



## FIRST iPAAC STAKEHOLDER FORUM

Brussels, 20 September 2018

### Summary Report

The first iPAAC Stakeholder Forum was held at the Belgian Ministry of Employment on the 20 September 2018 in Brussels. The Forum gathered iPAAC Collaborating Partners from across the cancer community to reflect on the objectives of the iPAAC Joint Action and objectives of the Forum. The meeting was organised by the National Institute of Public Health of Slovenia (NIJZ). Some 60 participants from major European cancer organisations took part in this one-day meeting.

The objectives of the Stakeholder Forum are to:

- Inform stakeholders and provide them with first-hand information;
- Gather views and contributions on various elements of the Joint Action;
- Assess the potential stakeholder contributions in each Work Package;
- Disseminate results throughout the stakeholder groups.

The programme consisted of three main sessions.

#### Introductory session

Tit Albreht (National Institute of Public Health, iPAAC Scientific Coordinator) provided an overview of the main objectives of the Joint Action and its Work Packages in the introductory session. Each Work Package Leader (or a representative) was also invited to present the main objectives and deliverables of their Work Package. The iPAAC Joint Action (JA) is divided into 10 Work Packages, with each Work Package responsible for fulfilling their specific objective. There are four horizontal Work Packages (that deal with the management of the Joint Action itself) and six core Work Packages (that deal with the content of the Joint Action objectives). The innovation that will be covered within the JA consists of further development of cancer prevention (WP 5), comprehensive approaches to the use of genomics in cancer control (WP 6), cancer information and registries (WP 7), improvements and challenges in cancer care (WP 8), mapping of innovative cancer treatments (WP 9) and governance of integrated cancer control, including a new analysis of National Cancer Control Plans (WP 10).

The following discussion focused on the differences between Member States in implementing cancer plans. Members of Work Package 4 who are visiting Member State representatives have received, generally speaking, many positive responses. The approach of visiting Member State representatives in different countries is seen as a promising alternative to gather more information from the representatives compared to solely conducting surveys. It was further acknowledged that there are

several countries that are more visible and more strongly represented within the iPAAC Joint Action in comparison to the previous CANCON Joint Action.

### **Session 1: Genomics in cancer control and care – the way forward**

Marc Van den Bulcke (Cancer Centre - Sciensano, Work Package 6 Leader) introduced the first session with a presentation on genomics and cancer. In order to successfully integrate genomics in the health care system, Work Package 6 aims to focus on developing practical guidance for Member States on four important aspects. These key areas are: a) Societal debate on ethical, legal and privacy issues on the use of genome information in healthcare; b) Stratified screening by genetic testing of high-risk cancer patients; c) Implementing precision genomics in medical care; d) Developing a strategy how to deal with 'Direct to Consumer' testing. Further, the focus will also be on education and training on genomics.

Wannes Van Hoof (Cancer Centre - Sciensano) focused on the importance of the societal debate on ethical, legal and privacy issues on the use of genome information in healthcare. While organising the societal debate is considered a promising approach to the application of genome information in health care, many questions are still unanswered and there is no clear and easy solution. Moreover, the use of genomic information in healthcare is considered a "wicked" problem, which also means that the problem will never be solved definitively. Lastly, an overview of several approaches on how to deal with wicked problems (authoritative, competitive or collaborative approach) was outlined.

Chloé Mayeur (Cancer Centre - Sciensano) further looked at the ways on how to best launch a societal debate on genomics. Nine initiatives across the USA, UK and Europe that focus on educating and informing the public about the role that genomics might play in the healthcare were overviewed. This was followed by the presentation of the current initiatives, which employed a focus groups study design and a citizens forum. In the focus group study the participants were shown an informational video (YouTube: 'Belgian Cancer Center') about next-generation sequencing (NGS) and then asked to formulate an opinion on specific theses about genomics. More information about the citizens forum can be found here ([English](#)) and here ([Dutch](#) and [French](#)).

Participants mentioned that the informational video about the NGS, which aims to educate the general public on genomics could also be used with patients. The informational video is currently available only in Dutch and French. However, the possibility to translate the video in other languages was also considered. It was further pointed out, that it would be crucial to translate the initiative in Belgium to other countries. One caveat of the study is that many profiles are not represented, which further means that the results cannot be extrapolated to other groups of people. Nevertheless, the results of this study provide a good starting point to understand the ways in which people develop perspectives and how different perspectives relate to one another.

### **Session 2: Innovative therapies in cancer**

Muriel Dahan (Institut National du Cancer INCa, Work Package 9 Leader) introduced the session with a presentation on innovative therapies in cancer. Multiple innovations were presented (breakthrough innovations, new types of medicines and new

modalities for administration). The main types of innovative immunotherapies in cancer were outlined. The focus within the Work Package 9 will be on checkpoint inhibitors and CAR-T cells. Moreover, potential other types of innovative immunotherapies could be investigated (new anti-cancer vaccines, oncolytic viruses, bi-specific antibodies, etc), especially with the horizon scanning activities.

The presentation then continued with an outline of the types of cancers for which checkpoint inhibitors have at least one approved therapeutic indication in the European Union. It was further acknowledged that CAR-T cells have been approved by the EMA in 2018 and they should be available on the market very soon for hematologic tumours. The arrival of CAR-T cells in Europe will make it necessary to address the issue of the restriction of their use to some specialized centres. There are also several challenges associated with CAR-T cells: complex product and pathway (the need for qualified centres), the possibility of life-threatening adverse reactions, large ongoing clinical development and very high prices for CAR-T cells. While the treatment with CAR-T cells may in theory require one single administration, it was said that we might expect the need for potential readministrations. The treatment with autologous CAR-T cells is very expensive because it requires individualized and complex production processes. Many additional costs also need to be considered such as the long length of hospitalization of patients prior and after administration of CAR-T cells, the need for highly trained professionals, and the management of side effects.

This was followed by an overview of the main objectives of Work Package 9 which are as follows: a) Map existing guidelines and reference frameworks regarding the use of immunotherapies in clinical practices and identify potential off-label use; b) Identify and validate predictive biomarkers for response, resistance or toxicity; c) Identify and predict impact of forthcoming innovative treatments (horizon scanning activities); and d) Identify tools that could be implemented in Europe for real-life monitoring of innovative treatments.

In his concluding words, Stefan Schreck pointed out that European Commission focuses on making a measurable difference within each Member State, which is also the main criterion for determining the success of any Joint Action. The European Commission has established a Steering Group, which recommends and prioritises among several good practices that are available for implementation in different Member States. Member States that are interested in implementing best practices have a possibility to be funded by available funding instruments. Participants further raised the need to define specific requirements and procedures for evaluating best practises. Lastly, the impact of the future EU research and innovation will be maximised through mission-oriented policy. Missions will set a clear direction by arranging the projects in such a way that will collectively achieve the predetermined concrete goals.

Many countries still do not place enough importance on implementing cancer plans. However, due to the differences in the economic status, not all practices could be applied in every country. While it is important to consider the ways in which to support the investment in health of Member States, the European Commission has to ultimately respect the responsibility for health in each Member State. It is a voluntary decision for each Member State to decide whether they want to implement certain practices or not.

Participants further emphasized that the cross-cutting issues across several Joint Action initiatives should be identified in order to avoid doubling the work.

With regard to the administrative issues, it was stressed that e-mail addresses of all Stakeholder Forum attendees will not be shared among the participants. Organisations wishing to become Collaborating Partners should send an e-mail to the Coordination Team ([ipaac@nijz.si](mailto:ipaac@nijz.si)). The process is open throughout the duration of the Joint Action.

**All of the presentations from the first Stakeholder Forum meeting** can be found at <https://www.ipaac.eu/news-detail/en/11-the-first-ipaac-stakeholder-forum-20-september-2018-brussels/>.