

**Focus Group Virtual Meetings, 23-25 June 2020**

Work Package 5 - Innovative Use of Health Data

# eHAction - JOINT ACTION SUPPORTING THE EHEALTH NETWORK

Fields marked with \* are mandatory.

eHAction - the Joint Action supporting the eHealth Network has received funding from the European Union's Third Health Programme (2014-2020) under grant agreement No. 801558.

## 1 First & Last Name + Email

\* 1.1 First Name

\* 1.2 Last Name

\* 1.3 Email

## 2 Nationality and Organisation

\* 2.1 I'm from

- EU member state  
 Non-EU country

\* 2.2 State

- Austria  
 Belgium  
 Bulgaria

- Croatia
- Cyprus
- Czechia
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Italy
- Latvia
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Poland
- Portugal
- Romania
- Slovak Republic
- Slovenia
- Spain
- Sweden

### \* 2.3 County

- Afghanistan
- Albania
- Algeria
- Andorra
- Angola
- Antigua and Barbuda
- Argentina
- Armenia
- Australia
- Austria
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bhutan

- Bolivia
- Bosnia and Herzegovina
- Botswana
- Brazil
- Brunei Darussalam
- Bulgaria
- Burkina Faso
- Burundi
- Cabo Verde
- Cambodia
- Cameroon
- Canada
- Central African Republic
- Chad
- Chile
- China
- Colombia
- Comoros
- Congo
- Costa Rica
- Côte D'Ivoire
- Croatia
- Cuba
- Cyprus
- Czechia
- Democratic Republic of the Congo
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Gambia
- Georgia
- Germany
- Ghana
- Greece

- Grenada
- Guatemala
- Guinea
- Guinea Bissau
- Guyana
- Haiti
- Honduras
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kuwait
- Kyrgyzstan
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Mauritania
- Mauritius
- Mexico
- Micronesia
- Monaco
- Mongolia
- Montenegro

- Morocco
- Mozambique
- Myanmar
- Namibia
- Nauru
- Nepal
- Netherlands
- New Zealand
- Nicaragua
- Niger
- Nigeria
- North Korea
- North Macedonia
- Norway
- Oman
- Pakistan
- Palau
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Poland
- Portugal
- Qatar
- Republic of Moldova
- Romania
- Russian Federation
- Rwanda
- Saint Kitts and Nevis
- Saint Lucia
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Korea

- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Sweden
- Switzerland
- Syrian Arab Republic
- Tajikistan
- Tanzania
- Thailand
- Timor-Leste
- Togo
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States of America
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela
- Viet Nam
- Yemen
- Zambia
- Zimbabwe

#### \* 2.4 Membership

- I'm representing an international organisation
- I'm representing a national organisation
- I'm an individual expert
- I'm member of the eHAction team

#### 2.5 Organisation

## 3 Events & Sessions

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eAHction WP5 is organising 3 focus group events.

WP5 plans to find replies to questions regarding policy level unmet needs for common principles and practical guidance why and how to foster innovative use of health data, big data and AI, as well as how to implement available relevant recommendations.

You are kindly invited to register to 1 or more virtual meetings focusing on the above topic from the following perspectives:

1. Technology and Interoperability
2. Public Health and Research
3. Policy and Regulation

**\* 3.1 I register to Focus Group Meeting 1**

Technology and Interoperability - Tuesday, 23 June 2020

*Virtual meetings are offered at 10:00 and 14:00 CEST*

*Morning and afternoon sessions are options to discuss the same focal issues following the same programme.*

- YES  
 NOT YET

**\* 3.2 Please select which session(s) you'd prefer to attend on 23 June 2020.**

*If you'd like to attend this event, please select option 1, option 2 or both*

- 10:00-12:00 AM CEST  
 14:00-16:00 PM CEST

**\* 3.3 I register to Focus Group Meeting 2**

Public Health and Research - Wednesday, 24 June 2020

*Virtual meetings are offered at 10:00 and 14:00 CEST*

*Morning and afternoon sessions are options to discuss the same focal issues following the same programme.*

- YES  
 NOT YET

**\* 3.4 Please select which session(s) you'd prefer to attend on 24 June 2020.**

*If you'd like to attend this event, please select option 1, option 2 or both*

- 10:00-12:00 AM CEST  
 14:00-16:00 PM CEST

**\* 3.5 I register to Focus Group Meeting 3**

Policy and Regulation - Thursday, 25 June 2020

*Virtual meetings are offered at 10:00 and 14:00 CEST*

*Morning and afternoon sessions are options to discuss the same focal issues following the same programme.*

- YES  
 NOT YET

**\* 3.6 Please select which session(s) you'd prefer to attend on 25 June 2020**

*If you'd like to attend this event, please select option 1, option 2 or both*

- 10:00-12:00 AM CEST  
 14:00-16:00 PM CEST

Please note that morning and afternoon sessions shall be held in case at least 10 registrations would be submitted till 21 June 2020.

Morning and afternoon offered on the same day are options to discuss the same focal issues following the same programme.

## 4 Would you be interested in making a pitch?

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*What are the root causes of the main challenges regarding big data and artificial intelligence in health?  
- There are many policy and operational level recommendations in this topic. These recommendations target various challenges, and most of them are still relevant in most Member States and organisations. The result of our mapping showed that three reasons appeared as root causes slowing down or hampering translation of policy-level recommendations into actions: lack of trust, legal uncertainties, and lack of funding and financial.*

*Would you be interested in sharing your learnings, experiences, point of view or ideas regarding these findings?*

\* 4.1 I would be interested in presenting my learnings, experiences, point of view or ideas regarding one of the following issues during the meeting(s) in a 2 minutes pitch

- Lack of trust (ownership, privacy, security)
- Legal uncertainties
- Lack of funding and financing
- I'd prefer other topic
- No, thank you

\* 4.2 Please specify the topic of your pitch

\* 4.3 I'm interested in making my pitch at

*between 1 and 3 choices*

- Focus Group Meeting 1 - Tuesday, 23 June 2020
- Focus Group Meeting 2 - Wednesday, 24 June 2020
- Focus Group Meeting 3 - Thursday, 25 June 2020

## 5 Preparing the focus group meetings

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5.1 Would you mind answering some questions before submitting your registration?













- YES
- NOT YET

5.2 Please rate following principles considering if they could help to implement practical governance of big data with a special focus on data to be used (and the implementation of data access and use) in public health, research and quality assurance in healthcare on a European scale.



5 stars mean you find the idea 100% important and useful.

You need not rate all the statements. This is not a mandatory field, you can submit your registration without answering this question.

Work with anonymized data as far as possible for the purpose of secondary use of data and big data.	
Curricula of health professionals should be adapted to include digital health literacy + big data in all EU countries.	
Avoid evolution of new technical standards, but use already existing ones and maintain "zero trust".	
Choose the right customers, users and beneficiaries of the business model for open data and data sharing to foster data reuse.	
Communicate socially acceptable purpose to reuse data.	
Involve stakeholders in the reuse of data and creating value.	
Learn current and future stakeholder needs (incl. non-negotiables, differentiators and dissatisfiers)	
Develop digital health literacy of stakeholders to strengthen empowerment and adherence to data sharing and re-use.	
Treat health challenges in the urban environment with a special business model for data management & data governance.	
Create international terms of data ownership, sharing, exchange and access to mitigate risks regarding sensibility and privacy.	
Share common vocabulary to avoid misunderstandings and led to exploit the value of data.	
Measure, manage, engineer and communicate worth of the customers, users and beneficiaries of data sharing and access.	

5.3 Please share additional idea(s) that might be useful to successfully implement practical governance of big data with a special focus on data to be used (and the implementation of data access and use) in public health, research and quality assurance in healthcare on a European scale.

500 character(s) maximum

This is not a mandatory field, you can submit your registration without answering this question.

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