

Work Package 4: Integration in National policies and sustainability

WP4 - Cancer Control Policy Interview Survey: Methodological Report

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Abbreviations

JA	Joint Action
iPAAC	Innovative Partnership of Action Against Cancer
WP	Work Package
EU MSs	European Member States
EC	European Commission
GB	Governmental Board
RCC	Roadmap Coordination Committee
CCPIS	Cancer Control Policy Interview Survey
EPAAC JA	European Partnership of Action Against Cancer Joint Action
CANCON	Cancer control Joint Action

Executive Summary

The overall objective of the iPAAC Joint Action is to support EU Member States (MSs) in the development and implementation of innovative approaches to advances in cancer control. The innovation that will be covered within the work packages of this JA consists of actions in the field 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 Plans.

The key focus of the Joint Action is on implementation, reflected in the key deliverable: ***the Roadmap on Implementation and Sustainability of Cancer Control Actions***, which will support Member States in the implementation of cancer control actions by facilitating mutual learning among EU MSs. As Work Package 4 leader, the Belgian Cancer Center is responsible for the development of this final deliverable. The two main objectives of the WP4 are therefore to (1) collect and gather the material for developing the content of the Roadmap and (2) to build the Roadmap as a useful tool for EU MSs.

Regarding the content of the Roadmap, WP4 firstly supports the integration of the iPAAC core WPs 5-10 results into implementation support. The core WP leaders and their partners will contribute to the provision of evidence and background material, and to the translation of their results into the Roadmap. Secondly, the WP4 task is to explore the EU MSs experience in the implementation of cancer control policy. Therefore, the *Cancer Control Policy Interview Survey* will be conducted with health administrators and experts involved in cancer control actions implementation in EU countries.

Regarding the building of the Roadmap tool, the main task of the WP4 is to develop a format that suits the needs of the target groups, i.e. the health policy makers, administrators, the civil society; or other actors responsible of cancer control implementation. In addition, the tool has to facilitate the exchange of experience and to be user friendly.

To reach these objectives, the WP4 has two supporting platforms: the Governmental Board, composed by representatives of Member States; and the Roadmap Coordination Committee, composed by WP's 1-10 leaders, the EC and external experts. Both platforms meet bi-annually, back to back, to update Member States, partners and the EC on the results. Further, these discussion moments ensure that the Roadmap is developed in accordance to the needs of Member States and to discuss, agree and solve technical issues.

In the following, more detailed information is provided on the specific objectives and methods in the WP4, but also on the work process, rationale and timing.

1 Introduction

The Joint Action Innovative Partnership of Action Against Cancer (iPAAC)¹ is the third Joint Action dedicated to cancer control, following EPAAC² & CANCON³. This Joint Action is a collaborative policy project between 44 partners out of 24 EU Member States, co-funded by the European Commission and EU Member States (MSs).

While the purposes of the JAs EPAAC & CANCON were to develop policy recommendations supporting health policy makers, based on the best available knowledge or through piloting implementation, the main objective of the JA iPAAC is to provide EU MSs with concrete and practical support in the implementation of innovations in the field of cancer control.

Alongside the three transversal work packages (coordination, dissemination and evaluation), the work package 4 (WP4) on Integration in National Policies and Sustainability is responsible for the development of the final deliverable, the *iPAAC Roadmap on Implementation and Sustainability of Cancer Control Policy*. The six other work packages (5-10) contribute to the development and implementation of innovations in the specific fields of:

- Cancer prevention
- Genomics in cancer control and care
- Cancer information systems & registries
- Challenges in cancer care
- Innovative therapies
- Governance of Integrated and Comprehensive Cancer care

The final deliverable, the Roadmap on Implementation and Sustainability, merging all results, aims to facilitating experience exchange and mutual learning between EU MSs on the implementation of innovations in the field of cancer control.

1.1 Conceptual framework

The main objective of the Roadmap is to provide concrete and practical support to the implementation of cancer control policy, especially regarding the implementation of innovations. As the content of the Roadmap will gather information coming from different sources, it was important to ensure that all partners have the same understanding of „implementation“ and „innovations“.

For innovations, one could use the definition provided by the EC: *„Innovation can be defined by two elements. The first introduces the aspect of novelty: innovation is a new idea in relation to something that is established. This idea must find its way from theory to practice. As such*

¹ <https://www.ipaac.eu/>

² <http://www.epaac.eu/>

³ <https://www.cancercontrol.eu/>

innovation does not only relate to technical or scientific novelties, but may also pertain to processes and organizational change across sectors. The second contains a teleological criterion: a technical novelty or a new approach can only be regarded as innovative if it brings economic and societal benefits. Against this backdrop, an innovation is to be understood as a process through which the novelty has to win social recognition and acceptance over time.“ (EPSC, 2016)⁴

Therefore, the information included in the Roadmap will present not only information on innovations improving the quality of cancer care and control but also examples on innovative approaches bringing into practice novelties, including organizational process or changes facilitating this process.

For “implementation”, Nolte, Kluge and Figueras ⁵ describe it as “*processes involved in introducing innovation, commonly described as adoption, implementation, sustaining, spreading or diffusion, dissemination and, scale up. Each involves a series of processes in themselves, and they rarely follow a linear and predictable sequence. Instead, they tend to be ‘messy’, dynamic and interact in ways that are often not knowable. Some innovations in service organization and delivery are easier to implement, sustain and spread than others. Even a seemingly simple innovation may be difficult to implement. There is a need to consider the innovation in the context of the implementation processes, the intended users and other stakeholders involved, and the broader setting within which it is being introduced*”.

Also, to ensure complete and coherent description of these processes, the contributors to the Roadmap have been asked to follow as much as possible, when relevant, the *Quality Implementation Framework*, as described by Meyers, Durlak and Wandersman⁶.

Bearing this in mind, supporting EUMSs in the implementation of innovations in cancer control, implies the collection of different types of information which can support the actors involved along the multiple phases of implementation.

1.2 WP4: Rationale and objective

Previous Joint Actions regarding cancer control focused on innovative research and policy recommendations. IPAAC rather investigates how innovations can be implemented, looking at the provision of support for the implementation of these innovation, bringing them into practice.

As most EU MSs already deal with cancer control since, at least one decade (often much longer) and that they focus or priorities have been found to be slightly different, one could reasonably assumes that the sharing of their experience can be beneficial.

⁴ https://ec.europa.eu/epsc/publications/strategic-notes/towards-innovation-principle-endorsed-better-regulation_en#h-1

⁵ Nolte in Kluge & Figueras, 2018 - http://www.euro.who.int/_data/assets/pdf_file/0004/380731/pb-tallinn-03-eng.pdf?%20ua=1

⁶ <https://www.ncbi.nlm.nih.gov/pubmed/22644083>

Therefore, the Roadmap on implementation and sustainability of cancer control actions has been envisaged by iPAAC partners as a tool which encourages mutual learning among EU MSs, in the implementation of innovative cancer control policy.

In order to meet this overall aim, the WP 4 more specifically defined two objectives:

- The collection and gathering of relevant information to be included in the Roadmap
- The development of the Roadmap as an IT tool

1.3 Tasks and methods

These two objectives should be reached through the following four tasks:

- the collection of the cancer control implementation experiences in EU countries;
- the gathering of results from the iPAAC WPs 4-10, EPAAC, Cancon and possibly other JAs into the Roadmap;
- the translation of all results into the Roadmap format;
- the development of an IT structure and format of the Roadmap

To perform these tasks, several methods were chosen:

- the Cancer Control Policy Interview Survey (CCPIS) among EU MSs to collect their implementation experiences
- shared working documents between WP4 and the other core iPAAC WPs to facilitate the translation of their results into implementation support
- technical meetings with the partners and the EC
- reviews of the results from EPAAC, CANCON and other JA's
- governmental boards meeting to include MS's needs and perspectives
- close collaboration with the dissemination team (WP2) to technically elaborate the Roadmap

Besides these practical activities, the WP4 also had to envisage the sustainability of the Roadmap, i.e. the insurance of the further use and development of the tool.

The WP4 follows an interactive and dynamic process, in which feedback and input from different stakeholders is essential. It should be emphasized that the tasks and work methods do not follow a linear process, but are interconnected and influenced by each other.

1.4 WP4 Working, supporting and exchange platforms

In order to foster the interactive and dynamic work process of WP4, two working platforms are established. Both the Governmental Board (GB) and the Roadmap Coordination Committee (RCC) provide the necessary assistance to WP4 in the development of the Roadmap.

1.4.1 The Governmental Board (GB)

The iPAAC Governmental Board is composed by representatives of the EU Member States, representatives of the European Commission, the Work Package Leaders and two external experts. It gathers health policy makers, health administrators and experts from EU MSs. The representatives are appointed by their Ministry of Health, which can delegate someone from their own department, or can appoint another governmental institution to delegate a representative.

Twice a year, the Governmental Board is invited to discuss the iPAAC activities and achievements. In total, six Governmental Board meetings take place during the three years course of iPAAC. The main topics presented and discussed are: the objectives and work methods of all work packages; the development of the content and format of the Roadmap, (i.e. the type of expected results and the format in which this information is integrated into the final tool); and finally, the aspect of sustainability, i.e. how to proceed with the Roadmap after the JA.

The different understandings, questions and needs in regard to both the content and format of the Roadmap are discussed during these meetings. It ensures the development of a useful instrument for those involved in implementation, supporting them in their daily work. Moreover, the interactive approaches facilitate buy-in among stakeholders and support the promotion of the use of the tool.

Importantly, to ensure that the Governmental Board provides insights of those actually involved in implementation, it is of high importance to encourage the representation of health policy makers and/or administrators, rather than scientific experts or JA partners. This represents a possible risk for not only the focus of the meeting, but also for the conformity of the final tool to the needs of the end-users.

1.4.2 The Roadmap Coordination Committee (RCC)

The second supporting platform for the Work Package 4 is the Roadmap Coordination Committee (RCC). It consists of all Work Package leaders, representatives from the European Commission (DG Sante and CHAFFEA) and external experts. The Roadmap Coordination committee meets back to back with the Governmental Board, every six months. The focus and aim of the RCC meetings evolve according to the process of the Joint Action. By organizing both platforms back to back, it ensures that the discussions with the EU MSs representatives are translated into the technical work of the work packages.

The RCC allows the Work Package 4 to coordinate the integration of the Work Packages 5-10 results into the Roadmap. This technical platform facilitates the discussion and management of overlap among WPs, and all other technical issues arising regarding the content of the Roadmap. More concretely, all work packages discuss their objectives, work processes and expected results and potential synergies. During the course and work of the WPs, a common understanding of cross-cutting and recurrent issues among the work packages is discussed. This also includes making links between the WP4 CCPIIS results and the results of the core Work Packages 5-10.

1.4.3 External consulting experts

Two external experts are included in the RCC. One expert provides insights as an academic specialized in health policy implementation. His support represents an important added value for the WP4 methodological work and the systematic and rigorous approach in the use of the material collected through this JA, which is then presented in the Roadmap.

The second expert is an experienced health administrator of the Belgian Health Care System who supports the WP4 with his experience in the policy implementation process and helps to understand how health administrators can benefit from such a Roadmap facilitating mutual learning.

2 EU Cancer Control Policy Implementation Survey (CCPIIS): Exploring the implementation of innovative cancer control policies in EU MS

2.1 Rational & Objective

As a result from various initiatives regarding cancer control implementation^{7,8,9}, it has been found that there is a need to support EU countries in the practical implementation of cancer control actions (Hudson, Hunter and Peckham 2019¹⁰; Bullock and Lavis 2019¹¹; Evans and al 2013¹²; Lavis et al 2008¹³).

In order to have a better view and understanding of the experience of EU MSs in the implementation of cancer control recommendations, it has been agreed to survey MSs. In a first instance, an online survey was designed, but rapidly, important limits raised (Fricker et Schonlau 2002¹⁴; Wyatt 2000). The most important issue relate to the difficulty to control the

⁷ https://ec.europa.eu/health/non_communicable_diseases/cancer_en

⁸ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6530220/>

⁹ https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/CanCon_Policy_Papers_FINAL_Web.pdf

¹⁰ <https://www.tandfonline.com/doi/full/10.1080/25741292.2018.1540378>

¹¹ <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-019-0479-1>

¹² <https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-8-17>

¹³ <https://link.springer.com/article/10.1186/1748-5908-3-55>

¹⁴ <https://calhoun.nps.edu/bitstream/handle/10945/38734/Fricker5.pdf?sequence=1>

origin of the respondents (especially in case of shared responding). Indeed, a first challenge regarding online surveys is the lack of transparency regarding the respondents and the veracity and completeness of the information provided. Secondly, it brings along the risk to solely gather primary information.

To allow the control on the respondents (being actually those involved in the programs implementation) and to collect detailed insights on the implementation experience by means of follow-up prompts, the WP 4 has engaged in a mapping exercise by performing semi-structured interviews in EU countries.

First of all, meeting different actors involved in cancer control policy allows to touch upon different domains and topics along the cancer control continuum. This results in a broad range of images of the cancer control policy in a country. Secondly, the interviews facilitate the collection of first-hand and up-to-date information regarding past, ongoing and planned innovative programs. Further, semi-structured interviews have the advantage to get more detailed insights in a dynamic process, allowing to probe and go more in-depth at the moment itself. Besides, it allows to capture sensitive information which is not mentioned in other sources such as grey-literature, reports, etc. To better understand the experience of the implementation process in the local context, it is necessary to understand countries context and structure in which implementation is embedded. Last but not least, interviews can create a sense of co-ownership & co-creating. Visiting each EU MS, demonstrates the importance of the EU MS voice regarding the input on content & format of Roadmap. Moreover, it emphasizes the commitment of ipaac to develop a tool useful for the EU MS.

This exercise is carried out during the first year and half of the Joint Action and has been called the „**EU Cancer Control Policy Interview Survey**“. By visiting the EU Countries (health administrators, experts, policy makers and stakeholders), the objective is to (1) organize a mapping exercise of planned and ongoing innovative cancer control initiatives and (2) identify the challenges encountered and the levers used while implementing these initiatives. To understand the context in which these processes take place, information on the specific country contextual features (socio-economic and health care system) are also gathered.

2.2 Data collection

The data collection initiated in July 2018 and finished in January 2020. The WP4 used a dynamic and semi-structured information gathering process. As presented by previous work, “(...) *Semi-structured interviews strike a balance between a structured interview and unstructured interview. In the semi-structured interviews the questions are open ended thus not limiting the of the respondents/interviewees choice of answers (Gubrium & Holstein, 2002, McCracken, 1988). The purpose is to provide a setting/atmosphere where the interviewer and interviewee can discuss the topic in detail. The interviewer therefore can make use of cues*

*and prompts to help and direct the interviewee into the research topic area thus being able to gather more in depth or detailed data set (Creswell, 2003, McCracken, 1988, Patton, 2002)."*¹⁵

The framework prepared by C. Adams¹⁶ provided the basis for this exercise.

The data collection and analysis can be divided into four phases:

- a "preparatory phase" including exploratory interviews;
- the data collection: performing the interviews;
- the reporting and validation process;
- the description of the general results (Nvivo)
- the cancer control domain specific analysis (Nvivo)

2.2.1 Preparatory Phase

Country profile

The *Country Profile Document* presents the core characteristics of the country health care system, including the type of reimbursement system, the political organization regarding health care (health care jurisdiction), the main actors involved in health care policy and & cancer control policy; the cancer control framework, etc.. Besides these contextual features, general information on the cancer control domains are collected. Through the consultation of available documents, plans and legal frameworks, the WP4 interviewers are aware of the established prevention programs, screening programs, care networks or other forms of organization of care and after care such as survivorship and palliative care programs.

To collect this information several internationally recognized sources are consulted (Health System in Transition, Health at Glance; WHO Cancer Control Profile, Tobacco Control Profile, website of MoH or NIPH, etc.). The gathered information can vary depending on the availability of these documents in English, and the up to date-ness of this information.

This preparatory exercise aims to collect already existing and available information online. This allows to already have an overview of the key contextual features possibly shaping implementation. It facilitates to have a better and faster understanding of the reflections provided during the interviews.

Selecting Respondents and Arranging Interviews

¹⁵ Srivastava, A. & Thomson, S. B. (2009). Framework Analysis: A Qualitative Methodology for Applied Policy Research. *JOAG*, Vol. 4. No. 2

¹⁶ C Adams. Conducting Semi-Structured Interviews. In Newcomer, Kathryn E., et al. *Handbook of Practical Program Evaluation*, John Wiley & Sons, Incorporated, 2015. ProQuest EbookCentral

The cancer control policy is discussed with local experts and experienced administrators, involved in the implementation. Therefore, WP4 aims to visit governmental institutions such as the Ministry of Health, department of health, governmental administrations, national institutes of public health, cancer centres, etc.

Depending on the national organization of cancer control, the relevant experts and institutions to be visited greatly varies. To facilitate the process and ensure the invitation of the correct stakeholders to the interviews, the iPAAC local contact person has the responsibility to identify the participants and coordinate the meeting arrangements. This increases the involvement of the most suitable actors during the interview.

The WP4 provided to the organizers a clear invitation mail in which the aim and objective of the interview is explained. Moreover, an interview-guide is also provided (see section below).

2.2.2 The Interview Guide

As prescribed by Combessie et al.¹⁷, the WP4 prepared an interview guide composed by the main themes having to be addressed during the interview. This document is quickly searchable and the order of the themes and questions follows a possible scheme although each interview has to follow its own dynamic.

The chosen themes correspond to the general cancer control domains (primary prevention, screening, diagnostics & treatment, organisation of care, after care, palliative care & cancer information systems).

The interview guide evolves and has to be adjusted. In the first versions, the questions were broad and the first interviews paved the way towards more specific questions and topics in the second version of the interview guide. Further, due to the interactive and dynamic character of the WP4, the interview guide became more specific as the format of the Roadmap became more clear.

The guide ensures that similar themes are addressed in all countries. Moreover it stimulates the discussion when necessary and recognises the need for an open discussion, which can be guided by the interests and reflections brought up by the interviewees. Since the aim is to explore rather than being exhaustive, it is not aspired to address all sub-questions during each interview.

Participants to the interview receive the interview guide in advance. This has multiple advantages, providing a framework on the aim and expectations of interview and:

- find the right attendees to cover the theme (cancer control domain)
- prepare themselves with appropriate numbers and documentation
- prepare a synthetic presentation of the domain (how it is organized in the country)

¹⁷ Combessie Jean-Claude, *La méthode en sociologie*. La Découverte, « Repères », 2007, 128 pages

2.2.3 The interviews

It should be noted that due to the specific characteristic of the CCPIIS and the participation of high level policy makers & experts, the ability to gather information can be subject to the willingness of participants and to practical considerations, such as possible time constraints or language barriers.

The semi structured interviews

After the preparatory phase, the interview takes place. At least two members of WP4 are present and assist each other during the different tasks. Both interviewers are involved in the discussion and take notes. This allows the WP4 to gather comprehensive and detailed information, taken on laptops during the 3-8 hours of the interview. The interviews are not recorded.

Since not only successes, but also barriers & challenges are topics of interest, a level of comfort/trusts is required.

The country reports (minutes of the interviews) and highlights (summary)

The minutes from both WP4 interviewers are gathered and drafted into a detailed document, following the structure of the respective interview. The purpose of this document is to provide an overview of the implementation experiences reported along cancer control domains. The aim is not to provide a state of play, nor to be exhaustive. However, it does allow the WP4 to capture a broad image on the perceptions of the main issues and topics of interest in the EU MS, concerning cancer control policy implementation.

After an internal review by all WP4 representatives, the draft minutes are sent for review to the local iPAAC contact person. As coordinator, they are responsible for the dissemination of the document among the participants. In the text, uncertainties are highlighted and additional information or documentation related to topics of interest for the Roadmap are requested. All participants can verify, change, adapt or complete the draft. The WP4 merges the feedback and creates a final document for every interview.

It is important to emphasize that all countries have the ownership of the report. This implies that these documents are for WP4 internal work only. Nevertheless, if a country wishes to use the report for other means or purposes, this is their own decision.

Alongside the detailed report (minutes), a summary of the main results is prepared by the WP4 and provided to the participants. This summary, referred to as the CCPIIS

“highlights documents”, firstly identifies the main reported actions/programs which could be interesting to include in the Roadmap. The WP4 identifies these actions during the development of the document and after double reading of the reports. At least two WP4 members internally discuss and agree upon the topics for every EU country.

Following the same process as for the minutes, the list of topics is provided to the local contact person which (together with the participants), confirm if these actions can be shared for mutual learning. This implies that ‘list of topics’ is open for modification by the attendees, which are invited to include, exclude or validate the topics.

Secondly, the highlights also presents the reported key contextual features, such as the cancer control framework, prerogatives regarding health care and cancer control, and reported key remaining challenges for which no solution is reported. It should be noted that the contextual features and challenges are summarized solely for the internal use of WP4 and will not be available in this format (country specific) for third parties.

The aim of the highlights is to support the WP4 to obtain an overview of reported results for each country and to facilitate their use for the two deliverables of WP4: *the “Report on CCPIS”* and *the “Report on Implementation and Sustainability of cancer control actions”*. In the first deliverable, results will be structured along the cancer control domains, and will not be country specific.