



## 2nd iPAAC Joint Action meeting

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Belgrade, 10 - 11 April 2019

Tit Albreht, Tina Lipušček, Nataša Voje, Karmen Hribar, Urška Kolar



Co-funded by  
the Health Programme  
of the European Union

# Review of the agenda – 10 April

## Status of the iPAAC Joint Action



9:00	Welcome
9:15	Status of the iPAAC Joint Action with an overview of Work Packages (WP 5 – WP 10) Tit Albreht, Project Coordinator WP Leaders (5-10)
11:15	Brainstorming workshop regarding the final deliverable – Roadmap Regine Kiasuwa Mbengi, WP 4 Leader
12:15	Lunch
13:15	Discussion regarding the final deliverable - Roadmap
14:15	Overview of Horizontal Work Packages <ul style="list-style-type: none"><li>• Dissemination activities</li><li>• Evaluation activities</li></ul> Tina Lipušček, Project Manager Ladislav Dušek, WP 2 Leader Mario Šekerija, WP 3 Leader



Review of the agenda – 10 April

## Status of the iPAAC Joint Action

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15:15	Evaluation Workshop with WP Leaders only
17:15	End of Meeting
20:00	Dinner

# Review of the agenda – 11 April

## Financial workshop on financial reporting

<b>9:00</b>	<b>Welcome</b>
<b>9:15</b>	iPAAC Financial Policy - overview of rules and principles Nataša Voje, iPAAC Financial Officer
<b>10:00</b>	Interim internal financial reports: - M1-M6 period: comments and observations - M7-M12: 4PM exercises Nataša Voje, iPAAC Financial Officer
<b>11:00</b>	Coffee Break
<b>11:30</b>	Submission of Periodic report M1-M18 to CHAFEA: - General rules on preparing financial reports and deadline - Procedure of submission of financial reports Nataša Voje, iPAAC Financial Officer
<b>12:30</b>	AOB – Q&A, Discussion and Open Issues from Day 1
<b>13:00</b>	End of Meeting, Lunch

# New Project Officer at CHAFEA

- Cinthia Menel-Lemos has taken over the portfolio at CHAFEA covering cancer and has officially replaced previous Project Officer Guy Dargent.
- Notification about all iPAAC meetings (Save the Dates and official invitations, minutes after the meeting, etc) should be sent to the following contact e-mail address:

[cinthia.menel-lemos@ec.europa.eu](mailto:cinthia.menel-lemos@ec.europa.eu)

We very much look forward to a great collaboration with Cinthia Menel-Lemos and are thankful to Guy Dargent for all the support in the past years!

# iPAAC kick-off meeting a year ago...





# 1st GOVERNMENTAL BOARD MEETING

27  
June

2018

Brussels

**35**  
participants &  
**20** countries  
represented!



## PARTICIPANTS:

- Representatives of Member States
- WP Leaders

# 1st STAKEHOLDER FORUM

**20  
September**

**2018**

**Brussels**

**Nearly 60  
participants!**

## PARTICIPANTS:

- Work Packages Leaders
- iPAAC's Collaborating Partners

Attendace of a **large range of stakeholders** who had an opportunity to provide input that can support the iPAAC Joint Action!

**2** thematic main sessions





# 2st GOVERNMENTAL BOARD MEETING

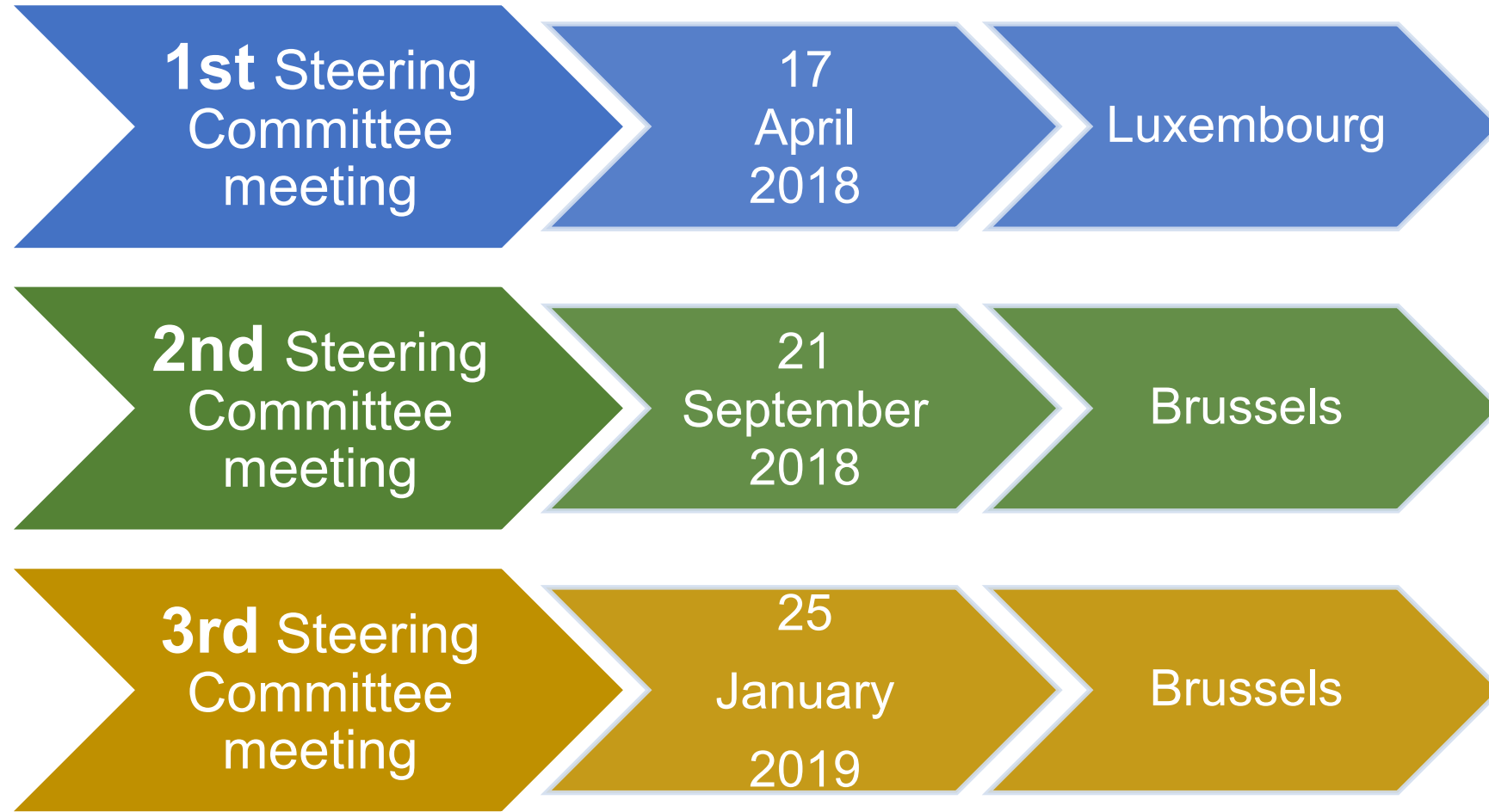


**40**  
participants &  
**19** countries  
represented!

## PARTICIPANTS:

- Representatives of Member States
- WP Leaders

# STEERING COMMITTEE MEETINGS



# The iPAAC Roadmap – key deliverable

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## **Key deliverable of the iPAAC Joint Action:**

**Roadmap on Implementation and Sustainability of Cancer Control Actions, which will support Member States in implementation of iPAAC and CANCON recommendations.**

## **Information for the iPAAC ROADMAP will be gathered from 3 sources:**

- 1. WP 4 Country visits**
- 2. WP 5 - 10 work**
- 3. Other Joint Actions**

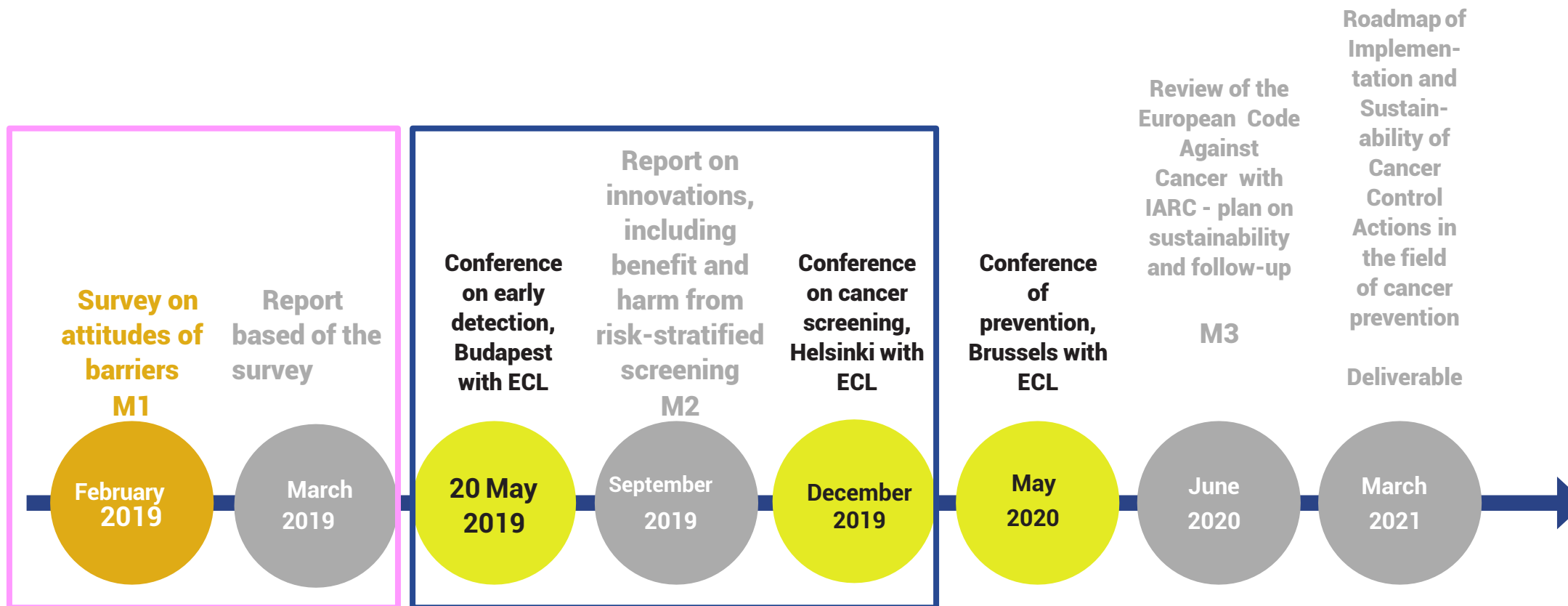
# The Roadmap – key deliverable

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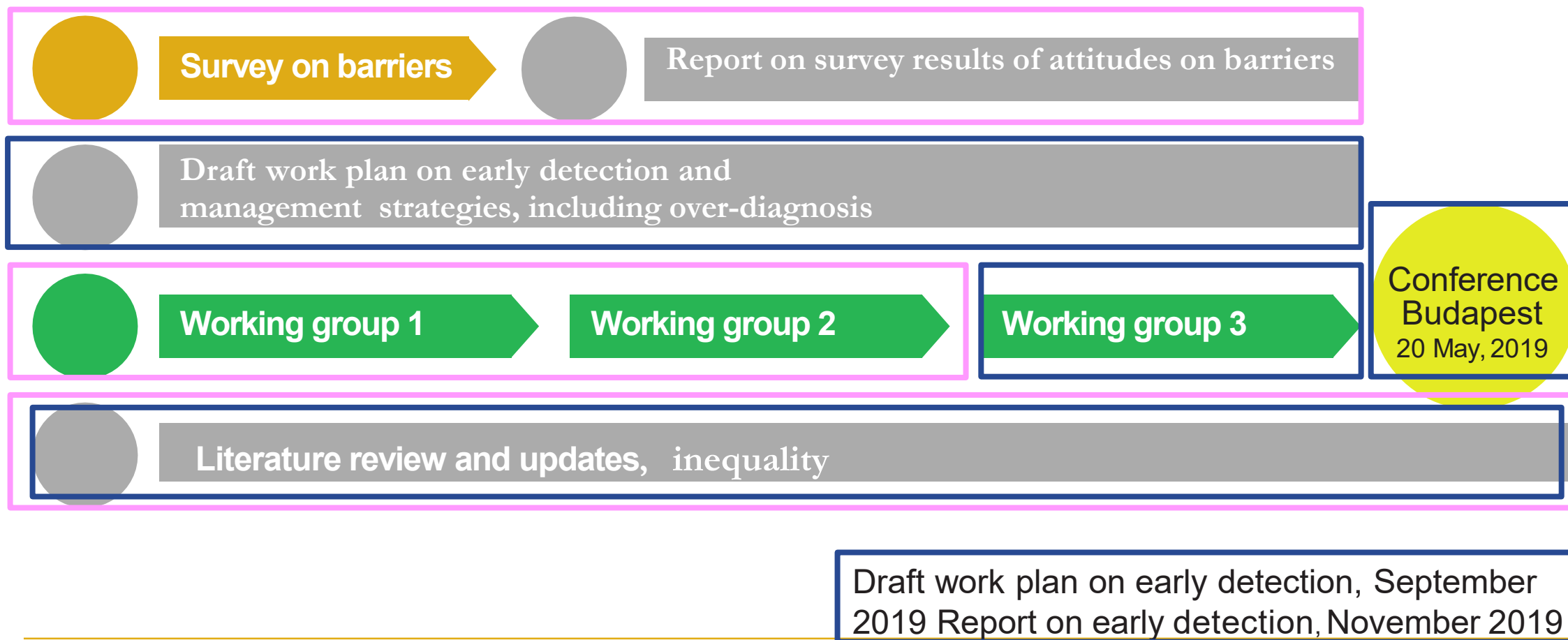
It is important to remember that:

- ✓ Actions need to be implemented throughout the Joint Action and not only at its end;
- ✓ There is a need for close collaboration between the JA and the Member States;
- ✓ Priority in planning in the first 18 months needs to be given to the actions and recommendations from the previous JAs;
- ✓ The new actions and recommendations proposed by the current JA need to be defined and proposed timely with the view of the finalisation of the project.

# IPAAC WP5 Timeline of key activities

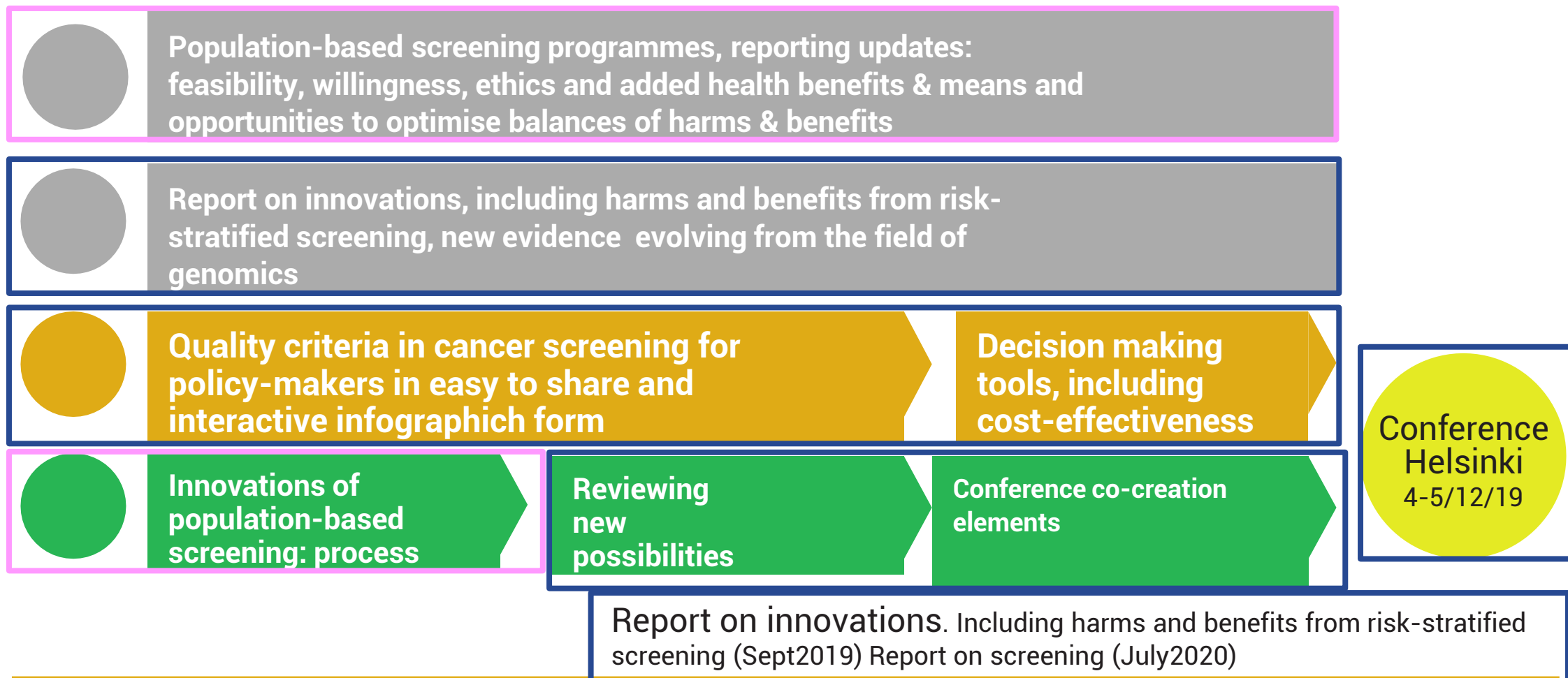


# IPAAC WP5 Task 5.1. Strategies for early detection

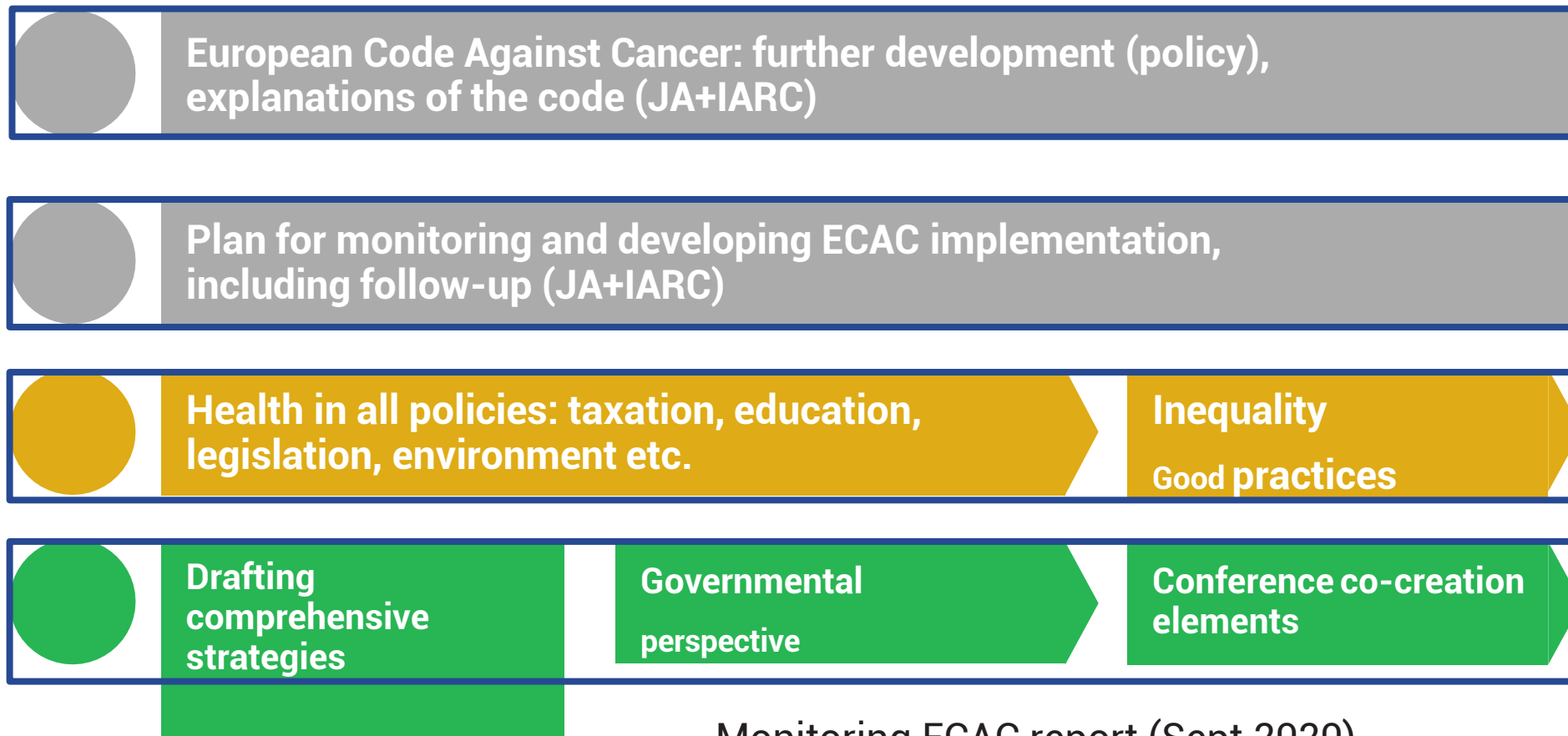




# IPAAC WP5 Task 5.2. Cancer screening



# IPAAC WP5 Task 5.3. Cancer prevention



Conference  
Brussels  
May 2020

Monitoring ECAC report (Sept 2020)  
Conference report (Nov2020)

# WP6 Genomics and Cancer

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Scope: Develop practical guidance for Member States on:

- 1) organizing the **societal debate** on ethical, legal and privacy issues on the use of genome information in healthcare
- 2) installing stratified screening by **genetic testing** of high-risk cancer patients
- 3) implementing **precision genomics** in medical care
- 4) how to deal with '**Direct to Consumer**' testing
- 5) **education and training** on genomics of health professionals, policy makers and the citizens

# WP6 Genomics and Cancer

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## **Meetings:**

- ☐ Kickoff meeting: 23 May 2018
- ☐ Meeting in Rome (Sept) on current implementation of Genomics in HCS, Education and Training and DTC testing
- ☐ WP6 meeting in Ljubljana (Nov) on ELSI and Stratified (genetic) screening

- **Task 6.1: Applying genome information in health care: a paradigm shift in healthcare**

Task Leader: Sciensano

Methodology on citizen participation

Examples from Be, F, 1000000 genomes EC initiative, UK,...

- **Task 6.2: Concept for the implementation of risk-adjusted prevention: the breast cancer case**

Task Leader: ISS

Principles (in collaboration with WP5)

Examples of implementing BRCA screening (It, Horizon MYPEBS project)

- **Task 6.3: Requirements and prerequisites for implementation of ‘omics’ in routine molecular diagnosis in oncology** Task Leader: Sciensano  
Roadbook(s) from Belgium, F(?), It (?)  
Experiences form UK, Scotland
- **Task 6.4: ‘Direct to Consumer’ genetic testing**  
Task Leader: ISS  
Review and practical guidance



- **Task 6.5: Education and training on genomics for healthcare professionals** Task Leader: ISS

Review

Tool for education purposes

**Task 6.6: Drafting of the Road Map – genomics**

Task Leader: Sciensano

# WP6 Genomics and Cancer

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## Upcoming

- ☐ One day meeting on ELSI, Stratified screening (May?) in collaboration with WP5
- ☐ One day meeting on genomics, DTC and education & training (June?) in collaboration with WP9
- ☐ Conclude on the WP6 fiches (Aug) – all taskleaders

# WP6 Genomics and Cancer

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## Topics

1. Citizen participation methodologies
  - Citizen forum Belgium (case study)
  - French approach on genomics acceptance (case study)
  - Sienna project results (research)*
  - Wellcome Trust initiative (research)*
1. Roadbook genomics in HCS (Be, F, It) (case studies)
2. WGS in HCS (UK, F, 1M Genomes project) (case study)
3. DTC policy
4. Tool for education & training on genomics

# WP 7 – Cancer Information and Registration

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Italian National Institute of Public Health (ISS)

## KEY HIGHLIGHTS OF THE PAST YEAR: **ADVANCING REGISTRIES DATASETS**

### **1. Task 7.1:** Survey on data sources available for linkage

- Response from 24 CR in 14 countries → survey needed to define pilot 7.3-7.4 protocols design
- Variations by country in type and number of accessible data sources
- Legal framework conditioning access, linkage, transfer to third parties → data sharing agreements (GDPR)

### **2. Tasks 7.2-7.5:** Piloting electronic integration to derive quality of care, costs, survivorship

- iPAAC pilots aimed at providing conceptual framework to derive standardised key indicators
- Interest to participate to pilots: 12 CR (10 countries)
- Index tumours decided (colon, rectum, pancreas, skin melanoma)
- Study protocols design discussed and approved in Rome meeting 12-13 March 2019, 1<sup>o</sup> Milestone
- Two options for integrated data analysis: centralised vs decentralised to solve legal issues

# WP 7 – Cancer Information and Registration

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Italian National Institute of Public Health (ISS)

## KEY HIGHLIGHTS OF THE PAST YEAR: **BETTER USE OF REGISTRIES DATA**

- 1. Task 7.6 Disseminating cancer prevalence indicators in Europe by country**
  - Complete prevalence (life-long) and by disease duration
  - Survivors by phase of care
  - Cured survivors
- 2. EUROCare-6 preliminary dataset ready : 22 countries (national coverage)**
  - Data quality checks completed
  - Preliminary analyses performed and sent to registries for double-checking
- 3. Consensus on target indicators in Rome meeting 12-13 March 2019, 1° Milestone**



# WP 7 – Cancer Information and Registration

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Italian National Institute of Public Health (ISS)

## PLANS FOR THE NEXT YEAR: **ADVANCING REGISTRIES DATASETS**

### 1. Task 7.1: Survey on data sources available for linkage

- Report on the state-of-the-art of integrated cancer information systems

### 2. **Tasks 7.2-7.5:** Piloting electronic integration to derive quality of care, costs, survivorship

- Discussion on file format and selection procedures: ad hoc call or site visits (apr-aug)
- Data linkage (sept-nov)
- Data analysis (dic-mar)





# WP 7 – Cancer Information and Registration

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Italian National Institute of Public Health (ISS)

## PLANS FOR THE NEXT YEAR: **BETTER USE OF REGISTRIES DATA**

### **Task 7.6** Disseminating cancer prevalence indicators

#### **1.** Finalise EUROCare-6 dataset

- 28 countries with national or regional population coverage

#### **2.** Data analysis and calculation of prevalence indicators by country

- Cancer- sex- age- specific → colorectal, pancreatic, skin melanoma (at least 10 major entities)
- Time projections to 2021 needed

#### **3.** Dissemination of methods and indicators

- Training to cancer registries and scientific community
- Possibly in the framework of ENCR-JRC training program (timeline tbc)

# WP 8 – Challenges in Cancer Care



## OBJECTIVES:

- To review and assess of the situation for neglected cancers with a special focus on pancreatic cancer, highlighting the challenges and opportunities for improving detection, diagnosis and access to expert clinicians in order to increase the quality of care and outcomes, and raising awareness within the EU Policy and Research agenda.
- To identify the potential use and existing barriers for shared information systems, decision support systems, information and communication technologies, and 'big data' in the context of MDTs and cancer care management, and its consequences for the implementation of MDTs in EU countries.
- To propose a set of measures aimed at improving the sustainability of cancer care in European countries, taking into account the challenges posed by trends in cancer incidence, assessment of clinical effectiveness, efficient resource allocation, affordability, and equity of access to good quality cancer care.
- To assure that pain control is considered a priority in cancer and to distinguish the needs of long term survivors from those of palliative care patients. Identify evidence based guidelines and areas for improvement in guidelines implementation, education of oncologists and in organization of multidisciplinary approaches including oncologists, pain and palliative care specialists
- To highlight an homogenous approach to palliative care based on CANCON recommendations including patient care pathways, national policy and sustainability, innovative therapies, cancer registry and clinical data bases. Identify areas of development and challenges posed by innovative therapeutic approaches such as early integration of palliative care in the oncology care pathways, focusing on the available models of integration and on how palliative care and oncology can respond to the availability of personalized medicine guiding the use of target therapies and immunotherapies both in clinical practice and in research.



# WP 8 – Challenges in Cancer Care



## **Task 8.1: Definition of neglected cancers: the case for pancreatic cancer**

Task Leader: ISS, Participating Partners: ICO, SAM(VUHSK), IPHS, BcSAS

- Mailing list with interested partners (September 2018)
- Literature review to understand the different meanings given to the expression “neglected cancer” in international literature.
- Analysis of the last available data on incidence, mortality and survival for all solid cancer entities. This was done because one possible definition of neglected cancer is a “highly frequent tumour with poor prognosis”.
- Discussion at the end of December (with deadline January 25<sup>th</sup>) to reach an agreement on the following two issues:
  - The definition of neglected cancer
  - The possible cut-offs for the three indicators to define where a cancer may be considered neglected.
- Preliminary list of core clinical variables for cancer registries in pancreatic cancer circulated (*March 2019*)

*Report expected before June 2019*



# WP 8 – Challenges in Cancer Care



## **Task 8.2: Neglected cancers: proposal of criteria for reorganisation of treatment delivery**

Task Leader: ICO, Participating Partners: SAM (VUHSK), WIV-ISP, IPHS

- Literature review carried out (March / April 2019) with a focus on policy measures to reorganize treatment delivery of pancreatic cancer.
- Workshop planned for discussion in September 2019, Bratislava; with scientific societies, patients representatives, experts and national cancer plans.
- Final report expected November 2019
- ECCO (subcontract): Essential requirements for pancreatic cancer. December 2019



# WP 8 – Challenges in Cancer Care



## **Task 8.3: MDTs and potential impact of new technologies and systems. Assessment of the opportunities for improving integration of cancer care**

Task Leader: ICO, Participating Partners: IPHS, BcSAS, NIJZ, SAM (VUHRSK)

- Selection of care studies: ongoing with the support of ECCO.
- Site – visits: expected for *May to June 2019*. Methodology approach: multiple-case study.
- *Report delivered in November 2019*



# WP 8 – Challenges in Cancer Care



## Task 8.4: Economics of cancer care

Task Leader: ISS, Participating Partners: ICO, SAM (VUHSK), NIJZ, NIPH (IPMN), ISS (MoH)

4.1: To review international experiences in promoting allocative efficiency and identifying low-value or inappropriate cancer care and to map the desirable characteristics of interventions targeted to health care providers for improving the level of appropriateness in clinical care.

- Survey prepared and circulating.
- *Meeting in September 2019*

4.2. To review the recent developments in reimbursement models and experiences in introducing innovative treatments in European health systems, with special focus on radiation oncology and complex cancer surgery as case studies

- Literature review for reimbursement in radiotherapy oncology (*expected May 2019*)
- Literature review for reimbursement in surgical oncology (*expected September 2019*)
- Workshop to review the pros and cons of each reimbursement model with scientific societies, patients representatives and experts (*January 2020*)
- *Report expected April 2020.*





# WP 8 – Challenges in Cancer Care



## Task 8.5: Pain management in the context of cancer care

Task Leader: ISS, Participating Partners: ICO, ISS, THL

- Literature review on pain prevalence, barriers to adequate pain management with focus survivors.
- *Report expected September 2020*



# WP 8 – Challenges in Cancer Care

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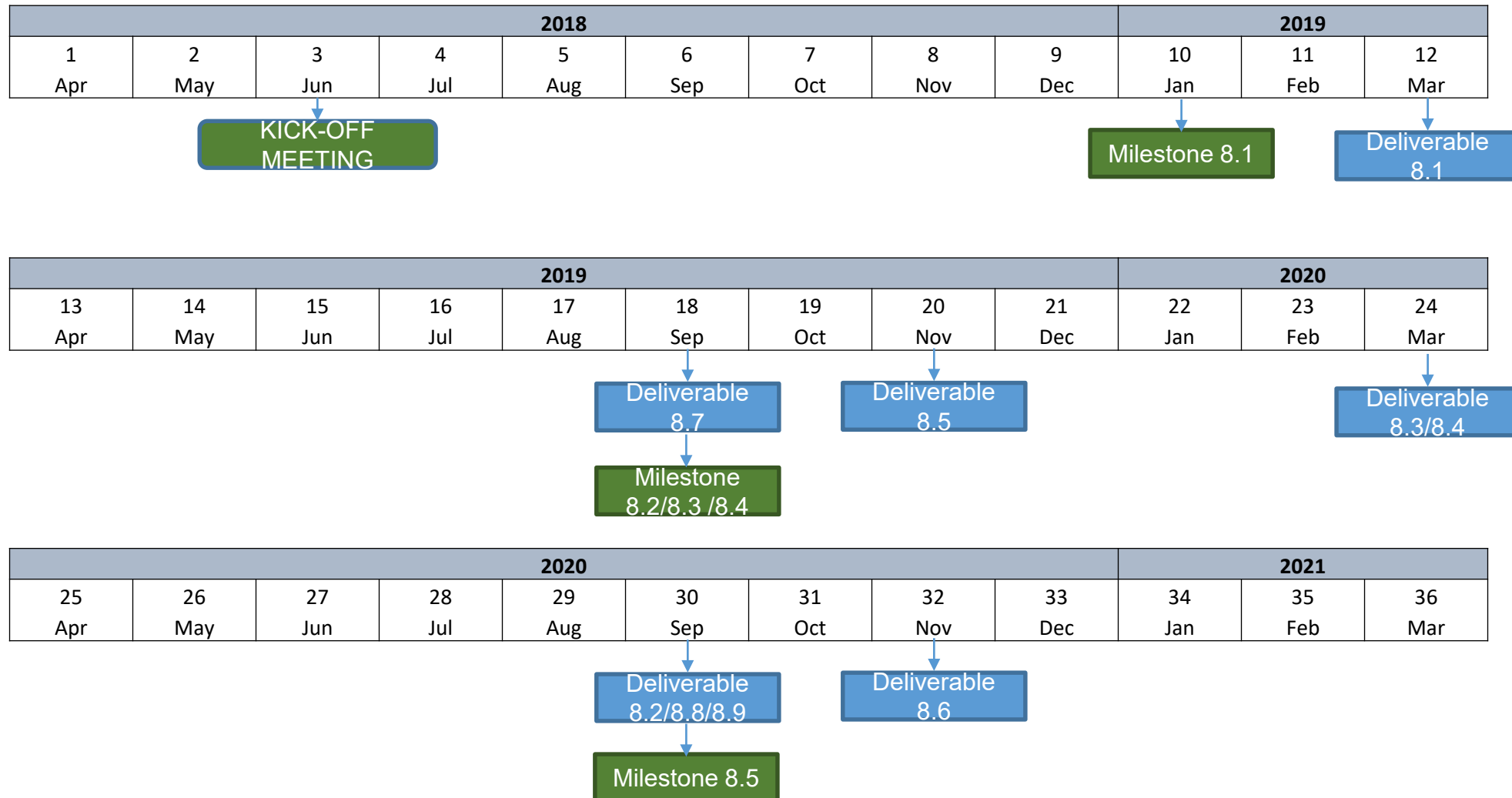
## **Task 8.6: Palliative care**

Task Leader: ISS, Participating Partners: ICO, THL

- *Report expected September 2020*



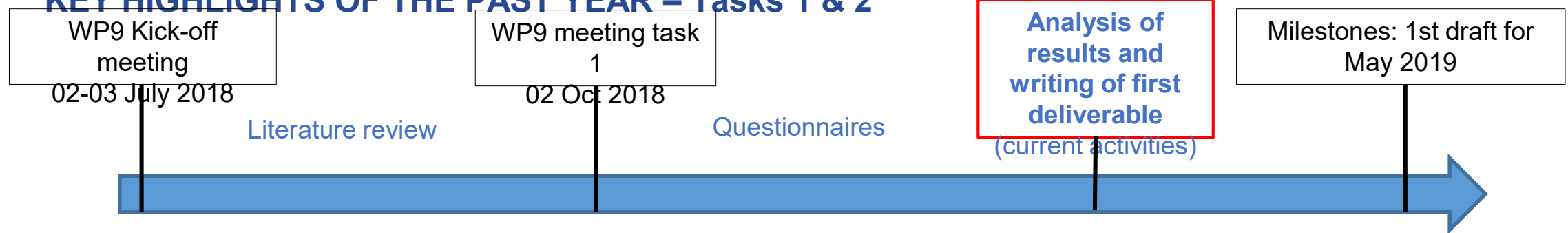
# WP 8 – Challenges in Cancer Care



# WP 9 – Innovative Therapies in Cancer

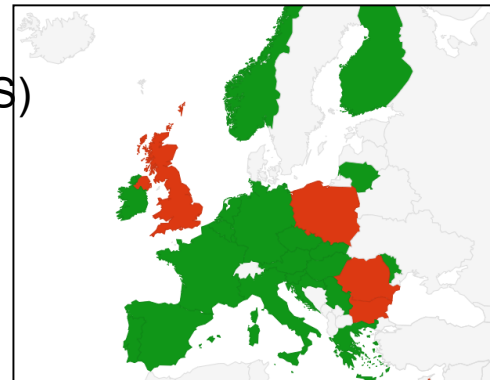
## French National Cancer Institute (INCa)

### KEY HIGHLIGHTS OF THE PAST YEAR – Tasks 1 & 2



#### Main results from lit. review:

- 120 CPG placing innovative immunotherapies (ITS)
- Off-label recommendations identified mainly for small target groups, rare cancers
- Place of innovative immunotherapies could differ between guidelines, especially when comparison data are missing
- Hard to keep updated GPC in this fast evolving field



Completion of 1st  
questionnaire by iPAAC  
partners

#### Main results from questionnaire:

- Only half of the EU countries have included innovative ITS in at least one CPG
- Comparison between countries and between therapeutic indications regarding access in terms of reimbursement and restrictions of uses
- Existing early access programs

# WP 9 – Innovative Therapies in Cancer

## French National Cancer Institute (INCa)

### KEY HIGHLIGHTS OF THE PAST YEAR – Task 2 & 3 - Horizon scanning systems & Biomarkers

WP9 Kick-off meeting 02-03 July 2018

WP9 meeting task 2 & 3  
06 March 2019 - Bruxelles

WP9 Horizon scanning  
meeting  
November 2019 - INCa

Preparation of the task

- Literature review
- Meetings with Euroscan, IHSI

Presentation of methodology for retrospective analysis to evaluate the efficiency of HS in oncology

Review of existing  
Horizon scanning systems  
and organizations



Identification of key figures and  
issues associated with  
innovative cancer therapies



- Highlight methodological specificities needed in HS systems in the field of oncology, especially for
  - cell and gene therapies
  - Biomarkers
- Assessment of inequalities between European Countries

# WP 9 – Innovative Therapies in Cancer

French National Cancer Institute (INCa)

## PLANS FOR THE NEXT YEAR – Task 1 & 2

- Consolidation of the deliverable linked to task 1 to present results from literature review and questionnaires
- Review and validation of the deliverable by WP9 partners. Finalized version expected for September 2019
- Consolidate main fields of interests for the roadmap:
  - List of clinical practice guidelines providers in Europe in the field of oncology
  - Examples of fruitful collaborations for the production of CPG; and of endorsement methods
  - Examples of reimbursement models enabling fast access
  - Examples of frameworks enabling early access to innovative immunotherapies for an unauthorized indication
  - Innovative cancer therapies in clinical practice guidelines: remaining challenges (acceptability of off-label recommendations, how to improve production and update of CPG, visibility?, need to create a public financing system to implement studies comparing several innovative therapies between them when no comparison data are available)
  - Remaining challenges: Link with ECL – European Fair Pricing Network (increase transparency of innovative therapies prices – joint negotiations in EU)?
  - Remaining challenges for access to innovative therapies across Europe (including inequities)

# WP 9 – Innovative Therapies in Cancer

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French National Cancer Institute (INCa)

## PLANS FOR THE NEXT YEAR – Task 2 & 3 – Horizon Scanning systems

- Conduction of the retrospective analysis with the help of the questionnaire
- Additional meeting will be organized in November 2019 to validate task 3 deliverables
- For the roadmap, the following points could be included:
  - Generalities on Horizon scanning systems: definition, purposes, main methodological steps to follow to implement an HSS
  - Present some existing European HSS in place
  - Present the main ongoing collaboration initiatives existing in Europe
  - Present specificities to be considered in the HS methodology for the oncology field with a focus on innovative immunotherapies, gene and cell therapies (with the example of CAR-T cells) and biomarkers
  - Highlight challenges related to the assessment of impact of innovative therapies in the field of oncology

## PLANS FOR THE NEXT YEAR – Task 4 – Real-life monitoring of innovative immunotherapies

- Meeting dedicated to task 4 to be organized in February 2020

# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## KEY HIGHLIGHTS OF THE PAST YEAR 2018/19

**Goal:** “....develop practical instruments (...) (to ensure) a standardized (...) comprehensive oncological care in all Member States that is tumour-specific and delivers (...) high-quality care to all patients. These instruments should be used by NCCPs for the governance of oncological care”.

**Task 1:** Assess and review NCCPs; develop recommendations on how the results of tasks 10.2-10.5 could be included in updated NCCPs ✓

- 1.1. Survey on National Cancer Control Programmes/Cancer Documents in EU (M12) ✓
- 1.3. Preliminary literature research on the conceptual model of governance and stewardship of cancer care (M12)

**Task 2:** Review and assess existing models of oncological patient pathways; develop a generic patient pathway for CCCNs ✓

- 2.1. Literature Review of existing models of oncological patient pathways (M12) ✓
- 2.1. Agreement of definition of patient pathways (M12)

**Task 3:** Review and assess implemented QI; develop standardized methodology; develop set of general and tumour specific QI for CCCNs *delayed ready in M14*

- 3.1. Literature Review of already implemented Qis and their respective methodology which was used (M12) –





# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## KEY HIGHLIGHTS OF THE PAST YEAR 2018/19 (cont.)

**Task 4:** Review and assess existing PROMs; develop a framework for the implementation and pilot the framework in CCCNs

- 4.1. Preliminary results of literature review of existing models of collecting PROMs (M18)

**Task 5:** Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements

- 5.3. Establishment of CCCN pilot sites: Charité Hospital, Berlin/Germany & Lower Silesian Oncology Centre, Wroclaw/Poland (M3)
- 5.1. Generic and tumour-specific requirements for the set-up of CCCN developed and agreed (M12)

**Overall:** Synergies between work packages identified

- Task 3 QI and WP 7.2 (= Piloting the integration of data on care pathways)
- Task 4 PROMs and WP8.1 (= Definition of neglected cancers: the case for pancreatic cancer)
- Task 5 CCCN and WP 8.2 + WP 7.2 (8.2 =Neglected cancers: proposal for criteria for reorganization of treatment delivery [of pancreatic cancer] ; 7.2 = with the goal to use the same key figures/quality indicators)



# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## PLANS FOR NEXT YEAR 2020

**Goal:** “....develop practical instruments (...) (to ensure) a standardised (...) comprehensive oncological care in all Member States that is tumour-specific and delivers (...) high-quality care to all patients. These instruments should be used by NCCPs for the governance of oncological care”.

**Task 1:** Assess and review NCCPs; develop recommendations on how the results of tasks 10.2-10.5 could be included in updated NCCPs

- 1.2. Discussion how / in which form the results of task 2-5 will be included in NCCP review report (M30)
- 1.4. Survey on the level of implementation of stewardship for cancer care on the national level (M24)

**Task 2:** Review and assess existing models of oncological patient pathways; develop a generic patient pathway for CCCNs

- 2.2. Systematic review of existing methods for describing and implementing patient pathways (M18)
- 2.3. Model of patient pathway for the use in CCCN's is developed (M24)

**Task 3:** Review and assess implemented QI; develop standardized methodology; develop set of general and tumour specific QI for CCCNs

- 3.2. Development of a standardised methodology to derive QI's (M18)
- 3.3. Development of set of general and tumour-specific QI's for the use in CCCN (M24)



# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## PLANS FOR NEXT YEAR 2020 (cont.)

**Task 4:** Review and assess existing PROMs; develop a framework for the implementation and pilot the framework in CCCNs

- 4.1. Literature review of existing models of collection PROMs in cancer care finalized (M18)
- 4.2. Development of recommendations for PROMs collection in routine cancer care (M24)

**Task 5:** Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements

- 5.2. Development of a framework for the monitoring of implementation of defined requirements in CCCN's (M18)
- 5.3. Support of the pilot-CCCN to implement the requirements and the results of task 2-4; preparation of the peer-review (M24)

## Roadmap

- Continuous discussions and agreement on contributions of WP 10 to Roadmap development once template and outline is agreed and available



**Thank you all for your great collaboration!**