WELCOME to the 3rd iPAAC Stakeholder Forum meeting

21 April 2021

Co-funded by
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AUDIO AND VIDEO RECORDING

The Stakeholder Forum meeting will be audio and video recorded. The recording will only be used to write effective meeting minutes after the meeting. The recorded session will be deleted as soon as the minutes will be finalised and the recording will not be published anywhere. The access to the recorded session will be limited - it will only be accessible to the Project Management. Your attendance at this meeting is regarded as your consent to its' recording.

THIRD iPAAC JA STAKEHOLDER FORUM MEETING

21 April 2021

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AGENDA	
12:30 – 12:45	Networking coffee with Wonder.me platform
12:45 – 14.20	Opening plenary •Welcome from the iPAAC Project Management Team •Update on iPAAC – opportunities •WPs updates (WP 2 – WP 10) •Putting the Work Packages in perspective: format and uses of the key deliverable, i.e. the Roadmap on Implementation and Sustainability of Cancer Control Actions (WP 4) •Stakeholder involvement
14:20-14:30	Coffee Break
14:30 – 14:45	**Information from DG SANTE** Matthias Schuppe, DG SANTE
14:45 – 15:00	**Information from JRC** Ciarán Nicholl, JRC
15:00 – 15:15	Discussion
15:15 – 15:20	Conclusion of plenary session and presentation of breakout session
15:20 – 15:30	Coffee break
15:30 – 16:45	Breakout sessions
	Breakout Session 1 Cancer Prevention & Cancer Information and Registries **Breakout Session 2** Genomics in Cancer Control & Innovative Therapies in Cancer **Breakout Session 3** Challenges in Cancer Care & Governance of Integrated and Comprehensive Cancer Care
16:45 – 17:30	Closing plenary • Summary and wrap-up from each Breakout session • Expectations and remarks from the Commission • Closing remarks and action points from iPAAC Coordinator
17:30	**End of meeting**

3RD iPAAC STAKEHOLDER FORUM

21 April 2021

Three Thematic Breakout Sessions

WP 5 & WP 7
Cancer Prevention &
Cancer Information and
Registries

WP 6 & WP 9
Genomics in Cancer
Control & Innovative
Therapies in Cancer

WP 7 & WP 10
Challenges in Cancer Care
& Governance of
Integrated and
Comprehensive Cancer
Care

IPAAC JA IN THE FINISH LINE

Notable achievements in the past three years:

- ✓ First Periodic Technical and Financial Report submitted and accepted in January 2020

- ✓ iPAAC website regularly updated, regular newsletters

- ✓ Project management meetings running according to plan

- ✓ Several topical online webinars successfully organised

- ✓ Dissemination of iPAAC at various events (e.g. live session at the 16th World Congress on Public Health in October 2020)

IPAAC JA IN THE FINISH LINE

Main changes:

- ✓ Katarina Krepelkova has taken over the portfolio at CHAFEA covering cancer from 1st November 2020 and has officially replaced previous Project Officer Cinthia Menel-Lemos.

- ✓ Amendment of the iPAAC Grant Agreement based on a 9-month extension has been approved in February 2021.

  - End date of the Joint Action: 31st of December 2021

IPAAC JA IN THE FINISH LINE

The main activities focus around **the following key pillars:**

- ✓ **Roadmap on Implementation and Sustainability of Cancer Control Actions ("Roadmap")**;

- ✓ Development of **innovative actions** in the fields of cancer prevention, screening, genomics, cancer information and registries, care, therapies and governance.

- ✓ Organisation of the **iPAAC Final Conference** during Slovenian presidency in December 2021.

MATCHING BETWEEN IPAAC AND EBCP

Topic	iPAAC	EBCP
Health promotion and screening	Implementation of European Code against Cancer Reviewing additional evidence on screening	Strong focus on health determinants, interventions and strengthening of screening
Genomics and cancer	Continuation of work done in the previous JA, building on the Policy Paper developed there	Included in the first three pilars
Current issues in cancer care	Special focuses: ‚neglected' cancers (ex. pancreatic), economics of cancer, MDTs	Third pillar is all about cancer care
Immunotherapy in cancer	Reimbursement models for immunotherapy	Therapy as a part of the third pillar and survivorship
Governance	NCCPs, standards, PREMs and PROMs, patient pathways, CCCNs	Governance and organisational models

SUSTAINABILITY OF THE PROJECT RESULTS

➢ Slovenia will include cancer as one of the priorities of the Presidency - final conference programme/agenda needs to be defined early in order to provide room for political and policy discussions

➢ Discussing how to maximise our outputs - publications, webinars (defining dissemination priorities during COVID-19)

➢ iPAAC deliverables effectively transferred into some type of practical use:

- There is a need to make own promotion of the Roadmap
- Work on the screening programmes, including QA, but also monitoring and continued work on the assessment of potential new screening programmes and early detection of cancer
- Expansion of the dataset in population-based cancer registries, especially to include the data on survivorship
- Quality indicators and sets of standards for providers, patient pathway development, accreditation issues

IDENTIFYING OPPORTUNITIES FOR FURTHER COLLABORATION WITH IPAAC PARTNERS

➢ Discussions on how to continue working together for those interested -> EU4Health Programme

➢ Topical interests for the following:

- Collaboration in the same cf. similar consortium on selected cancer policy topics

- Different combinations of partners joining different tenders coming up in 2021 and 2022 on Horizon Europe as well as EU4Health programme

- Potential topics of interest:

  - Cancer screening programmes

  - Survivorship

  - Implementation of National Cancer Control Programmes

  - Quality in cancer care and cancer control

  - Patient pathways – management of the different segments of the cancer trajectory

WP 5 – CANCER PREVENTION

Cancer Society of Finland (CSF)

1. Main results/outputs (completed/forthcoming)

- Survey to find solutions and understand barriers to early detection/diagnosis (M5.1.)

- Advancing population-based screening programmes, future risk-adjusted modifications (M5.2)

- Develop sustainability plan and monitoring for the European Code Against Cancer (M5.3.)

- Fisabio: inequalities and Best practices contest

- Three comprehensive conference reports, 2 completed, one in process (June)

- Quality criteria and governance of screening online infographs(in prosess) based on CanCon JA

- Strategies for advancing early detection (in process)

- Final deliverable for the Roadmap, in the area of prevention, one pagers (in process)

WP 5 – CANCER PREVENTION

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Cancer Society of Finland (CSF) (continued)

2. Dissemination of the WP 5 results/outputs

- Four co-creational meetings with engaged participants (70+66+over 100 + over 100)

- New ideas, multi-stakeholder perspective, social media + publications, 2 stakeholder events

3. Challenges, questions and open issues to be discussed

- Bridging the information gap: early diagnosis

- Bridging the implementation gap: EU council recommended cancers: breast, colorectal, cervical

- How to get more resources and advocacy for prevention in cancer control?

- Social innovations - how to collect good ideas that go across borders?

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WP 6 – GENOMICS IN CANCER CONTROL AND CARE

Sciensano (SC)

1. Main results/outputs (completed/forthcoming)

- 14 one pagers (ELSI, Genetic Testing, NGS implementation, DtC testing, training)

- 5-6 scientific publications

2. Dissemination of the WP 6 results/outputs

- Webinars end May/early June on each task

- Symposium 'Cancer and genomics': end

3. Challenges, questions and open issues to be discussed

Link to EBC plan, MoC, E4H program and EHDS

WP 7 – CANCER INFORMATION AND REGISTRIES

Italian National Institute of Health (ISS)

1. Main results/outputs (completed/forthcoming)

Priority 1: Advancing registries piloting linkage with administrative data

A. Survey to cancer registries (CRs) to census electronic data sources available for linkage, Task 7.1

B. European pilot applications: 7.2 Quality of Care 7.3 Costs of Care 7.4 Long-term outcomes of AYAs survivors

- Methodology, index tumours, target indicators, common procedures shared and adapted to available data
- Feasibility assessed for registries in Italy, Belgium, Spain, Norway, Poland, Croatia, Slovenia, Greece, Portugal
- Validation of resulting indicators ongoing and *recommendations for data 're-use'* as part of the Roadmap

C. Czech pilot: Integrated Cancer Information System at national level, Task 7.5

- ICT model interconnecting the national CR to multiple data sources (administrative and clinical)
- Publication of rules for network of regional cancer centres, including monitoring of performance indicators

Priority 2: bridging information gaps on cancer survivors

D. Population-based indicators on cancer prevalence in Europe, Task 7.6

- Finalisation of the Joint European Cancer Registries dataset (29 countries, 119 registries, EUROCARE-6 project)
- Methodology to estimate *complete* and *limited duration prevalence* by MS with *time projections* to 2020 (25 cancer types)

WP 7 – CANCER INFORMATION AND REGISTRIES

Italian National Institute of Health (ISS)

2. Dissemination of the WP 7 results/outputs

- **Publications –** 3 papers published, 1 forthcoming, other 3 envisioned

- **Meetings** – 2 meetings with engaged participants and collaborating partners, results dissemination in National or International multi-stakeholder meetings (WCPH-EUPHA 2020, GRELL 2021)

- **iPAAC Roadmap** – piloted models, protocols and recommendations to integrate registries datasets to be included in final documentation

- **European initiatives in collaboration with ENCR-JRC**
  - *Distance training* addressed to CRs on methods and software to derive prevalence indicators (22-23 June 2020)
  - ECIS web-site integration: new *on-line* session to *access iPAAC prevalence estimates 2020*

- **In collaboration with ECPC dissemination initiatives on cancer survivorship** (epidemiological data supporting patients' social inclusion)

WP 7 – CANCER INFORMATION AND REGISTRIES

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Italian National Institute of Health- ISS (continued)

3. Challenges, questions and open issues to be discussed

- Knowledge gaps due to fragmented and inefficient use of health data. Obstacles linked to personal data protection rules, lack of interoperability, open data access and re-use of data for research (link to EU Health Data Space initiative)

- Heterogeneous *data access regulations* for cancer registries across MS ('very strict' but possible vs 'no rules' but impossible)

- Appropriate *legislation* would help? i.e. enlarging scopes of cancer registration (from epidemiology to research on health services) or regulating open data and data re-use for research

- Advancing cancer information requires further *resources*. Registries are already established and more sustainable. Promoting digitalization, data integration, National/European scale-up analysis would produce savings.

WP 8 – CHALLENGES IN CANCER CARE

Catalan Institute of Oncology (ICO)

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

1. Main results/outputs (completed/forthcoming)

Neglected cancers

- Reviews: Definition of neglected cancers + Literature on indicators of incidence, prevalence and survival in pancreatic cancer

- *Bratislava Statement*, supported by scientific societies, patients' representatives and cancer plans.

- ECCO Essential Requirements for pancreatic cancer, supported by scientific societies

Supporting innovation in complex surgery and radiotherapy, and improving efficiency

- Expert consensus: A new reimbursement system is proposed based on a two-tier approach (one for proven evidence-based interventions, another for emerging innovation with uncertain definitive value.

- Lit. review: European best practices in identifying and withdrawing low value care.

Palliative care

- Lit. review: Integration between palliative care and oncology, and implementation of CPG on pain control in oncologist education and MDTs

2. Dissemination of the WP 8 results/outputs

- **Members of the European Parliament (MEP) against cancer session**: "Tackling challenges in cancer care and improving its governances in the EU. Recommendations from the iPAAC Joint Action. 15 March 2021"

- Publication of the "**Bratislava Statement**" (ESMO Open) (22 policy recommendations to increase health systems' capacities)

- **Online webinar** "Facing the harsh reality of **pancreatic cancer**: policy measures and health system strategies", Sept 2020, 50 participants.

3. Challenges, questions and open issues to be discussed

- Scientific societies are easy to contact and eager to collaborate in a sustainable way, but not other stakeholders (e.g., cancer plans)

- Challenge: balance the European Beating Cancer Plan priorities, our focus and the priorities set up by NCCP from the different MS.

WP 9 – INNOVATIVE THERAPIES IN CANCER

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

French National Institute of Cancer (INCa)

1. Main results/outputs (completed/forthcoming)

- **Tasks 1 & 2**: two deliverables completed

  - **Innovative cancer therapies in clinical practice guidelines (July 2019)**

  - **Reference frameworks linked with the access to innovative immunotherapies (July 2019)**

- **Tasks 2 & 3:** one deliverable completed: **Horizon scanning systems applied for cancer control in Europe (Sept 2020)**

- **Task 4:** one deliverable : **Real life monitoring of immunotherapies focus on patients treated with CAR-T cells (expected to be finalized in June 2021).**

2. Dissemination of the WP 9 results/outputs

- Local stakeholder forum (december 2019), international/european congress (DIA, ASCO, WCPH in 2020)

- Final WP9 workshop to present results of the WP9 will be planned at the end of 2021

3. Challenges, questions and open issues to be discussed

- The WP9 leader has changed: Marianne Duperray has replaced Sophie Negellen in January 2021
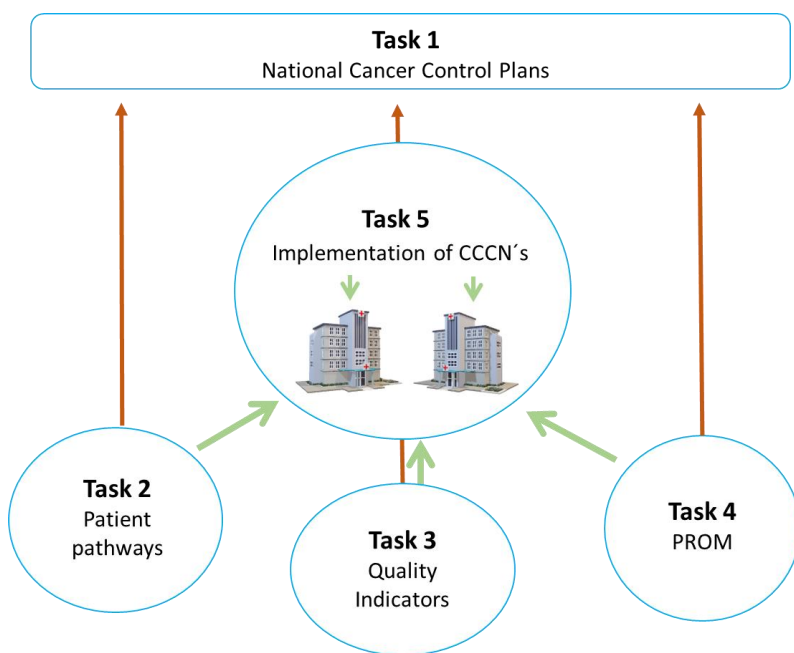
WP 10 – GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE
GERMAN FEDERAL MINISTRY OF HEALTH AND GERMAN CANCER SOCIETY (DKG)

1. Main results/outputs (completed/forthcoming)

Comprehensive Cancer Care Networks (CCCN)

- Task 1: Assessment of **NCCPs**, if the following topics (task 2-5) are already addressed
- Task 2: Methodology for the development of tumour-specific **patient pathways** completed and two patient pathways for colorectal and pancreatic cancer for the use in CCCN developed
- Task 3: Methodology for deriving **quality indicators** finalized and a set of quality indicators for colorectal and pancreatic cancer defined
- Task 4: Framework for implementation of **patient-reported outcome measures** developed
- Task 5: **Set of Standards** for the with requirements for colorectal and pancreatic cancer and set-up of **CCCN** as well as a **framework for monitoring** and quality improvement process within CCCNs was developed and piloted in 2 CCCNs.
- Task 1: **Recommendations** how to integrate results from WP 10 for the update of NCCPs will be developed based on results from task 5

→ **Results from task 2-5 are currently being implemented in 2 pilot-CCCN.**

WP 10 – GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE
GERMAN FEDERAL MINISTRY OF HEALTH AND GERMAN CANCER SOCIETY (DKG)

2. Dissemination of the WP 10 results/outputs

Events (in addition to the local stakeholder meetings)**:**
- **MEP against Cancer (15 March 2021, online):** Tackeling Challenges in Cancer Care and Improving its Governance in the EU – Recommendations from iPAAC (WP 8 & 10)
- **ECPC (planned October 2021, online):** Governance of integrated and comprehensive cancer care – practical instruments for the set-up of Comrpehensive Cancer Care Networks

Scientific Journal Publications:
- **Task 1**: *Governance in/of Cancer Care and Stewardship in Cancer Control: Creation of Definitions* (published)
- **Task 2:** *Paving the way for patient pathways: sythesizing a user-centred method design with results from a systematic literature review* (published)
  Patientenpfade in der Onkologie – Hilfe zur Sicherstellung von Patientenzentriertheit und Versorgungskontinuität (published)
- **Task 4**: *Implementation of patient-reported outcome assessment in routine cancer care – a systematic review of multicentric programs in Europe.* (published);
- **Task 3**: The iPAAC Evaluation Tool for QIs in oncology (iET-QIs) incl. set of tumour-specific QI derived (in preparations);
  Task 5: CCCN structure, set of standards and evaluation framework, Case study (in preparations)
  Implementation of CCCN in real life setting: recommendations and lessons learned (in preparations)

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3. Challenges, questions and open issues to be discussed

Completion of task of WP 10

If both CCCN audits cannot be conducted in May 2021 and on-site verification of implemented structures and processes is due to COVID not possible

→ counter measure: options for online audits will have to be explored and discussed
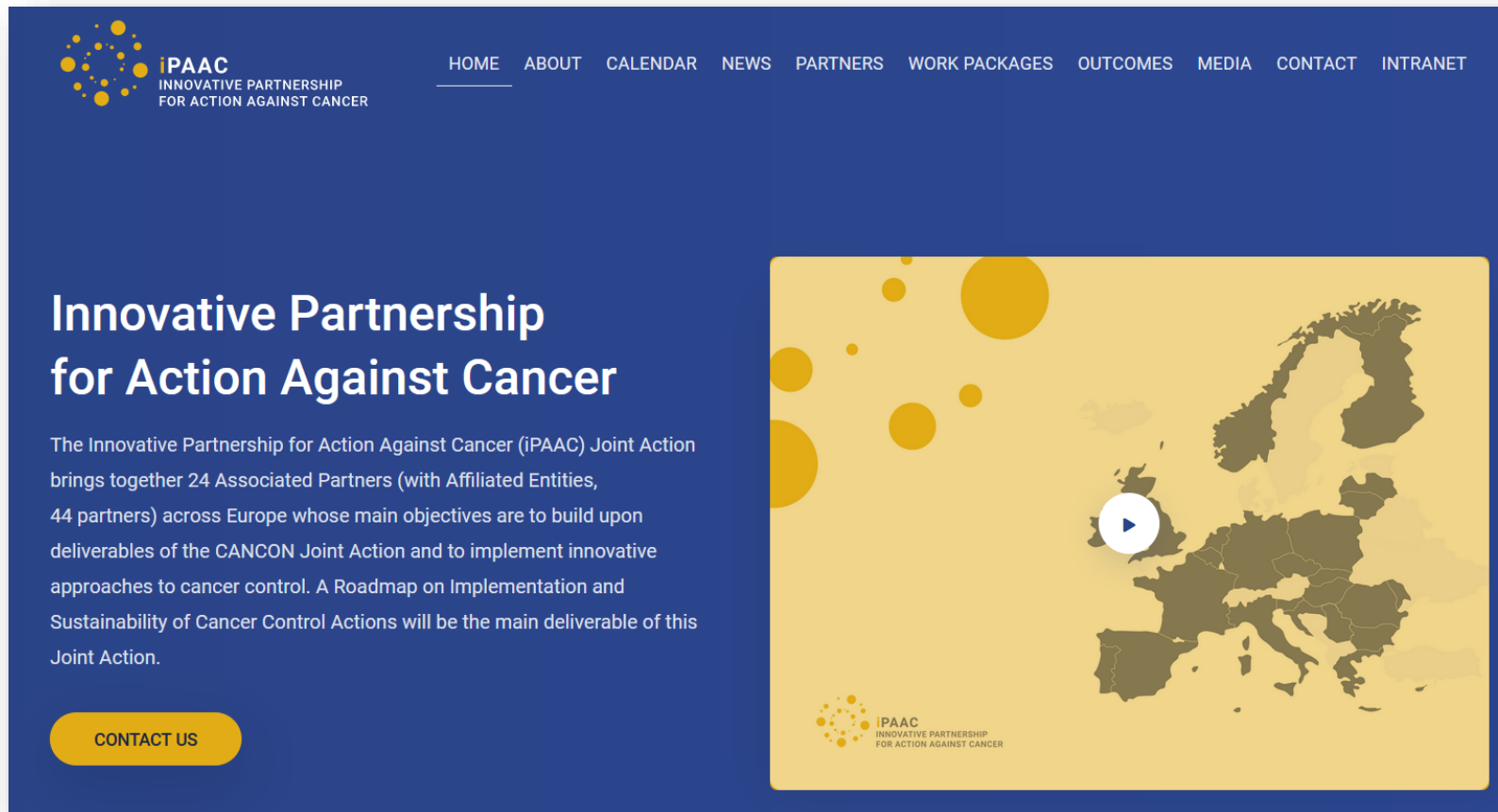
WP 2 – DISSEMINATION

1. Main results/outputs (completed)

- Graphic identity for iPAAC developed
- Leaflet
- iPAAC website online
- Dissemination strategy finalised

Main results/outputs (ongoing & forthcoming)

- Ongoing updates of web portal
- Layman version of the final report (end of JA)
- Local stakeholder forums
- Cooperation with WP4
  - Roadmap online tool

KEY CHANNEL: IPAAC WEB PORTAL

- Information materials
- Webinars, local stakeholder forums
- **Outputs from WPs**
- News articles, papers
- Intranet
  - meeting documents
  - outcomes

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WP 2 – DISSEMINATION

CHALLENGES, QUESTIONS AND OPEN ISSUES TO BE DISCUSSED

- possibility to organise dissemination meetings in person and travelling is disrupted, novel approaches needed, in addition to tools described in dissemination strategy
- organisation of local stakeholder forums
- collaboration with external stakeholders: **help with dissemination is always welcome**

WP 3 – EVALUATION

1. Main results/outputs (completed/forthcoming)

✓ Evaluation Strategy

✓ Interim Evaluation Report

✓ First Focus Group & Survey

✓ LSF Croatia

o Second Focus Group & Survey – **postponed GB meeting planned for April 1st**

o Workshop on Impact and Sustainability – process evaluation

o Workshop on Impact and Sustainability – outputs and outcomes evaluation

o Final Evaluation Report

WP 3 –EVALUATION

2. Dissemination of the WP results/outputs

- Dissemination day at CIPH October, 2019

- LSF (Croatia) January 28th, 2021

- Regular informative articles on CIPH's official web page

- Informative articles in other relevant publications

- Materials for LSF (informative flyer)

3. Challenges, questions and open issues to be discussed

- Date for the next GB (merging FG & first part of the Workshop?)

WP 4 – INTEGRATION IN NATIONAL POLICIES AND SUSTAINABILITY

1. **Main results/outputs**

Completed
Available at: https://www.ipaac.eu/en/work-packages/wp4/
- **CCPIS Report** (and the related methodological paper)
- List of **challenges** reported
- List of **one pagers** (from countries and from WPs) ≈ 200

Forthcoming
- **Case study** on "the use of the Roadmap": cognitive sequelae of treatment in adults cancer survivors

- Opportunities for **mutual learning/experience exchange** (framework and flagships from the EBCP)

- **The Roadmap:** one pagers, background documents and references, "how to use"

WP 4 – INTEGRATION IN NATIONAL POLICIES AND SUSTAINABILITY

2. Dissemination of the WP 4 results/outputs

- 2 "joint events" with ECL and ECPC (separately)

- SGPP (?)

- iPAAC website

- 1st prototype presented and discussed in June 2021

- Real-life demo (based on the case study) at the final conference (Dec 2021)

3. Challenges, questions and open issues to be discussed

- Prioritization of issues (OPs and challenges) for MTL and EE

THE IPAAC ROADMAP

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Main objectives

-> to be used as a supporting tool for cancer control policy implementation

-> gathers information from the iPAAC WPs 5-10 and EU countries

-> can be considered as a database that can continuously be filled in

-> no ranking or evaluation of the actions included (different level of quality and implementation)

The main interface of the iPAAC Roadmap are the ONE PAGERS

Three main **types** of one pagers:
- *the actions (examples of implemented initiatives or programs)*
- *policy and legal frameworks*
- *planning for implementation (e.g. Roadbooks)*

Information provided concerns:
- *practical implementation steps*
- *scope of the initiative (objectives and content)*
- *actors involved and resources required*

Target **audience**: those involved in cancer control policy implementation
- Health administrators/ advisers
- Experts
- Lobby and advocacy groups

Title • max 15 words (objectives/ expected results and (main) added values)

Country • Setting • Cancer control domain

Possible settings: regional; national; local; hospitals or clinics; primary care settings; screening centers; etc.

TYPE & STATUS

Is this one pager describing (please select one option):
- Program
- Legal framework
- Roadbook/ Implementation plan/ Strategy
- Recommendations or guidance for implementation (e.g. guidelines; methodologies)

Status (please select the most appropriate description)

In the planning phase – Pilot - Fully implemented and ongoing – Fully implemented and terminated –In the process of adoption by the Parliament – Adopted by law

PROBLEM & OBJECTIVE • max 60 words
- What is the rationale for implementation (i.e. why should a country implement this practice? to solve which problem)
- What is/are the objective(s) ? (i.e. what does the implementation aim for? what are the expectations and at which level (individual, society, healthcare setting, etc...)?

KEY CONTEXTUAL FEATURES • max 100 words
- the specific contextual characteristics of the healthcare system to take into account
- (legal) frameworks in which the program takes place
- the responsible body/ies involved + extent of their prerogatives or role + the name/type of organizations
- socio-economic and/or societal challenges related to the example

KEY COMPONENTS AND STEPS • max 20-40 words/bullet point

This section describes how the program was rolled out (use succinct bullet points)

Which steps have been followed/are foreseen for the implementation (with dates when possible) ? E.g.: evaluation, expert consultation, law enactment, etc.

ADDED VALUE • max 100 words

What are the main benefits for the individuals?
What are the main benefits for the society?
Have the targets been reached? Is the objective met?

LESSONS LEARNED • max 100 words

description of the key success factors in ensuring the effective formulation and implementation of the policy or measure (bullet points and/or brief description)

Last update of the one pager: (month and year)

THE IPAAC ROADMAP

Questions and thoughts are welcome…

THANK YOU!