

# NEWSLETTER



**eHAction**

Joint Action supporting  
the eHealth Network



Co-funded by the European  
Union's Health Programme  
(2014-2020)

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# Foreword

by Henrique Martins,  
eHAction Coordinator

Dear Reader,

Welcome to the first eHAction newsletter!

As eHAction coordinator and recently elected co-chair of the eHealth Network, I am delighted to introduce this first edition of eHAction's quarterly newsletter.

The eHAction newsletter's objective is to engage and update citizens, participants and interested parties alike on the news and developments of eHAction's strategy and implementation.

This first newsletter includes an Editorial, a Top Stories section with the most relevant news and past events and a first Work Packages (WP) presentation. One by one we will present our WPs so that you will gain an insight into all our activities. At the end you will get to know of the upcoming meetings and events. Please note that a subscription box is also available at eHAction's website.

We hope you enjoy our first steps to share with you what we are doing in the world of health.

Member States and Countries are facing common challenges on the sustainability of health systems. Therefore, Member States are encouraged to meet eHealth objectives, at a country and regional levels, on the promotion and use of Information

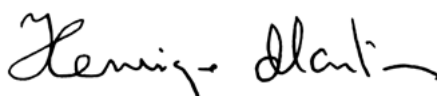
and Communication Technology (ICT) in health care development. These objectives may be aligned with their own national strategies, implementation guidelines, the European Union (EU) governance and strategic implementations.

These strategic implementations highlight the importance of eHealth as a service for public health and cross-border access and, consequently, to gain wide acceptance from citizens.

The EU health strategy "Together for Health" supports the overall Europe 2020 strategy, aiming to transform the EU into a smart, sustainable and inclusive economy, promoting growth for all. Simultaneously, the digital society brings new challenges and opportunities for the health sector. This also extends to citizens using digital tools for health purposes, proactively as patients.

On behalf of eHAction team, we are keen to respond to the interests of our readers and look forward to your feedback, comments or suggestions on this first edition by using the contact addresses [diogo.gomes@spms.min-saude.pt](mailto:diogo.gomes@spms.min-saude.pt) and [margarida.marques.ext@spms.min-saude.pt](mailto:margarida.marques.ext@spms.min-saude.pt)

I hope you enjoy this first edition.  
With warm regards



Henrique Martins  
eHAction Coordinator

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# Who's the man behind eHAction's Coordination?

Henrique Martins.

Henrique Martins is an Internal Medicine Specialist, university professor and an international author on health management, leadership and medical informatics. He obtained his doctorate from the Judge Business School, University of Cambridge with a thesis on "The use of Mobile ICT in clinical Settings". Currently, he's the chairman of SPMS – Shared Services for the Ministry of Health in Portugal, thus representing eHAction's coordination, and was recently elected co-chair of the eHealth Network.

Throughout his career, eHealth has always been the main focus. Between 2010 and 2013, he worked as the Chief Medical Information Officer at the Hospital Fernando Fonseca - a 730 bed hospital - where he set-up the new Electronic Health Record and created the Centre for Investigation and Creativity in Informatics ([www.ci2.pt](http://www.ci2.pt)). During this time, he also supervised projects in robotics, mobile computing, database exploration and intelligence systems.

From 2011 to 2013 he worked for the Ministry of Health as Advisor for Health IT to the Health Secretary of State. In this role, he was responsible for the implementation of the new Health Information Sharing Platform for Electronic Health Records, Electronic Prescription and Clinical informatics. In April 2013, he became the President of the Shared Services for the Ministry of Health (SPMS), the national agency responsible for cooperation matters in the field of eHealth, for the procurement of healthcare commodities and the IT Central for the Portuguese National Health Service (SNS) ([spms.min-saude.pt](http://spms.min-saude.pt)).



## Henrique Martins claims that if he was a med, he would be Adrenaline EV:

*Adrenaline (existing in our body, being a stress hormone that responds to danger, sudden emotions, challenges, risks) can be, and is daily, used to resuscitate hearts, recover heart rate and combat anaphylactic shock among other applications.*

*Why? Because I do not like allergic reactions and I like stress. In short, I like to fight for what I believe in, and it revives me daily.*

Working at EU level since 2012, Henrique Martins was national coordinator for Portugal in the epSOS project ([www.epsos.eu](http://www.epsos.eu)), which aimed to develop a service infrastructure for cross-border interoperability between electronic health record systems in Europe. He was the Coordinator of the thematic network EXPAND, which followed on epSOS, bridging into deploying sustainable cross-border services under the Connecting Europe Facility (CEF). After epSOS ended, Henrique Martins proposed the creation of the eHealth Network Subgroup for Implementation (SG4i) that worked to prepare Member States in legal and procedural mechanisms, preparing MS for CEF calls. Henrique Martins was also involved in other European projects with high visibility such as Trillium Bridge, VALUeHEALTH, eSENS, eStandards, ProEmpower and EURO-CAS.

As well as part of an informal taskforce linking eHealth community to the Rare Diseases Joint Action, he was nominated as eHealth representative and chair of the eSENS advisory board.

Since having previously chaired eHMSEG, Henrique Martins represents Portugal at the European eHealth Network (eHN), established under the European Union cross-border directive, since its beginning in 2012, having actively participated or chaired work in four subgroups of the eHN: subgroup for drafting the Multiannual Work Programme (MWP) 2015-2018; SG on CEF and SG for Implementation (SG4i), and SG drafting MWP 2018-2021.

# eHAction

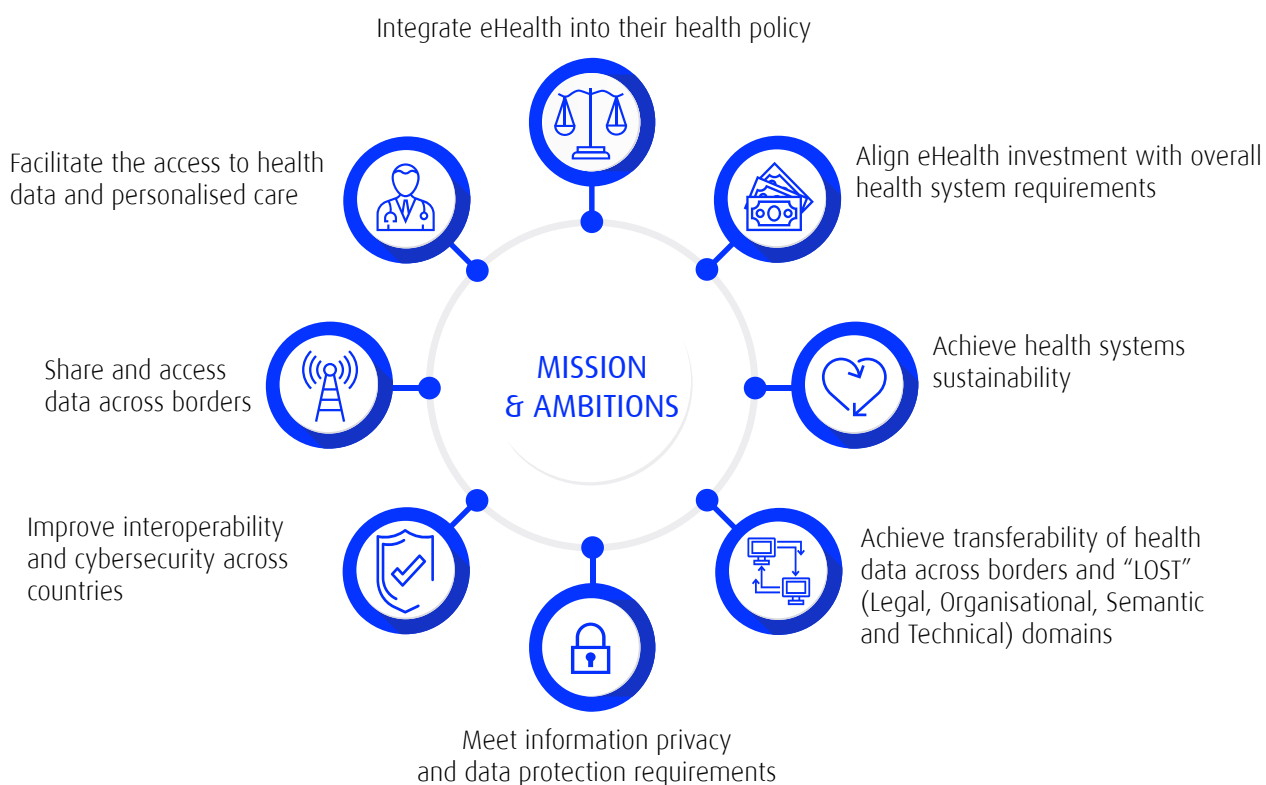
## eHealth Network

The eHealth Network (eHN) is a voluntary network created under Article 14 of Directive 2011/24/EU, established in order to ensure progress on eHealth and to bridge the gaps between the governance, strategy and operational levels. Responsible at a strategic level for all the eHealth policies in Europe, it provides a platform for Member States' competent authorities responsible for eHealth and is scientifically and technically supported by a Joint Action (JA).

## What is a Joint Action (JA)?

A JA is a collaborative action between Member States/ Countries (MS/C) which are committed to develop and improve the EU's 3rd Health Programme. Together, in this collaborative JA, it is more efficient to share, refine and test methods, tools and use cases, and to generate new approaches within the eHealth scope.

This Joint Action works towards delivering sustainable, economic and social benefits for European eHealth systems and services. Based on interoperable applications, the aim is to achieve high levels of trust and security, enhancing continuity of care and ensuring access to a safe and high quality healthcare.

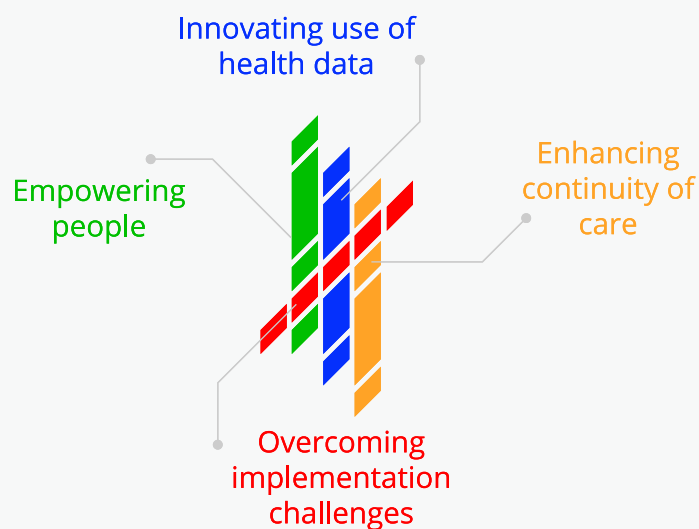


# Multiannual Work Programme (MWP) 2018-2021

The eHN is the co-ordinating and governing body, while eHAction – Joint Action supporting the eHealth Network – is designed to support the Network in all aspects which are defined in the Multiannual Work Programme 2018-2021 (MWP) and beyond, where appropriate.

eHAction aims to develop strategic recommendations and instruments that could feed into political discussions and facilitate cooperation in the four priority areas that are specified in the eHN MWP 2018-2021:

The eHealth Network sub-group working on the MWP 2018-2021 considered the following four priority areas:



Priorities of MWP 2018-2021

Work on MWP 2018-2021 started in March 2017 and was refined by MS and the European Commission in close cooperation with the Coordinator of this JA.

With the four main priority areas in which the eHealth Network's activities are identified, organizational meetings were held to define and structure the next steps and, to form what the eHAction would be, as well as its impact on society.

# eHAction - Joint Action supporting the eHealth Network

eHAction is the Joint Action supporting the eHealth Network, which, in its Multiannual Work Programme 2018-2021, sets targets for exploring eHealth to facilitate the management of chronic diseases and multi-morbidity, by increasing sustainability and efficiency of health systems, and by facilitating personalized care and empowering the citizen.

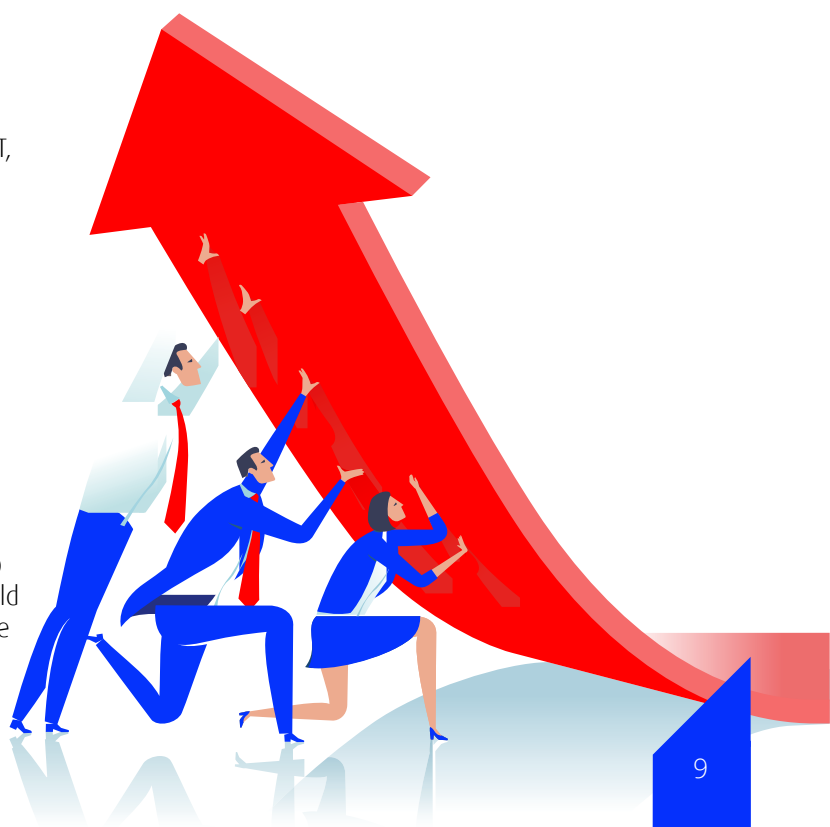
Specifically, it will work to find ways to empower people by giving them an active role in managing their health care data and processes, to use health data in an innovative way and to enhance continuity of care through the use of interoperable and cross-border solutions. The eHAction is in line with the Third Programme of EU actions in the field of health contributing to foster health in Europe by promoting the use of eHealth in a structured policy framework.

The eHAction also functions as a platform for organizational, strategic and technical cooperation between MS/C, including close collaboration with EC, DG SANTE, DG CONNECT and DG DIGIT and other EU stakeholders.

The commitment undertaken by eHAction shall lead to quality results for the continuity, safety and efficiency of ICT, supporting healthcare. Therefore, this will result, as much as possible, in practical results for the users (citizens, healthcare providers, health professionals, decision makers, etc.).

Even though eHAction official kick-off was on the 22nd of June 2018, the project was in motion before that. By the time the European Commission appointed the group working commission on the Multiannual Work Programme, the four priority areas to be addressed by the next Joint Action were outlined.

The general objective of eHAction is to act as the main preparatory body for the eHealth Network which is the main addressee or “customer” of the Joint Action. eHAction aims to develop strategic recommendations and instruments that could feed into political discussions and facilitates cooperation in the four priority areas that are specified in the eHN MWP 2018-2021.



# eHAction Work Packages

## What is the main goal?

eHAction strategy is to develop guidance and tools that can promote political discussion and further alliances in the five top priority areas.

**1**

### COORDINATION

- Coordinate the different parts of the work from both, administrative and content perspective as laid out in the general description of objectives of this JA;
- Ensure timely submission of the project's deliverables intended for submission to the eHN prior to their bi-annual meetings in order to support the work progress of the eHN members.

**2**

### DISSEMINATION

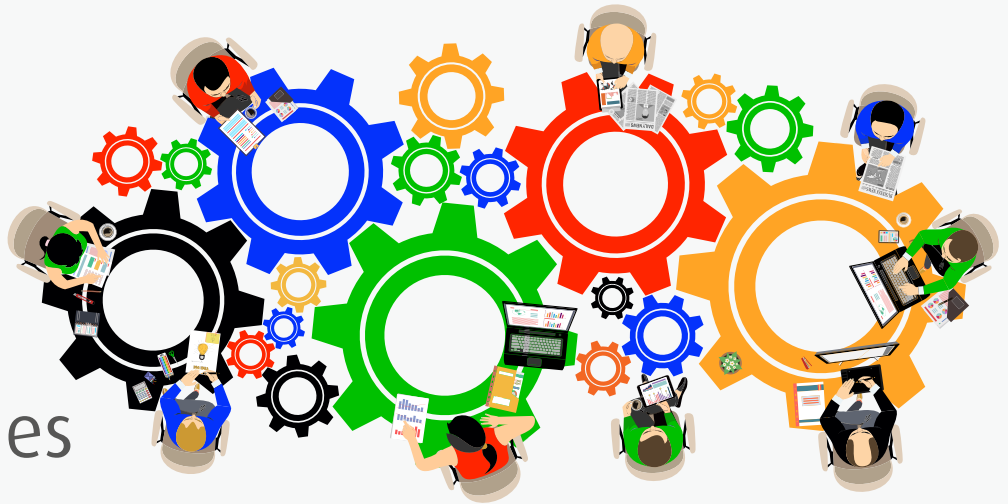
- Develop an effective, macro and common dissemination strategy as laid out in the general description of objectives of this JA;
- Inform the Member States and countries communities about the JA, its orientation and available outputs for further exploitation.

**3**

### EVALUATION

- Elaborate high quality products that add value to the eHealth Network at the policy level;
- Verify if the action is being implemented as planned and reaches its objectives;
- Evaluation tasks and activities focused on the eHealth Network as the main target group but also on the performance of the WPs delivering input to the eHealth Network.

# Core Work Packages



4

## EMPOWERING PEOPLE

- Engage citizens, as individuals and users, who should take an active role in this Action;
- Empower people to partake in their health and care process by building their capacity to use, understand and control their medical data;
- Provide patients with the opportunity to participate actively in the decision making process on their clinical status, alongside their medical professionals.

5

## INNOVATIVE USE OF HEALTH DATA

- To benefit society from the analysis of large volumes of health data, generated across the healthcare and other sectors.

6

## ENHANCING CONTINUITY OF CARE

- Prepare healthcare systems and providers to adopt and implement interoperable cross-border solutions - a key priority to ensure progress in eHealth.

7

## OVERCOMING IMPLEMENTATION CHALLENGES

- Implement Interoperability Guidelines in healthcare ecosystems;
- Interoperability has been identified as a crucial communication promoter and enabler of the exchange and use of patient information between healthcare providers, such as: hospitals, government, insurers, etc., especially in the context of cross-border health services.

8

## eHEALTH NATIONAL POLICIES AND SUSTAINABILITY FOR EUROPE

- Introduce the best principles, to ensure post-2021 continuity of eHealth.



# Top Stories

June 16th, 2017 Brussels

## **Preparatory Meeting of the eHealth Network Joint Action**

European Commission and Project Coordinator

July 18th, 2017 Brussels

## **2nd Preparatory Meeting**

September 07th, 2017 Brussels

## **3rd Preparatory Meeting**

February 26th, 2018 Brussels

## **4th Informal Preparatory Meeting**

June 20th, 2018 Lisbon

## **JAsEHN Closing and Handover Meeting**

June 21st, 2018 Lisbon

## **eHAction Kick-off**

July 9th – 10th, 2018 Lisbon

## **EHRxF Working Group Workshop**

September 25th, 2018 Brussels

## **2nd EHRxF Working Group Workshop**

October 12th, 2018 Brussels

## **6th eHealth Stakeholders Group Meeting**

October 16th 2018, Brussels

## **eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels

## **1st Steering Council Meeting**

October 18th, 2018 Amsterdam

## **eHAction WP 4 Workshop**

The first meeting with the 21 countries involved in the project established the project coordination and overall project management.

Portugal, represented by SPMS, EPE, assumed the project's coordination. Lessons learnt from JAsEHN were discussed. The logo, slogan and website were presented for the first time in this meeting. The overall objectives for the 3rd Joint Action on eHealth were outlined for the Health Programme 2020, Multiannual Work Programme 2018-2021, Digital Single Market strategy.

The development of content and division for Work Packages started. Stakeholders involvement and financial and administrative issues were debated.



▲ Preparatory meeting of the eHealth Network Joint Action | June 16th, 2017 | Brussels

July 18th, 2017 Brussels

### **2nd Preparatory Meeting**

This preparatory meeting occurred at the negotiation phase before the final submission.

The alignment of the proposal and the discussion of topics to be included in eHAction's submitted proposal were debated, as well as the Stakeholders involvement, financial and administrative issues.

September 07th, 2017 Brussels

### **3rd Preparatory Meeting**

February 26th, 2018 Brussels

### **4th Informal Preparatory Meeting**

June 20th, 2018 Lisbon

### **JAsEHN Closing and Handover Meeting**

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September 07th, 2017 Brussels  
**3rd Preparatory Meeting**

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**4th Informal Preparatory Meeting**

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October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

Work Packages and division of tasks and deliverable were established and consolidated. The results of the Open Consultation with Stakeholders were discussed.

It was established that the handover from JAsEHN to eHAction would take place in June 2018.



Informal Steering Council | September 6th and 7th, 2017 | Brussels

February 26th, 2018 Brussels  
**4th Informal Preparatory Meeting**

June 20th, 2018 Lisbon  
**JaseHN Closing and Handover Meeting**

June 21st, 2018 Lisbon  
**eHAction Kick-off**

July 9th – 10th, 2018 Lisbon  
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October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

Information from the Commission on the Digital Single Market, mHealth and standardisation and interoperability was shared. Administrative issues were consolidated for the final proposal. The need for the creation of synergies with other Joint Actions was debated.

An evaluation was carried out on external stakeholders' comments and involvement.

General outlines for Work Packages Tasks were presented. The final proposal for eHAction presented to the consortium.



4th Informal Preparatory meeting | February 26th, 2018 | Brussels

June 20th, 2018 Lisbon

**JAsEHN Closing  
and Handover Meeting****June 21st, 2018 Lisbon  
eHAction Kick-off****July 9th – 10th, 2018 Lisbon  
EHRxF Working Group  
Workshop****September 25th, 2018 Brussels  
2nd EHRxF Working Group  
Workshop****October 12th, 2018 Brussels  
6th eHealth Stakeholders  
Group Meeting****October 16th 2018, Brussels  
eHAction WP 5 Kick-off  
Meeting****October 17th, 2018 Brussels  
1st Steering Council Meeting****October 18th, 2018 Amsterdam  
eHAction WP 4 Workshop**

The European Commission commended the “2nd Lisbon eHealth Summer Week” for strengthening synergies and sharing good practices in digital health. Promoted by SPMS, EPE, the initiative was held from June 19th to the 22nd, at the Centro Cultural de Belém, while simultaneously meetings on international projects were held at SPMS’ facilities in Lisbon and Porto.

With the participation of over 200 experts from the European Commission, ministries, universities and agencies, the debate focused on the implementation of eHealth services on a European scale and on international projects in which SPMS, EPE collaborates, such as EURO-CAS, HealthelD and eHMSEG, among others.

JAsEHN was operating from May 2015 until June 2018. The project was funded by the European Commission and acted as the main preparatory body for the eHealth Network, the highest decision-making body of the European Union in the field of eHealth.

The second day was dedicated to the JAsEHN Closing Meeting, where each WP leader and co-leader gave their input about this Joint Action to support the eHealth Network. The closing segments of each WP started with WP5 – supported by respective chairs, current tasks leaders and former task co-leaders; followed by WP6, WP7 and WP8. WP4 closed the segment of each WP presentation and focused on the lessons learnt when working with stakeholder organisations.

On a final note, the JAsEHN Project Coordinator reviewed the lessons learnt during the project. The European Commission gave its final note from JAsEHN as a three years’ major project in the European Union. The morning session ended with a formal handover to the eHAction Project Coordinator. During the afternoon session, WP2 introduced a final presentation of dissemination activities, on the lessons learnt; on the maintenance strategy of project documents and website; and lastly, feedback gained from public presentations of JAsEHN. Following the WP2 presentation, WP3, as quality manager, introduced a final presentation of evaluation questionnaire results and on the risk management. WP1 wrapped up the afternoon session with a discussion on housekeeping and financial issues, followed by the next steps to take in the project.

The evening session ended with a JAsEHN and eHAction Joint Dinner with all JAsEHN and eHAction members at Centro Cultural de Belém, where everyone could enjoy a panoramic view of the river and “Padrão dos Descobrimentos”.





2nd Lisbon eHealth Summer Week | June 20th 2018 | Lisbon



JaseHN & eHAction Joint Dinner | June 20th 2018 | Lisbon

June 21st, 2018 Lisbon  
**eHAction Kick-off**

July 9th – 10th, 2018 Lisbon  
**EHRxF Working Group Workshop**

September 25th, 2018 Brussels  
**2nd EHRxF Working Group Workshop**

October 12th, 2018 Brussels  
**6th eHealth Stakeholders Group Meeting**

October 16th 2018, Brussels  
**eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

The kick-off meeting of eHAction, the third Joint Action supporting the eHealth Network, was held on June 21st at the Centro Cultural de Belém, in Lisbon.

The launch of eHAction, under the coordination of SPMS, EPE, representing Portugal, was one of the highlights of the week with the first public presentation of the project.

As coordinator of eHAction, SPMS, EPE promoted cooperation initiatives among Member States for the development and implementation of projects that seek to foster the sharing of information among health professionals, improving access to citizens and the provision of cross-border health.

SPMS, EPE once again boosted Portugal's strategic positioning in the eHealth area by promoting debates and dissemination of knowledge and good practices in digital health on a global scale.

During this week, everyone's presence and inputs were vital to move forward with the ideas and projects we have in hand that aim to improve health information management in Europe for professionals and citizens.

"Joint Action means we're here to do things, not just discuss them. And we are here to do them together", said Henrique Martins, Chairman of the Board of Directors of SPMS, EPE at the opening session. Coordinated by Portugal, represented by SPMS, the eHAction is focused on citizenship, innovation and speed of implementation.

Under the motto "eHealth for the best healthcare to everyone from anywhere in Europe" the session focused on the principles of cooperation between Member States, sustainability and better eHealth services for better health care, "for everyone, anywhere around Europe".

The lines of action for the Multi-Annual Work Programme 2018-2021 were presented by representatives of each Work Package, in a joint collaboration that aims to meet the objectives in five priority areas: empowering citizens, innovative use of health data, improving continuity of care, overcoming implementation challenges, and strengthen eHealth policies and sustainability.

In addition to coordinating eHAction, SPMS, EPE is responsible for its dissemination, aiming to improve information accessibility for citizens and professionals in the eHealth area.





2nd Lisbon eHealth Summer Week | June 21st 2018 | Lisbon

July 9th – 10th, 2018 Lisbon  
**EHRxF Working Group Workshop**

September 25th, 2018 Brussels  
**2nd EHRxF Working Group Workshop**

October 12th, 2018 Brussels  
**6th eHealth Stakeholders Group Meeting**

October 16th 2018, Brussels  
**eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

Within the framework of the EU joint action “eHAction”, SPMS, EPE promoted the first workshop on Electronic Health Record Exchange Format (EHR), in support of an electronic health record at European level.

The first eHAction workshop took place in Lisbon at SPMS, EPE headquarters, on July 9th – 10th 2018. The meeting, focused on the Electronic Health Record Exchange Format, discussed legal, organizational, semantic and technical issues in order to develop better eHealth solutions.

“There is only one way to do a workshop ... and that is to work!”, said Henrique Martins, Chairman of SPMS’s Board of Directors, at the start of the meeting. In order to promote interoperability of health data exchange at European level, representatives from over 15 Member States and the European Commission discussed ideas on legal, organizational, semantic and technical issues of the EHR (Electronic Health Record). As part of the Horizon 2020 program of the European Commission, the development of the project is based on the creation of a tool with technology-neutral architecture, to be used throughout Europe, by citizens and professionals from both the public and private sectors.

During the session, the expectations of the European Commission were presented, based on three main pillars: citizen’s secure access to and sharing of health data; better data to promote research, prevention and personalized health and care; and digital tools for citizen empowerment and for person-centred care.

On the second day of the workshop, the representatives from the European Commission and Member States defined content and structured priorities until the next workshop.

The debate on the Electronic Health Record Exchange Format was mainly focused on stakeholders, content, structure priorities, target audiences, as well as the creation of working groups to analyse the feasibility of integrating functionalities that ensure the future implementation of this project.

Outlining strategies such as the adoption of use cases for the application of EHR, with the aim of defining decisive points in practical cases, like the translation of medical documents, also assumed a central role in the debate.

At the end of the workshop, the working group took stock of the project, by deciding on the deadlines, dates and topics for the next workshop scheduled for September in Brussels.

In conclusion, the main objective of the group is to foster the access to citizens to their data across borders, and give concrete inputs and recommendations to the European Commission about the EHR Exchange Format.



▲ Lisbon EHR exchange Format Working Group Week | July 9th – 10th 2018 | Lisbon

September 25th, 2018 Brussels  
**2nd EHRxF Working Group Workshop**

October 12th, 2018 Brussels  
**6th eHealth Stakeholders Group Meeting**

October 16th 2018, Brussels  
**eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

Representatives from 14 countries out of a total of 23 MS gathered on September 25th, in Brussels, for the 2nd workshop on the Electronic Health Record Exchange Format (EHRxF).

During the session, the European Commission and the MS/C involved in the EHRxF debated the project's recommendation parts 2 and 3 and explored ideas on the standards used by MS/C information blocks (imagining data, laboratory data, technical and semantic standards).

To promote interoperability of health data exchange at European level, the consortium agreed on a common approach, furthering the project's developments to create a tool with technology-neutral architecture, to be used throughout Europe, by citizens and professionals from both the public and private sectors.



2nd EHR Exchange Format Workshop | 25th September 2018 | Brussels



October 12th, 2018 Brussels

## 6th eHealth Stakeholders Group Meeting

October 16th 2018, Brussels  
**eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

The 3rd Joint Action supporting the eHealth Network was presented to stakeholders on October 12th at the 6th eHealth Stakeholders Group Meeting in Brussels.

As coordinator of “eHAction – 3rd Joint Action supporting the eHealth Network”, SPMS, EPE is represented by Diogo Martins and Diogo Gomes, Coordinators of International Projects and Communication, respectively, who introduced the project’s objectives to stakeholders in the name of the consortium constituted by 21 active entities.

At the meeting several partners and representatives of the European Commission, DG Santé (Directorate General Health and Consumers EC), DG CONNECT and DG DIGITAL, were involved and discussed topics such as the European Health Record, common semantic strategy, development of the project implementation, among other points.

As Portugal’s representative, SPMS takes responsibility for the coordination of eHAction – 3rd Joint Action and its dissemination, aiming to reinforce stakeholder involvement and improve access to information for European citizens and professionals on eHealth.



6th eHealth Stakeholders Group Meeting | 12th October 2018 | Brussels



6th eHealth Stakeholders Group Meeting | 12th October 2018 | Brussels

October 16th, 2018 Brussels  
**eHAction WP 5 Kick-off Meeting**

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

The kick-off meeting of the Work Package was held on the 16th of October 2018 in Brussels. The main objectives of the event were to discuss the content of the work plan for Work Package 5 (WP5), as well as preparing the work for delivering the report on identified cross-border use cases for innovative use of health data. The meeting was attended by experts from 8 Member States interested in WP5.

Participants agreed that the successful implementation of the WP depends on proper use of key definitions tailored to the tasks of the work package. Therefore, the meeting contained a workshop to review available definitions and proposing for adoption those that are important to empower patients, policy makers and professionals about the innovative use of health data.

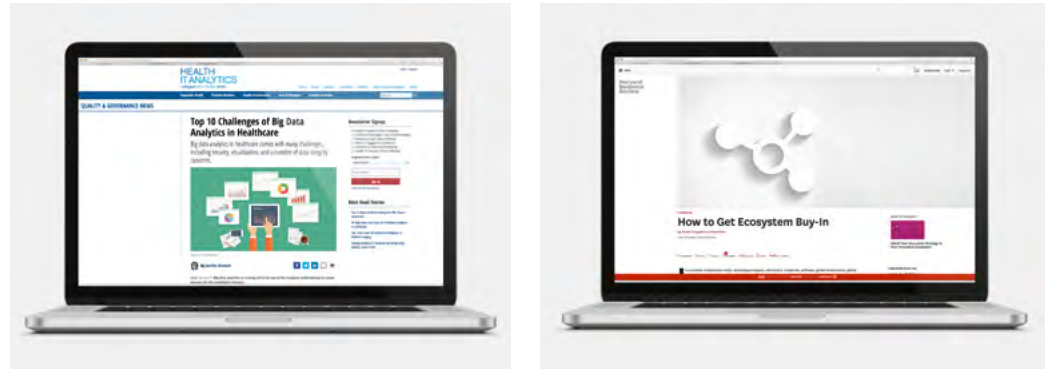
Experts agreed on defining Health data, Big data in health, Big data analytics in health and Innovative use of health data.

The working definitions will be introduced to and discussed by the eHealth Network in November 2018. Definitions reflect the value-based approach followed in WP5, where value refers to satisfaction of a specific need and replicability at an economical cost.

Participants also agreed that identification of the key stakeholders is essential as well, and it is also important to understand their motivations (as well as the “non-negotiables”, “differentiators” and “dissatisfiers” of these motivations). Assessing these features and attributes would help to understand the motivations of stakeholders.

In the context of preparing the work for delivering the report on identified cross-border use cases for innovative use by health data, experts of the Member States had a discussion and agreed on the methods of literature review, interviews, a questionnaire and the timetable for undertaking these tasks.





"Top 10 Challenges of Big Data Analytics in Healthcare", by Jennifer Bresnick. In *Health IT Analytics Website*, June 12th 2017.  
 "How to Get Ecosystem Buy-In", by Martin Ihrig and Ian MacMillan. In *Harvard Business Review Website*, March-April 2017.

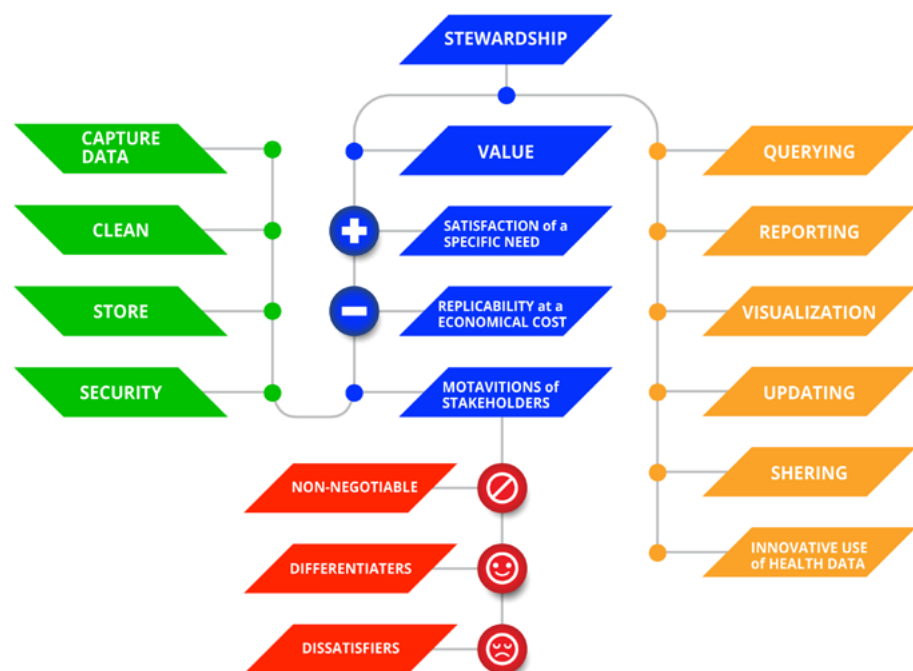


Diagram | Developed based on the previous articles

October 17th, 2018 Brussels  
**1st Steering Council Meeting**

October 18th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

On October 17th, the 1st Steering Council took place in Brussels. Dissemination and stakeholders' engagement strategy was the principal focus of this meeting.

The 1st Steering Council began with a welcome, round table and introduction. In the scope of the meeting, WP 1 Coordination started by discussing the following topics: activities and eHAction project plan; project handbook; collaborative platform and eHN calendar.

Following the WP 1 presentation, WP 3 Leaders delivered the evaluation strategy. The group gave inputs and comments about eHAction deliverables and other documents. At the end of the 1st Steering Council, the next activities, future meetings and workshops were presented.



1st Steering Council | 12th October 2018 | Brussels



1st Steering Council | 12th October 2018 | Brussels

October 17th, 2018 Amsterdam  
**eHAction WP 4 Workshop**

On Thursday, October 18th, 29 experts from 18 different countries travelled to Amsterdam to discuss and work on 'patient empowerment'.

Work Package leaders Estonia and the Netherlands invited their contributors to attend the kick-off workshop for Work Package 4 'empowering people' in the Sheraton Hotel at Schiphol Airport. The aims and objectives of the day were to meet one-another face to face, to get a common understanding on the content of patient empowerment and to work on a work approach for the upcoming years.

Laurens Rijpstra from the Dutch Patient Federation started the workshop with a motivational presentation and Kahoot quiz with relevant eHealth questions. Throughout the rest of the day, the attendees were divided into four parallel workshops on patient access and use of data, telehealth, mobile health and digital health literacy. The scope of the mentioned subjects, the relevant stakeholders and the approach for the upcoming months were discussed during the workshops.

At the end of the day everybody went home motivated and involved to deliver and consider this important topic on empowering people.





eHAction WP 4 Workshop | 18th October 2018 | Amsterdam

# Work Package 5

## Innovative Use of Health Data

In every newsletter, there will be a glimpse of each WP and their connection with eHAction. In this newsletter, we are pleased to present the WP 5 mission, objectives and description of tasks.

The work package has a vision to develop innovative usage of data across the healthcare sector knowledge base for healthcare policy and other purposes. WP5 looks at data as the key driver of disruptive innovation in the economic, societal and social systems. Therefore, WP5 is committed to make an impact on the use of health data, as well as assisting data-driven innovation leading to patient-centred health systems, evidence-based health policies and decision-making.

Secondary use of data and big data can provide value for research, teaching, managing and planning healthcare systems. It can also be a great opportunity for the development of personalised medicine, the improvement of the effectiveness of medicine, efficiency of health systems, and continuity of care. WP5 faces the problem of lacking awareness of these potential benefits of the need or sharing expertise.

The phenomenon of big data is still new and there is much uncertainty on how to go forward to benefit from big data on the practical level. On the policy level, it is important to strengthen the awareness of the possibilities and to highlight the potentially beneficial impacts of big data in health.

The healthcare sector is a data-intensive industry generating large volumes of data. There has been tremendous growth in the range of information that is being collected, such as clinical, genetic, behavioural and environmental data from an array of devices including electronic health records, genome sequencing machines, patient registries, social networks and smartphone applications that monitor patient health.

The combined use of large volumes of fragmented health data could unlock great potential in the healthcare sector. Powerful data analytics can discover patterns that will lead to new preventive, diagnostic and therapeutic avenues; can help remove inefficiencies in care processes and reduce waste; and help make better management and clinical decisions that will improve the performance of health systems (e.g. in terms of procedures, quality of care, patient safety and patient outcomes).

Newly available technologies offer the opportunity to integrate big data sets and could enable exact, rapid and personalised diagnosis, treatment, detection, tracking, prevention and control, such as system or policy development.

However, developing, testing, providing, maintaining and improving data provenance management, trusted big data solutions and cybersecurity are key challenges in exploiting opportunities, advantages and potential offered by any innovation in the use of health and care data.

The overall objective of WP 5 is to support the application of good practices in Member States and provide guidelines guidance at EU level on handling of big data in health within the existing EU regulatory framework, and consequently to ease the uptake of innovative usage of data across the healthcare sector for the benefits of society, individuals and performance of Member States' health systems.

In order to ensure wide adoption and sustainable use of health data and utilization of Cross Border eHealth Information Services (CBeHIS), WP5 supports the application of good practices in Member States and provides guidance at EU level on handling big data in health (large routinely or automatically collected datasets, which are electronically captured and stored) within the existing EU regulatory framework, and consequently aims to ease the uptake of innovative usage of data across the healthcare sector for the benefits of society, individuals and performance of Member States health systems.

## The aim of the Work Package 5 is:

- to enable the communication of the value of big data to different stakeholder groups and to provide a way for public health promotion, preventive measures and care from the analysis of big data across the healthcare sector and MyData following FAIR data principles (i.e. Findable, Accessible, Interoperable, Reusable);
- to collect and to compile the experiences of Member States for developing knowledge bases and a framework for continuous exchange of best practices at EU level;
- to build practical guidance on practical governance of big data and knowledge to Member States based on the big data efforts and practices of Member States – improving recognition of the practical conditions for rational governance of big data in eHN and Member States (in order to ensure patient-centred health systems, evidence-based health policy and decision-making, as well as data-driven innovation).

Secondary use of data and big data can provide value for research, teaching, managing and planning healthcare systems. It can also be a great opportunity for the development of personalised medicine, the improvement of the effectiveness of medicine, efficiency of health systems, and continuity of care. However, an EU approach for sharing expertise but also raising the awareness of the potential benefits of the secondary use of health data is lacking.



3 Main Focus Areas of WP5



# The Work Package consists of the following tasks:

## TASK 5.1

### **Mapping, awareness raising and policy relevant actions on innovative use of big data in health**

The task is assessing the effects of GDPR and reviews MS/C policy level efforts on governing big data in health, and also assesses the implications of FAIR data principles. It identifies obstacles preventing MS/C policies from being replicable either in other MS/C or on EU level, and investigates how to overcome these.

The task will provide an initial set of enabling actions for the information of the eHN by translating recommendations of the EU Study into operationalized solutions that can be communicated for increased awareness.

WP5 will review the effects of GDPR and policy level efforts on governing big data in health, as well as expectation, definitions, scope, terms, conditions, obstacles, importance, added value of use of health data and big data.

Delivery of an initial set of enabling actions to support awareness raising and communication of the added value of big data to different stakeholder groups, especially on the Governance level in Member States is expected in May 2020.

## TASK 5.2

### **Sharing and learning best practices on European level**

The task defines and uses methods to identify underlying needs and barriers experienced by stakeholders (pros & cons) affecting efficient and effective sharing of best practices in order to reach the objectives of the WP and the JA.

It investigates already formalized cross-border use cases such as European Reference Networks for rare diseases as well as practical solutions in R&D including analytics in order to identify new possibilities for innovative use of big data on the European scale, to assess feasibility of network optimization to cross-border IT infrastructure and data flow management and to enhance interdisciplinary and openness, the most potential usage and stakeholders that could benefit.

WP5 will deliver identified cross-border use cases, including assessment of pros & cons of stakeholders, assessment of criteria for defining which use cases of Big Data use in healthcare have the best potential to improve the sustainability of healthcare systems and provide examples for benchmarking and practical solutions with potential for European scale benefits (Delivery in November 2019).

## TASK 5.3

### **Towards an attempt to define common principles for practical governance**

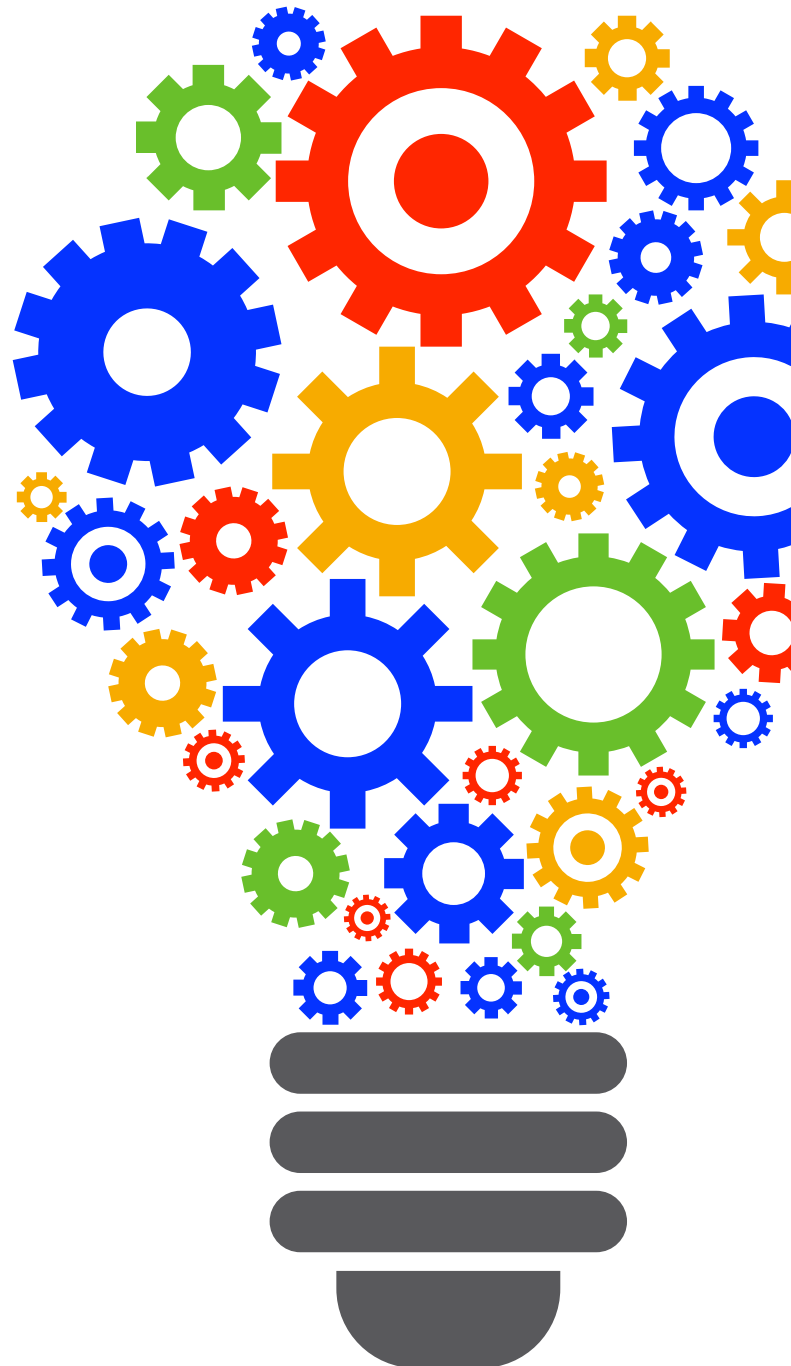
The task will deliver recommendations for the eHN on the implementation of common principles for practical governance of big data with a special focus on data to be used in public health, research and quality assurance in healthcare on a European scale with guidance on implementation of data access and use.

Recommendations will include a proposal for the eHN on the guidance and framework for the implementation of common principles for practical governance of big data including privacy protection and security aiming at improving health data transferability across borders, such as the implementation of data access and use on a European scale.

WP5 will focus on helping Member States to utilize the potential of harnessing new opportunities arising from big data and improved data analytics capabilities, as well as from personalized medicine, use of clinical decision support systems by health professionals and use of mobile health tools for individuals to manage their own health and chronic conditions.

## WP5 will deliver recommendations (in May 2021):

- to facilitate preparation of actions to improve the comparability, accuracy and reliability of health data and to encourage the use of health data to enable more transparent and patient-centred health systems focusing on health outcomes and evidence-based health policy and decision-making, as well as to promote data-driven innovation;
- to enable the use of health data for research and innovation, in full compliance with data protection requirements and FAIR data principles;
- to apply network optimization to cross-border IT infrastructure and data flow management;
- to foster patient-centred interoperability;
- to improve service effectiveness for the individual patient in which benefits are experienced locally;
- to enhance interdisciplinary and openness that removes barriers between data sources and infrastructure to provide 'fit for purpose' data platforms.



# Kick-off meeting

The kick-off meeting of the Work Package was held on the 16th of October 2018 in Brussels. The main objectives of the event were to discuss the content of the work plan for Work Package 5 (WP5), as well as preparing the work for delivering the report on identified cross-border use cases for innovative use of health data. The meeting was attended by experts from 8 Member States interested in WP5.

Participants agreed that the successful implementation of the WP depends on proper use of key definitions tailored to the tasks of the work package. Therefore, the meeting contained a workshop to review available definitions and make a proposal for the adoption of those ones that are important to empower patients, policy makers and professionals about the innovative use of health data.

Experts agreed on defining Health data, Big data in health, Big data analytics in health and Innovative use of health data. The working definitions will be introduced to and discussed by the eHealth Network in November 2018. Definitions reflect (i. a.) the value-based approach followed in WP5, where value refers to satisfaction of a specific need and replicability at an economical cost.

Participants also agreed that identification of the key stakeholders is essential as well, and it is also important to understand their motivations (as well as the “non-negotiables”, “differentiators” and “dissatisfiers” of these motivations). Assessing these features and attributes would help to understand the motivations of stakeholders.

These phrases were quoted from the HBR article: “How to Get Ecosystem Buy-In”, by Martin Ihrig and Ian MacMillan, HBR MARCH-APRIL 2017. Simplifying what Ihrig and MacMillan wrote:

- Non-negotiables are the performance features that make an offer minimally acceptable: e.g. timely and accurate diagnosis;
- Differentiators are the features that positively distinguish an offering from the competition: e.g. lack of side effects from medication;
- Dissatisfiers are the attributes that Stakeholders are not happy about, but they may be willing to endure them for a time if compensating differentiators exist: e.g. anxiety about complications / cost of treatment.

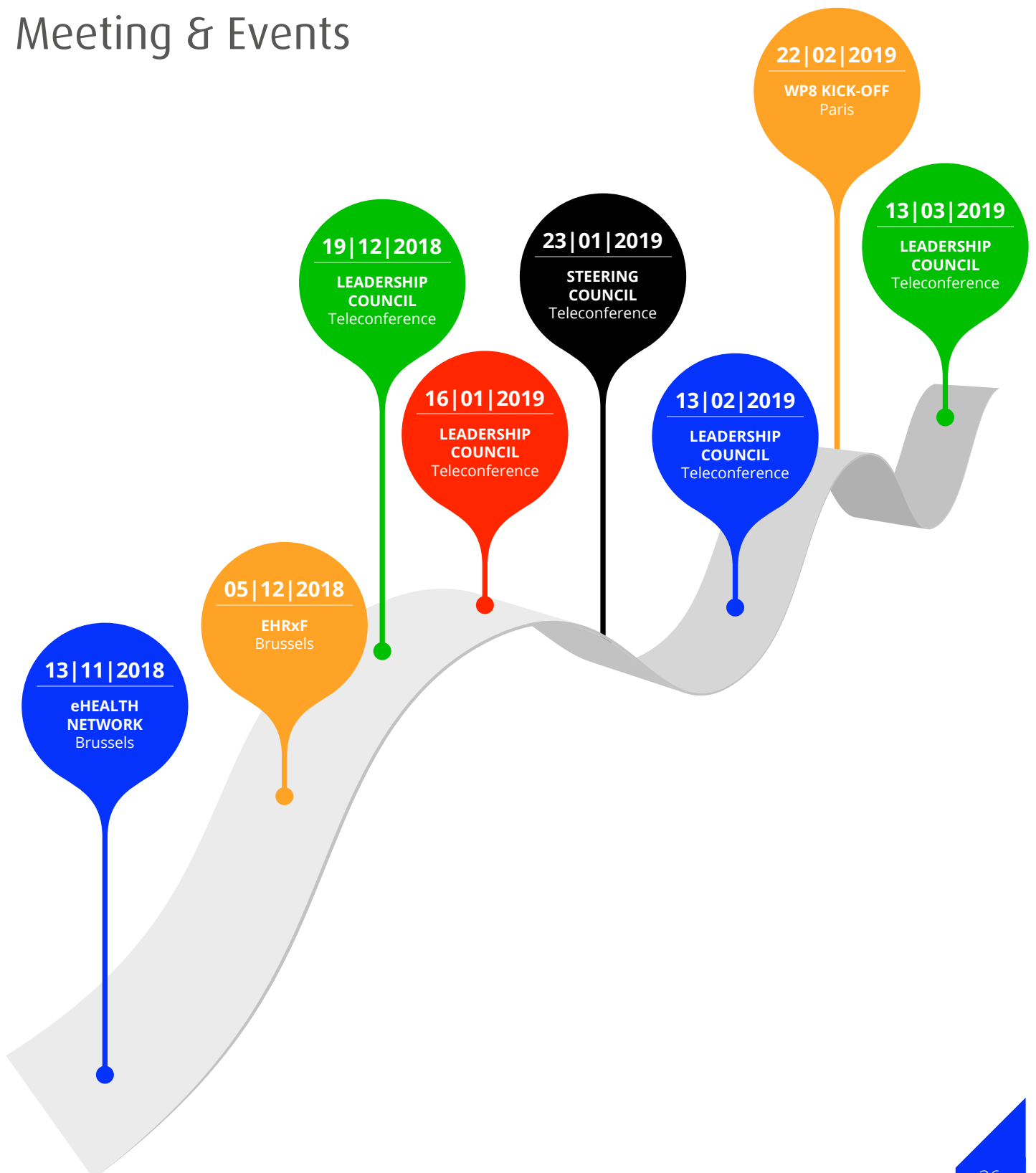
These examples should be translated to the situations in capturing, storing, and querying data, as well developing, reporting, visualization and sharing risk stratification and predictive analytics or enhancing care coordination. This translation may lead to new questions, and the questions may be put up from different points of views, e.g.:


- Can innovative use of health data provide any differentiator for better patient access? or
- Can big data literacy be a differentiator for better care coordination? etc.

In the context of preparing the work for delivering the report on identified cross-border use cases for innovative use of health data, experts from the Member States had a discussion and agreed on the methods of literature review, interviews, a questionnaire and the timetable for undertaking these tasks.

# Upcoming

## Meeting & Events





It was a pleasure to share our work  
with you and we are looking forward to the future.

Wishing you a great  
holiday season and a prosperous 2019!

All the best,  
eHAction Consortium

**PRESS CONTACTS:**

- **DIOGO MARTINS**, INTERNATIONAL PROJECTS COORDINATOR AT SPMS, EPE. (+351 910 273 213), [DIOGO.MARTINS@SPMS.MIN-SAÚDE.PT](mailto:DIOGO.MARTINS@SPMS.MIN-SAÚDE.PT)
- **DIOGO GOMES**, COMMUNICATIONS AND PUBLIC RELATIONS COORDINATOR AT SPMS, EPE., (+351 912 106 789), [DIOGO.GOMES@SPMS.MIN-SAÚDE.PT](mailto:DIOGO.GOMES@SPMS.MIN-SAÚDE.PT)
- **LÍLIA MARQUES**, INTERNATIONAL PROJECTS MANAGER AT SPMS, EPE., (+351 939 006 022), [LILIA.MARQUES@SPMS.MIN-SAÚDE.PT](mailto:LILIA.MARQUES@SPMS.MIN-SAÚDE.PT)
- **MARGARIDA MARQUES**, INTERNATIONAL PROJECTS COMMUNICATIONS OFFICER AT SPMS, EPE., (+351 916 011 501), [MARGARIDA.MARQUES.EXT@SPMS.MIN-SAÚDE.PT](mailto:MARGARIDA.MARQUES.EXT@SPMS.MIN-SAÚDE.PT)



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