Centre where cancer patients and survivors can deposit and share their data for personalised care
	Including survivorship care in cancer care pathways	the iPAAC Roadmap CanCon Guide, chapter 7		
	Providing survivorship care for people living in rural areas		Strengthen and integrate telemedicine and remote monitoring in health and care systems	
	Lack of funding for psychosocial care	the iPAAC Roadmap		
Monitoring and research	Performing PROMs and PREMs and introducing in clinical care	the iPAAC Roadmap	the 'Better Life for Cancer Patients Initiative', including 'Cancer Survivor Smart-Card' and a virtual	the creation of a European Cancer Patient Digital Centre (ECPDC), in which cancer patients and survivors can deposit their health data in a

				'European Cancer Patient Digital Centre'	standardised, ethical and interoperable manner. The repository would include a summary of treatments and integrate patient-reported outcomes
	More timely and effective transfer of research results and innovative approaches into routine oncological care	CanCon Guide, chapter 7			
Quality	Take into account the comorbidities in cancer care	the iPAAC Roadmap			The Mission on Cancer aims to contribute to a better understanding of (late) treatment side-effects, symptoms, comorbidities, functional disability and psychosocial needs, to relieve symptoms, improve palliative care and survivorship support
	Assessment of compliance to guidelines	The iPAAC Roadmzp			
	Quality management – the use of evidence based quality indicators to monitor cancer care	the iPAAC Roadmap			
	Waiting time for cancer care				
Networks	Concentration of care for complex surgery and rare cancer care	the iPAAC Roadmap CanCon Guide, chapter 5			
	Funding of networking activities: shared patients, governance, infrastructure, IT, etc.	the iPAAC Roadmap			Set up a network of Comprehensive

		CanCon Guide, chapter 5		Cancer Infrastructures within and across all EU Member States to increase quality of research and care

Table 7. Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of cancer care and organization initiatives or measures.

2.1.5 Cancer information systems and registries

Cancer information systems intersect all dimensions of cancer control and are mainly organized through cancer registries. However, their mandate and subsequent ability to support evidence-based cancer control policy varies widely. The possibility to link with other health, administrative or socio-economical information sources is key but requires legal, ethical and technical adjustments. Enhancing digitalization, data integration and interoperability 'by design' is crucial and requires global strategies and resources. In a context of increasing prevalence the lack of data on the whole disease trajectory, including quality of life and survivorship, is considered critical. Also, patient and carers perspectives need to be integrated to ensure meeting their needs and support development of patient-centred interventions.

Themes	Challenges	JA's material	EBCP flagships and actions	Cancer mission recommendations
Centralization	Harmonization of local/regional cancer registries	the iPAAC Roadmap		
	Delay in registration			
Legal frameworks and mandates	Lack of compulsory registration	the iPAAC Roadmap	Cancer Inequalities Registry The Knowledge Centre on Cancer will be launched in 2021 within the Joint Research Centre will contribute to the European Cancer Imaging Initiative, the European Health Data Space and research carried out under the Cancer Mission. The European Health Data Space (EHDS), which will be proposed in 2021, will enable cancer patients to securely access and share their health data in an integrated format in the electronic health records between healthcare providers and across borders in the EU.	
	Lack of legislation regarding the secondary use of data			
	Missed opportunity for quality evaluation			

Table 8. Challenges reported in the 28 EU MSs during the iPAAC Cancer Control Policy Interview Survey, related to the implementation of cancer information systems.

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Co-funded by
the Health Programme
of the European Union

2.1.6 Transversal issues

TRANSVERSAL ISSUES
The involvement of patients in the decision-making process
Socio-economic differences in the access to healthcare services ; insurance of equity in the access to healthcare services
Translation of needs and expectations of health professionals to policy-makers
Improve the effectiveness of communication and coordination across sectors, in particular across in-patient and out-patient settings
The balance between the scientific evidence and the interest and needs of the professionals and stakeholders
Organization of the (compulsory) continuous education
Organize benchmarks
Format for cooperation between EU MS (other than Joint Actions), to share knowledge, without EC taking a delegating role
Legislation to translate data towards readable, understandable information on quality of health services for patients
The the lack of a national cancer plan or a specific oncological strategy
Translation of scientifc knowledge for the general population
Legal of legal power and funding for the national cancer program
Mutual learning among EU countries on cancer control practices
Need of approval of the ministry of finance for the national cancer program
Not enough resources for the follow-up, monitoring and evaluation of the national cancer program

2.2 Mutual learning

Support for knowledge exchange among EU countries on cancer control policy implementation is critical to ensure optimal outcomes. The aims is to close the gap between what we know and what we do. Overall, EU countries are engaged in many cancer control efforts, with differing foci according to specific national needs, political agendas and resources.

Mutual learning allows for integrating knowledge and experiences gained in different contexts, including the building of consensus about necessary transformations to reach sustainability solutions. To successfully achieve mutual learning, appropriate conditions are required. These range from identifying key success factors and threats, the development of a common language and agreed upon indicators, and transparency with respect to failures of implementation or areas for further development. European MSs encounter similar barriers when implementing and could learn from each other.

To foster improvements in the health care system (HCS), better patient outcomes and quality at lower cost requires incremental changes in HCS performance or broader paradigm shifts.
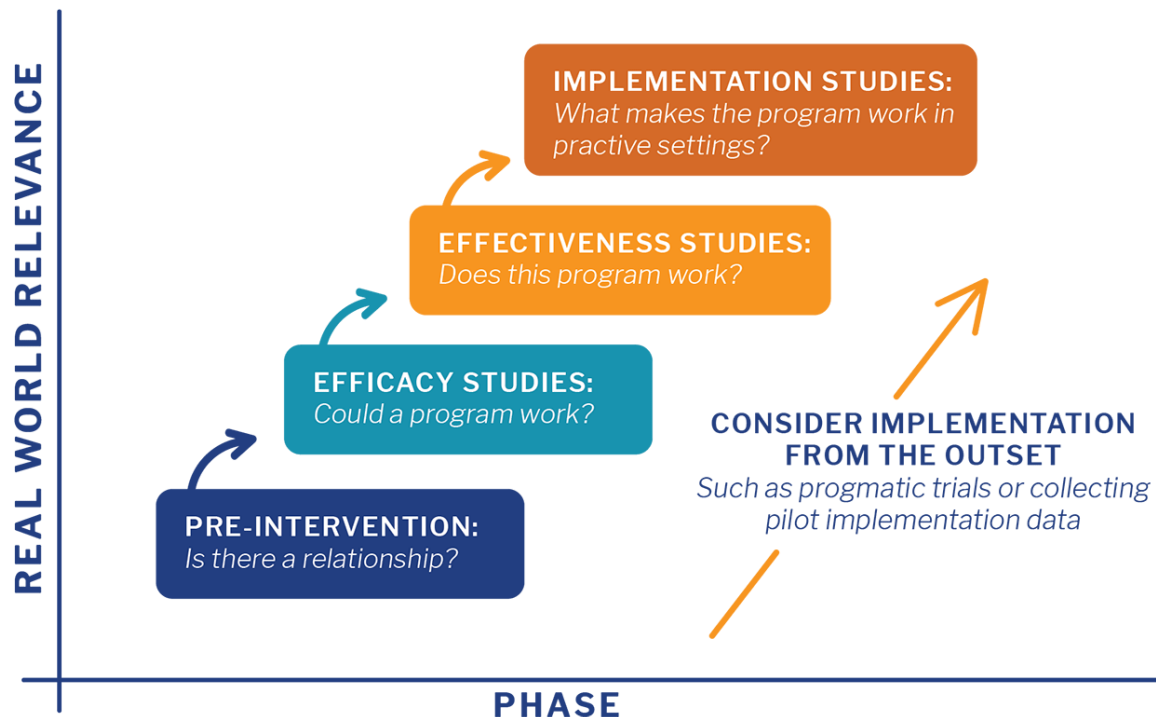
Bottlenecks for implementation can be found both at national, subnational level, and also in the cross border provision of care.

Improving the uptake of cancer control interventions relies on:

- Dialogue and partnerships amongst stakeholder groups (e.g., patients, providers, organizations, systems, and/or communities),
- Goal setting and commitments,
- Taking stock of specific HSC contextual factors,
- Monitoring and reporting,
- Piloting, adaptation and scale up of intervention.

The challenges that have been identified in the CCPIS report provide concrete opportunities for discussing the aforementioned determinants of implementation. Mutual learning is an opportunity for the stimulation of debate and exchange of experience on opportunities and limitations of real life implementation. The ultimate aim is to facilitate the dissemination of good practices between governmental representatives, independent experts and other relevant stakeholders. Discussing 'what makes a program work?' is the core of mutual learning exercises:

- Example Intervention: Directed at changing clinician behavior, and/or organizational practice,
- Outcomes (focus on process/the field): Acceptability, adoption, appropriateness, feasibility, fidelity, transferability, implementation cost, …,
- Unit of analysis: The clinician, team, facility, or organization,

iPAAC INNOVATIVE PARTNERSHIP FOR ACTION AGAINST CANCER

Co-funded by
the Health Programme
of the European Union

REAL WORLD RELEVANCE

IMPLEMENTATION STUDIES:
What makes the program work in practive settings?

EFFECTIVENESS STUDIES:
Does this program work?

EFFICACY STUDIES:
Could a program work?

PRE-INTERVENTION:
Is there a relationship?

CONSIDER IMPLEMENTATION FROM THE OUTSET
Such as progmatic trials or collecting pilot implementation data

PHASE

2.3 Remaining challenges and opportunities

2.3.1 Europe's Beating Cancer Plan

Europe's Beating Cancer plan sets out actions to support, coordinate or supplement Member States' efforts at every stage of the disease: from prevention, early detection, diagnosis and treatment, to an improved quality of life for cancer patients and survivors. The aim is to tackle the entire disease pathway. It is structured around four key action areas where the EU can add the most value: (1) prevention; (2) early detection; (3) diagnosis and treatment; and (4) quality of life of cancer patients and survivors.

The Cancer Plan is structured around four key action areas with 10 flagship initiatives and multiple supporting actions. It will be implemented using the whole range of Commission funding instruments, with a total of €4 billion being earmarked for actions addressing cancer, including from the EU4Health programme, Horizon Europe and the Digital Europe programme. The EBCP is supported by actions spanning across policy areas from employment, education, social policy and equality, through marketing, agriculture, energy, the environment and climate, to transport, cohesion policy, and taxation.

2.3.2 The European Commission's (EC's) Cancer Mission

Cancer affects everyone regardless of age, gender or social status and represents a tremendous burden for patients, families, and societies at large. If no further action is taken, the number of people newly diagnosed with cancer every year in Europe will increase from the current 3.5 million to more than 4.3 million by 2035. The Mission on Cancer aims to save more than 3 million lives, improve life expectancy, achieve a thorough understanding of cancer, prevent what is preventable, optimise diagnosis and treatment, support the quality of life of all people exposed to cancer and ensure equitable access to the above across Europe

The objectives of the Cancer Mission are to unite countries to substantially reduce the cancer burden in the EU, to improve the quality of life of patients with cancer, and to achieve a 10-year cancer-specific survival for 75% of the adult patients diagnosed in 2030 in EU MSss with a well-developed health-care system. Achieving these objectives will require EU-wide harmonization of priorities and policies, improved research coordination, and increasingly efficient and flexible funding mechanisms. The Board's Mission outline with the input of citizens, patients and MSs' stakeholders in 13 recommendations.