



iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

SECOND iPAAC JA STAKEHOLDER FORUM MEETING

Brussels, 10 December 2019

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the Health Programme
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FIRST HALF OF THE iPAAC JA

Notable achievements:

- ✓ Signing of Grant Agreement
 - ✓ Signing of iPAAC Consortium Agreement
 - ✓ Submission of Periodic Technical and Financial Report in November 2019
 - ✓ iPAAC website and regular newsletters established
 - ✓ Project management meetings running according to plan
 - ✓ Currently in **Month 21** of the JA
- ➡ **We are progressing according to the plan with minor delays!**

FIRST HALF OF THE iPAAC JA

Notable achievements:

- ✓ The main activities focus around two key pillars:
- ✓ **Roadmap on Implementation and Sustainability of Cancer Control Actions („Roadmap“)** and;
- ✓ Development of **innovative actions** in the fields of cancer prevention, screening, genomics, cancer information and registries, care, therapies and governance.

WP4 INTEGRATION IN NATIONAL POLICY & IMPLEMENTATION

WP4 main objective: *Develop the „Roadmap on Implementation and Sustainability of Cancer Control Actions“*

Sub-objectives:

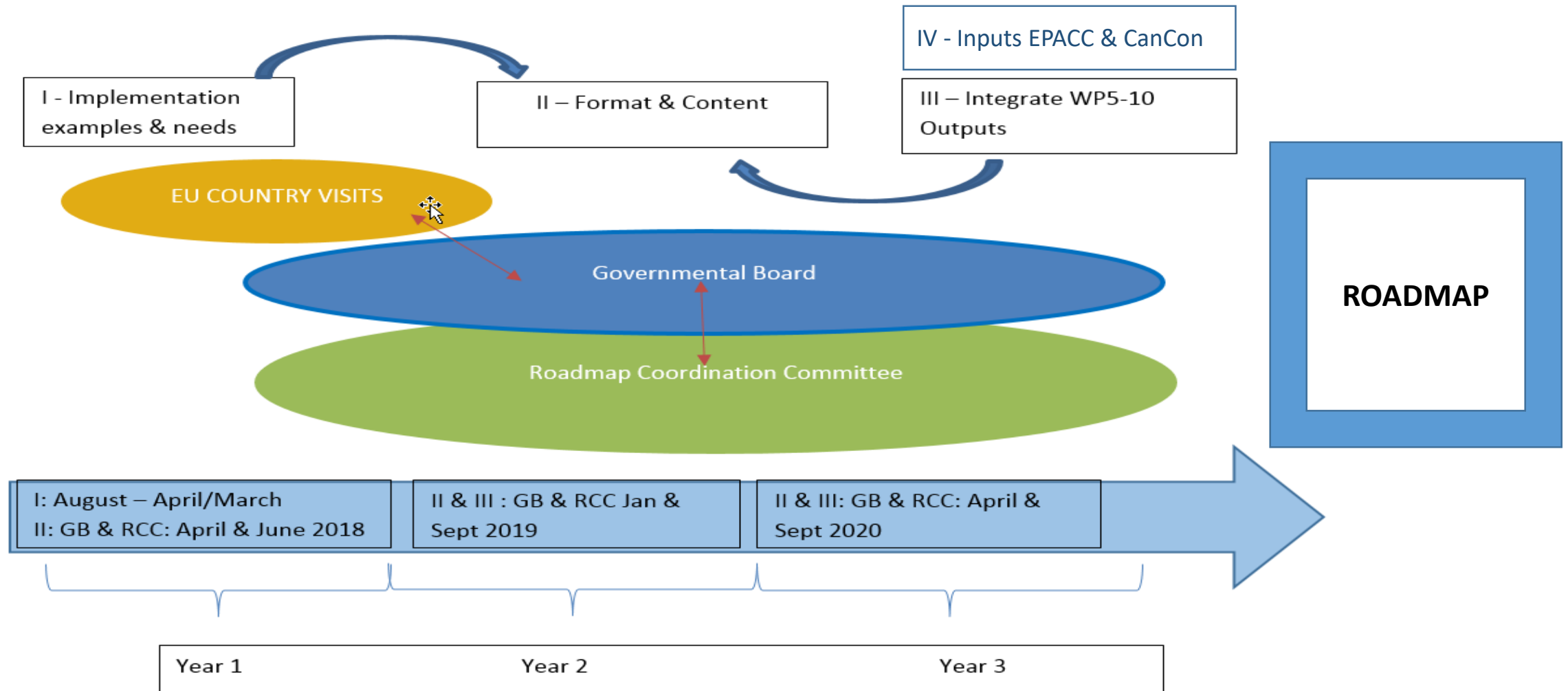
- collect the content (EU MSs experience/needs/challenges; WPs5-10; previous JAs on cancer control; other JAs with relevant results)
- prepare and develop the structure/platform for the Roadmap
- prepare the format for presenting the content

WP4 Support Platforms:

Roadmap Coordination Committee

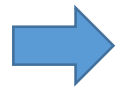
Governmental Board

WP4 WORK PROGRESS



CANCER CONTROL POLICY INTERVIEW SURVEY“ (CCPIS)

- The main activity of Work Package 4 : **Cancer Control Policy Interview Survey“ (CCPIS): in-depth interviews**



the collection of experience of EU Member States in cancer control policy implementation.

- **26 countries** have been visited
- It is aimed to further include another 3 countries (Sweden, Estonia, Poland) by the end of 2019
- WP4 Deliverable: Report on Cancer Control Implementation Survey - March 2019

FORMAT OF THE ROADMAP

- Web-based tool
- Searchable platform
- Encourage and **facilitate mutual learning** among EU MSs
- Provide to those who are responsible of policy implementation with concrete examples of what/how they can implement it

WHAT'S IN THE ROADMAP?

iPAAC WPS 5-10 RESULTS

Implemented programs
Plans for implementation
Toolbox material

e.g. experience from pilots
e.g. roadbook/ recommendations
e.g. results from lit. reviews/surveys

CCPIS

Implemented actions
Plans for implementation
Toolbox material (legal framework)



Implemented actions
Plans for implementation
Toolbox material

**CANCON
EPAAC**

OTHER JAs

FORMAT OF THE ROADMAP

Information will be in the format of „One-Pagers“ which will be displayed in the Roadmap

“One-Pagers”

- Information on implementation actions and implementation plans: innovative approaches
- Essential information on a particular action, issue, topic in a concise, comprehensive way: implementation related features
- Link to theoretical, scientific frameworks as background information related to the „One-Pager“

GOVERNMENTAL BOARD (GB)

Governmental Board (GB) has been set up to:

- ensure that the „Roadmap“ would correspond to the needs of the users (i.e. health administrators and responsible of health policy implementation and experts)
- Members: Representatives from EU MS involved in cancer policy implementation, WP Leaders, the iPAAC Project Management Team, EC representatives and external experts.

1ST GOVERNMENTAL BOARD MEETING

27
June

2018

Brussels

35
participants &
20 countries
represented!



PARTICIPANTS:

- Representatives of Member States
- WP Leaders

2ND GOVERNMENTAL BOARD MEETING



40 participants
& **19** countries
represented!

PARTICIPANTS:

- Representatives of Member States
- WP Leaders

3RD GOVERNMENTAL BOARD MEETING

9.-10.
October

2019

Barcelona



54 participants
& **24** countries
represented!

PARTICIPANTS:

- Representatives of Member States
- WP Leaders

1ST STAKEHOLDER FORUM A YEAR AGO

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



1ST iPAAC STAKEHOLDER FORUM

20 September 2018

TWO THEMATIC MAIN SESSIONS



WP 6
Genomics in Cancer
Control and Care



WP 9
Innovative Therapies
in Cancer

2ND iPAAC STAKEHOLDER FORUM

10 December 2019

TWO THEMATIC MAIN SESSIONS



WP 5
Cancer prevention



WP 7
Cancer Information
and Registries

WP 5 – PREVENTION AND SCREENING

Cancer Society of Finland (CSF)

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA:

- **Early diagnosis:** co-creational conference in Budapest 20.5.2019
- Survey on barriers of early diagnosis on European level on M.1. February-March/2019
- **Cancer screening:** Report of innovations, including harms and benefits from risk-stratified screening M.2 September 2019

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- **Early diagnosis:** Conference report, November 2019
- **Cancer screening:** co-creational conference in Helsinki & Conference report in July 2020
- **Early detection:** Draft work plan on early detection and infographic on quality criteria in screening February-March 2020
- **Prevention:** co-creational conference on European Code Against Cancer (ECAC) & prevention 29.4.2020 in Lyon IARC HQ & Conference report on prevention November 2020
- Monitoring report on ECAC, September 2020
- Review of ECAC recommendations, based on expert groups, November 2020 M.3

Cross-cutting: inequalities – best practices competition, its materials and results (FISABIO)

Cancer Society of Finland (CSF)

3. INVOLVEMENT OF COLLABORATING PARTNERS

Collaborating partners have received internal news and alerts (save the dates), including the survey and save the dates and invitations to the open conferences (Budapest, Helsinki, Lyon). Attending these conferences means active participation, because the delegates are working in groups with co-creational methods, thus contributing to the conference reports.

4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

How to better involve collaborating partners in cross-cutting themes of innovation and inequality? The tasks of early diagnosis, screening and prevention: provide an e-platform for brainstorming, polls etc.? Best ways to increase interaction?– The 3 dedicated conferences do not allow much time to anything else than what is in the WP5 description in addition to group work.

Belgian Cancer Centre – Sciensano (SC)

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

- One pagers have been prepared on: NGS use in oncology in Belgium
- Draft guidance for task 6.1, 6.2 and 6.4
- Scientific papers in preparation for 6.1, 6.4 and 6.5

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- One pagers for all tasks
- Guidance documents for 6.1, 6.2 and 6,3
- Scientific papers for each task

Belgian Cancer Centre – Sciensano (SC)

3. INVOLVEMENT OF COLLABORATING PARTNERS

- Translate WP6 finding into one-pagers
- Participate at 2 symposium (ELSI in march 2020, Genomics end 2020)

4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

- Sustainability of the one-pagers
- Opportunities for collaboration

Italian National Institute of Public Health (ISS)

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

- Survey to map administrative data sources available to integrate cancer registry data
- Workshop to agree on the study protocols of the pilots to integrate data sources with registry data
- Legal background approved for the National ICT model integrating multiple data sources in the Czech Republic
- Validated methodology to derive core cancer prevalence indicators by country in Europe

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- Standardised procedures to derive comparable indicators on quality of care, direct costs of care, and disease patterns of AYA survivors, through integration with administrative data sources
- Implementation and validation of the National Health Information system integrating epidemiological, administrative and clinical records to support quality improvement in cancer care in the Czech Republic
- Promoting systematic delivery of up-to-date population-based indicators on cancer prevalence in MS to boost the European Cancer Information System (ECIS)

Italian National Institute of Public Health (ISS)

3. INVOLVEMENT OF COLLABORATING PARTNERS

- European Network of Cancer Registries (ENCR) and National Associations (ReDeCAN, AIRTUM)
- Joint Research Center – European Commission (JRC)
- Patients Associations (Pancreatic Cancer Europe- PCE, ECPC)
- National Research Institutions and Universities (Tampere, Tor Vergata, CNR,)

4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

- Common standards and procedures to advance registry-based information on the whole cancer pathway
- Legal requirements to access additional data sources and enhance the scope of cancer registration
- Increasing the interoperability between epidemiological, administrative, clinical data sources

Catalan Institute of Oncology (ICO)

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

- Definition of “Neglected cancers” (e.g. pancreatic, stomach, liver or brain cancers) based on clinical and epidemiological variables
- Consensus on the policy measures (recommendations) to be undertaken concerning the patients’ diagnosis and treatment of pancreatic cancer care (The *Bratislava Statement*)
- Survey on low-value cancer care (explanatory factors) in European cancer centers and Cancer Plans
- Reimbursement for radiotherapy and complex cancer surgery: how to support innovation in payment models

Catalan Institute of Oncology (ICO)

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- Report with key criteria for organisation and implementation of ICTs and health information systems within the area of MDTs management
- Report of *Essential requirements for quality cancer care in pancreatic cancer*
- Report on the list of social and clinical demographic variables to describe pancreatic cancer patients pathways and monitor their outcomes
- Recommendations on the implementation of available guidelines on pain control in oncologist education and in MDTs
- Recommendations on integration between palliative and oncology

Catalan Institute of Oncology (ICO)

3. INVOLVEMENT OF COLLABORATING PARTNERS

Involving the *Belgian Health Care Knowledge Centre (Belgium)*, the *CIBERESP & CIBERONC networks of research (Spain)*, *INCA (France)* and the *Health Policy Partnership ALL.CAN (UK)* resulted in wider coverage of relevant issues (e.g., with the Consensus Statement on pancreatic cancer care). The contribution of scientific societies and patient groups in the discussion about how to improve the delivery of care in neglected cancers was also very fruitful.

4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

The issues that have been addressed in WP8 are at the crossroads between policy and healthcare. Our collaborating partners are committed to the need to discuss policy challenges based on the available evidence or expert consensus.

French National Institute of Cancer (INCa)

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

- Innovative cancer therapies in **clinical practice guidelines**
- Reference frameworks linked with the **access** to innovative immunotherapies
- + specificities to be considered for **biomarkers**

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- **Horizon scanning systems** applied for cancer control in Europe
- **Real-life monitoring** of innovative therapies

WP 9 – INNOVATIVE THERAPIES IN CANCER

French National Institute of Cancer (INCa)

3. INVOLVEMENT OF COLLABORATING PARTNERS



4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

- Challenges in integrating innovative immunotherapies into clinical practice guidelines
- Early access programs
- Innovative reimbursement systems enabling access to innovative medicines in cancer
- Challenges to be considered to properly anticipate innovative therapies in cancer with horizon scanning systems
- Ongoing initiatives for the real-life monitoring of innovative immunotherapies

WP 10 – GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE



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

1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA

- **Task 1.1.** Review and assessment of NCCPs was initiated by conducting a survey in EU member states, some EEA countries and EU candidate countries (total of 34 countries) with a 100% response rate
- **Task 1.3** Conceptual model for terminology and assessment of stewardship of cancer care was developed
- **Task 2.1** Literature review of existing models of oncological patient pathways was conducted
- **Task 2.2** Systematic review of existing methods for describing and implementing patient pathways was performed
- **Task 3.1** Literature review of already implemented quality indicators and the respective methodology which was used was conducted
- **Task 3.2** On the basis of the results of the literature review a standardized methodology was developed in order to derive QI for the use in CCCNs
- **Task 4.1** Literature review of existing models of collecting PROMs in routine cancer care was conducted
- **Task 5.1** Definition of CCCN pilot sites accomplished
- **Task 5.1** Development of Set of Standards (generic and tumour specific) for the set up of CCCNs was finalized
- **Task 5.2** Definition of a Framework to monitor the successful implementation of the two Sets of Standards drawn up and agreed



WP 10 – GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE



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

2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA

- **Task 1.2.** Development of recommendations through a consensus process in the working group on how the results of tasks 10.2-10.5 could be included in the updates of NCCPs in order to govern national oncological care
- **Task 2.3** Definition of terminological and methodological standards for the development of patient pathways through a consensus process with the working group
- **Task 2.4** Use of the agreed upon methodology to develop template patient pathways for CCCNs
- **Task 3.3** Use of the agreed upon methodology to derive a set of general and tumour specific QIs for the use in a CCCN
- **Task 4.2** On the basis of the literature review, development of an agreed upon framework for the implementation of PROMs & PREMs in routine care that enables providers to better serve individual patients (e.g.: treatment of impaired quality of life) and that enables cancer centers to compare their own patient reported outcomes data with that of others
- **Task 5.3** Implementation and roll out of two CCCNs in 2 Member States. The pilot CCCNs will implement and apply the deliverables developed under task 10.2-10.5. To assess the successful implementation, the pilot sites will be peer-reviewed and evaluated. A report will summarize findings and recommendations for further development.
- **Task 6** Roadmap on Implementation and Sustainability of Cancer Control Actions in the field of governance of integrated and comprehensive cancer care



WP 10 – GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE



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

3. INVOLVEMENT OF COLLABORATING PARTNERS

May 2019 and February 2020 Local Stakeholder Meeting in Germany: Meeting with national/international collaborating partners (patient organisations, scientific organisations, professional organisations etc.)

Collaborating partners in WP 10:

- ECCO
- All.Can Poland
- APSCO- Assessment of Psycho-Social and Communication Need
- JRC
- HOPE
- Digestive Cancers Europe
- PCE – Pancreatic Cancer Europe
- University Medical Centre Groningen

4. KEY ISSUES TO BE DISCUSSED WITH COLLABORATING PARTNERS

- Beside others:
 - Patient involvement in CCCN's
 - Is something missing?



WP2 DELIVERABLES & MILESTONES

- Leaflet (month 3)
 - Website (month 3)
 - milestone 3 (month 4)
 - Dissemination strategy (month 6)
 - milestone 4 (month 7)
 - Communication plan
 - Annual updates
 - Layman version of final report (month 36)
-
- graphic identity, updating the website, sharing of information from partners (local stakeholder forums), distributing newsletters, administration of Twitter account

IPAAC WEBSITE: WWW.IPAAC.EU



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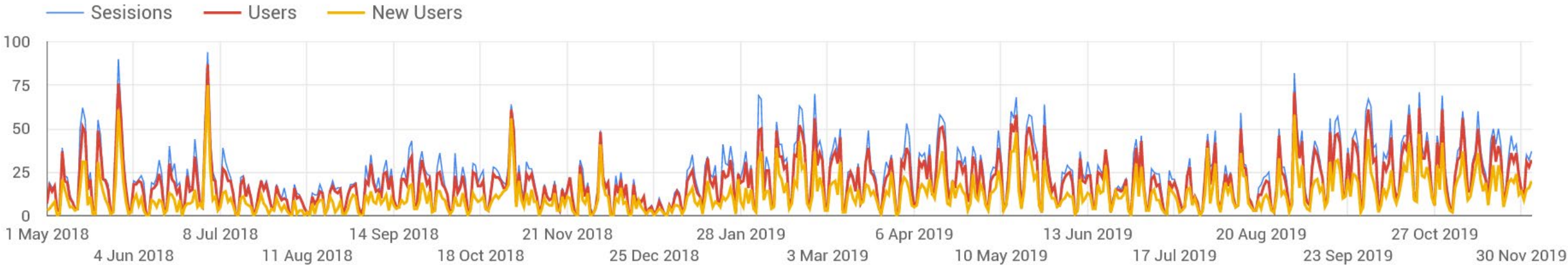
Innovative Partnership for Action Against Cancer

The Innovative Partnership for Action Against Cancer (iPAAC) Joint Action brings together 24 Associated Partners (with Affiliated Entities, 44 partners) across Europe whose main objectives are to build upon deliverables of the CANCON Joint Action and to implement innovative approaches to cancer control. A Roadmap on Implementation and Sustainability of Cancer Control Actions will be the main deliverable of this Joint Action.

[CONTACT US](#)



USER STATISTICS (MAY 1 2018 – DEC 4 2019)



Users: 7,004

Visits per user: 1.9

Visits: 13,330

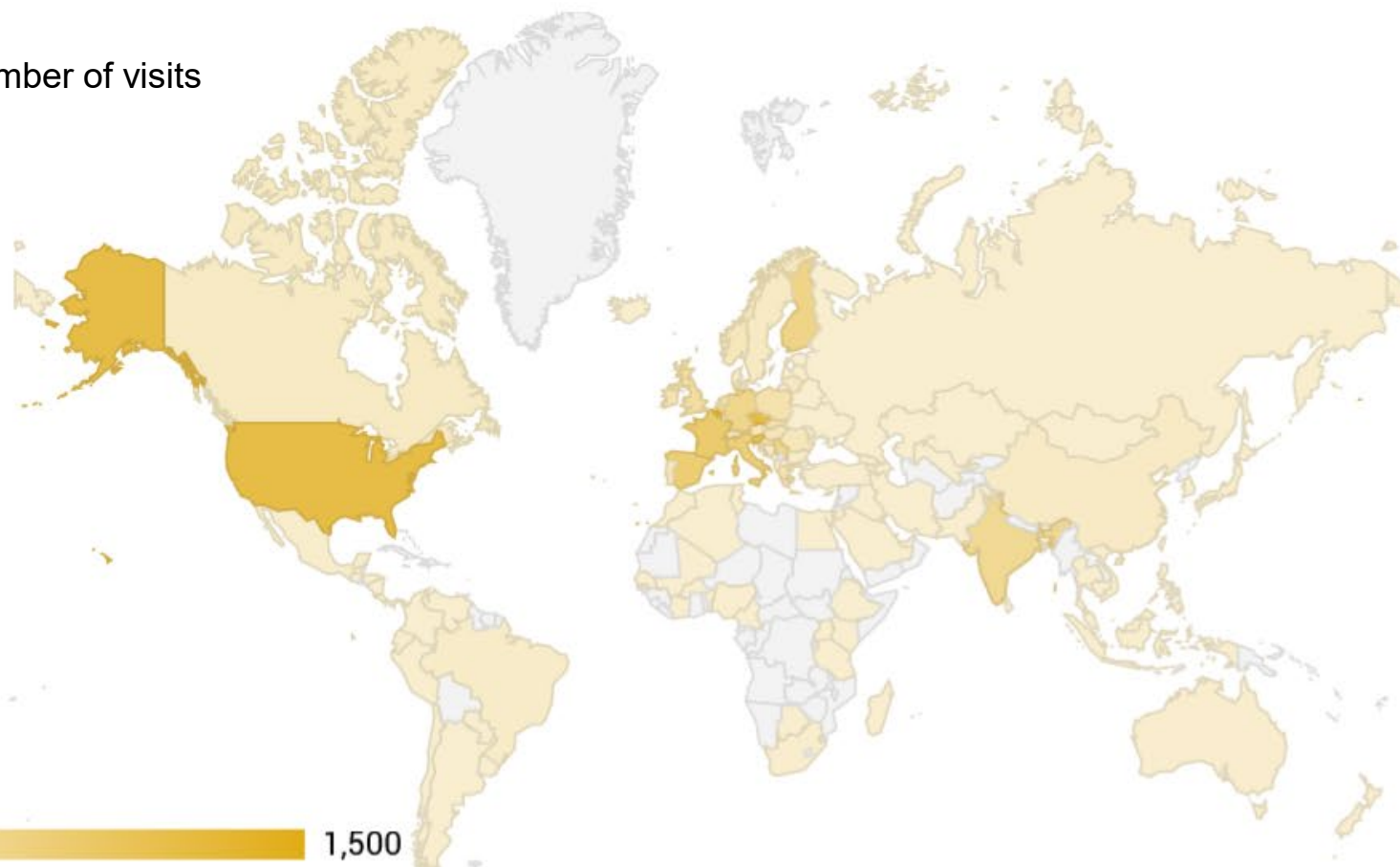
Average time: 00:02:48

Pages per user: 3.38

Total page views: 45,045

USER STATISTICS (MAY 1 2018 – DEC 4 2019)

Total number of visits



	language	visits
1.	en-us	5,069
2.	en-gb	1,073
3.	cs	712
4.	es-es	618
5.	fr-fr	606
6.	it-it	464
7.	cs-cz	313
8.	fi-fi	310
9.	de-de	304
10.	de	250

Croatian Institute of Public Health (HZJZ)

- 1. KEY DELIVERABLES & MILESTONES IN THE FIRST HALF OF THE iPAAC JA**
 - **Evaluation Strategy (milestone & deliverable)**
 - **Interim Evaluation Report (deliverable)**
 - First evaluation questionnaires (internal milestone)
 - First focus group, for WPLs (internal milestone)

- 2. KEY DELIVERABLES & MILESTONES IN THE SECOND HALF OF THE iPAAC JA**
 - **Workshop on Implementation and Sustainability for Member States (milestone)**
 - **Final Evaluation Report (deliverable)**
 - Second focus group, for WPLs (internal milestone)

STATUS OF COLLABORATING PARTNERS

- Currently more than 50 Collaborating Partners
- GDPR and Collaborating Partner Forms
- Collaborating Partners can be added at any time throughout the course of the iPAAC Joint Action



THANK YOU!