**InfAct: Population Health Information Research Infrastructure (PHIRI) for COVID-19**

The Horizon 2020 Work Programme 2018-2020 on European research infrastructures (including e-Infrastructures) has been amendment on the 17th of June.

The section is of particular interest to InfAct. InfAct is preparing a proposal to respond to this grant without call. The relevant section is pasted hereunder and initial ideas for the draft proposal are presented subsequently.

A meeting for discussion with partners is organised on Friday 26/06 at 13h-14h30.

The meeting is organised through Webex.

You can join the meeting using the following details:

[InfAct] PHIRI for COVID-19

Hosted by Petronille Bogaert

Friday, Jun 26, 2020 1:00 pm | 1 hour 30 minutes | (UTC+02:00) Brussels, Copenhagen, Madrid, Paris

Meeting number: 163 831 6074

Password: cmTmH7k2Dd6 (26864752 from phones and video systems)

https://sciensano.webex.com/sciensano/j.php?MTID=m8074c13486ab6dc1e0cd990da929f335

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You can also dial 62.109.219.4 and enter your meeting number.

Join by phone

+44-20-3478-5289 United Kingdom Toll

Access code: 163 831 6074

**Amendment: Work Programme 2018-2020 on European research infrastructures**

European Commission Decision C(2020)4029 of 17 June 2020). Full text available here: <https://ec.europa.eu/research/participants/data/ref/h2020/wp/2018-2020/main/h2020-wp1820-infrastructures_en.pdf>

**5. Mobilisation of Research Infrastructures for the COVID-19 Public Health Emergency**

As part of the EU response to the COVID-19 pandemic, for activities specifically linked to COVID-19, grants may be awarded without a call for proposal in accordance with Article 195(b) of the Financial Regulation 2018/1046, to address this exceptional emergency. The Funding & Tenders Portal will open a dedicated section where applications can be received. The invitation to apply for funding may also be limited to targeted entities. Entities will be targeted taking into account the need to achieve the underlying objectives in a quick and efficient manner considering the exceptional circumstances (“extreme urgency” due the COVID 19 pandemic).

Proposals should concern the setting-up of a *Population Health Information Research Infrastructure*, to collect and make available population health and relevant non-health data in MS and at EU level that can support research and policy decisions regarding the COVID-19 public health crisis. It should ensure, to the extent possible and in full respect of the GDPR, interoperability with other relevant administrative data infrastructures, for analytical purposes and to support policy-making, including in the areas of employment and social policy. It should thus form a cornerstone of the emerging European Health Data Space, and properly connect with the [EU COVID-19 Data Platform](https://www.covid19dataportal.org/). It will provide a comprehensive view on health data (including from in-depth analyses of patients’ biospecimen), data on social and physical environment (including behavioural data) and on health care services (promotion-prevention-cure and care), thus informing on the dynamics of human health, diseases and mortality. It will build on the EU Member States Joint Action on Health Information (INFACT).

The research infrastructure will involve and/or ensure full synergy with different types of actors and initiatives such as European research networks in the domain of population health; relevant national population data owners/curators (e.g. MS Health Data Space); national population health co-ordination entities; and EU and international data collectors and registries relevant for COVID-19 and future epidemics, notably ECDC, WHO, OECD, EEA, ESAF, JRC, EOSC, and European research infrastructures. Participation of experts in ethics and law as well as patient representatives is strongly encouraged.

The proposal should already present a number of research use cases that are of immediate relevance for public health policies or aspects of clinical management of the COVID-19 epidemic and disease, respectively.

The Commission considers that proposals requesting a contribution from the EU of up to EUR 5 million would allow this activity to be addressed appropriately. Nonetheless, this does not preclude submission and selection of proposals requesting other amounts. Given the nature of the expected project and in order to ensure that appropriately mandated entities from Member States, at EU and at international level are all duly involved, at most one proposal is expected to be funded.

Expected Impact:

* Provision of high quality and standardised COVID-19 relevant population health and care institutions data across EU Member States to inform policy-making and feed into pertinent health data registries, collections and statistics at EU and international levels.
* Identification of best practices for handling the COVID-19 epidemic at public health and clinical management level.
* Enable advanced research to address and find solutions to COVID-19 and other health crises, in connection to the EOSC and the related EU COVID19 Data Platform.
* Contribute to the formation of a true European Health Data Space thus responding to the EU’s Digital Health agenda.

**The Population Health Information Research Infrastructure (PHIRI) for Covid-19**

**Covid-19 sparks an outcry for cross country exchange**

Member States (MS) are individually developing studies, collecting data and interpreting results to address the Covid-19 pandemic. However, through the Joint Action on Health information (InfAct), partners at the core of the Covid-19 response teams have indicated a strong need to structurally exchange between countries. A rapid exchange between partners has been organized by InfAct where partners can approach each other for questions and share detailed approaches in a trusted environment. This allows for a quick exchange of data, indicators, good practices and experiences between countries. Similar initiatives in other networks are springing up like mushrooms reflecting MS’s demands, but a common European approach is lacking. The need for a structured European mechanism for Covid-19 exchange to organize and share information between countries is obvious, especially in the area of population health which has worldwide set the scene for any decisions taken in other sectors during the Covid-19 pandemic. It becomes also clear that information will be needed on the broader impact of Covid-19 on the health of populations. This includes secondary consequences of Covid-19 on long-term health and due to delayed medical treatment.



Source: Twitter post 7:04 PM · Mar 30, 2020 Victor Tseng

**A structured European exchange mechanism: PHIRI for Covid-19**

The Population Health Information Research Infrastructure (PHIRI), also known as the Distributed Infrastructure on Population Health, would be able to respond with a sense of urgency. It has been designed to make possible the identification, access, assessment and reuse for research population health and non-health data in MSs and across MSs that can underpin (public health) policy decisions. PHIRI can be set-up to accomplish this in the context of Covid-19.

PHIRI can offer a European mechanisms for structured exchange on real time population health information in current and future epidemics or crises. The aim is to share data and expertise between countries primarily at operational level through a one-stop shop on population health in close interaction with key stakeholders in the health information landscape. The primary activity will be to allow structure exchange of population health information through a platform with FAIR catalogues.

The PHIRI for Covid-19 has the objective:

1. To provide a **FAIR catalogue platform** on health and health care data for structured information exchange. It facilitates access to and use of high quality and standardised COVID-19 relevant population health (health status and determinants of health) and care institutions data across EU Member States. It provides the computing services and tools necessary for researchers to link different data sources and to use Pan-European data in a GDPR compliant, distributed way.
2. To provide structured exchange between countries on COVID-19 best practices and expertise. PHIRI shares public health and clinical management tools, protocols and guidelines identified at national and international level. It allows researchers to provide relevant and evidence based information ready for use in decision-making processes by citizens, clinicians, public health practitioners and **policy makers**.
3. To promote **interoperability** and tackle health information **inequalities**. PHIRI supports researchers to make their research FAIR and ELSI compliant, enhancing interoperability and standards. It provides **capacity building** for management of COVID-19 relevant population health and healthcare data starting from the phase of designing data collections to analysis, reporting and preservation. Training of the health research community involves both the data producers and data users.

**Potential modes of operation**

PHIRI operates in a bottom up approach by including a network of nodes which feed the information available in the one-stop-shop. The nodes include two types: national nodes (NN) units within MSs; and Pan-European domain specific Research Networks (RN) and their research communities. The FAIR catalogue platform will be centrally managed.

*Platform with FAIR catalogues*

* Build FAIR catalogue with metadata repository on population health information with information on their accessibility
	+ Including regional, national and international data sources
	+ Include a data management plan
	+ Fed by National Nodes and Research Networks
* Facilitate real time data exchange and data requests: securely make available federated data sets and variables in countries to monitor population health with controlled access policies through data access-granting organisation (DAO)
* Allow tools for analysis and queries searches
* Investigate data capture possibilities
* Provide overview of in development or ongoing studies in population health and contact points in countries
	+ Example: studies on Covid-19 health interview surveys and sero-epidemiology studies
* Provide overview of training materials
* Provide overview of policy and impact measures through existing initiatives.

*Working groups operating in selected themes*

* Primarily function to facilitate identification, convergence and harmonization of indicators to assess the broader impact of Covid-19 on the health of populations in collaboration with national and international actors.
* Discussing the latest developments and sharing newly developed or recently validated tools approaches, Standard Operating Procedures protocols and guidelines
	+ Examples:
		- Who is being tested?
		- Which indicators are being used to measure mortality, to measure the impact of lock-down measures, to measure the progression in elderly and care homes?
* Possible themes:
	+ Research methods
		- Covid-19 health interview surveys (indicators used sample sizes, number of waves, selection procedures, etc.)
		- Sero-epidemiology studies (testing tools used, sample sizes, number of waves, selection procedures, etc.)
	+ Capacity building exercises and training materials
	+ Knowledge translation and interaction with policy makers
	+ Digital tools and other technology used
		- Example: Applications to monitor movement of general public or patients such as Go.Data from WHO.
	+ Long term impact including inequalities

*Rapid exchange team*

* Provide rapid response to questions that are raised in countries
	+ Example: obligation to wear masks for children
* Rapidly spread internationally agreed standards, reports and initiatives possibly using data mining techniques

*Foresight, modelling and mitigation team*

* Based on the experience from Covid-19 identify what were the needs?
	+ What was the information that countries needed from other countries?
	+ Which guidelines from international organisations were needed?
	+ Can we anticipate responses and support needed in the future at European level?

**Potential work packages**

1. Coordination, management and communication
2. Engagement, outreach and sustainability
3. Building FAIR catalogue
	* Overview of (routine) data sources with available data codebooks and access information
	* Overview of tools, guidelines and protocols
	* Overview of in development or ongoing COVID-19 studies in population health and contact points in countries
	* Overview of training
	* Overview of policy and impact measures through existing initiatives.
* Sources from national level through national nodes
* Centrally store information that is fixed
1. Rapid exchange team: identifying and exchange (best) practices
2. Build federated, distributed infrastructure through use cases on specific population groups (see DIPoH Design)
	* Facilitate real time data exchange and data requests: securely make available federated data sets and variables in countries to monitor population health with controlled access policies through data access-granting organisation (DAO)
	* Allow tools for analysis and queries searches
	* Investigate data capture possibilities
3. Use cases with centralised analysis
	* Delayed medical care due to COVID-19: use case on cancer
	* Sero-epidemiology study
	* Health surveys (mental health, physical activity, nutrition, lifestyle, violence, social support, quality of life)
	* Other options: Burden of disease
4. Foresight, modelling and mitigation team

**Domains to be covered**

DIPoH facilitates the identification, access, assessment and reuse for research population health and non-health data in MSs and across MSs. It focusses on possible data sources for measuring population health and connecting these with relevant non-health data such as work, education, culture, leisure, mobility, consumption, etc. The aim is not to store data centrally or to duplicate what is already available, but provide a clear overview of what is available through a federated approach in close cooperation with regional, national and international players and organization active in the field.

* A comprehensive view on health data
	+ Population health data (administrative data, age, gender, geographic, contacts, mobility, mental health, NCD risk factors)
	+ Epidemiological (incidence case reporting, tested/positives, mortality, surveillance data link with TESSY/ECDC, epidemiological modelling)
	+ Risk factors for outcomes: life style, immunology, genomic
	+ Inequality data: stratification by socio-economic variables, health literacy
* Data on social, economic, cultural and physical environment (including behavioural data, food, education, work environment, sickness leave/return to work, housing, school)
* Data on health care services (promotion-prevention-cure and care) primary, secondary and tertiary care and elderly care
	+ Clinical profiles, care level information (hospitalisations, ICU, respiratory support, severeness of symptoms, outcomes, hospital mortality, autopsies)
	+ Individual health records (symptoms, contacts, consultation, treatments, outcomes, in and outpatient follow-up)
	+ Resources: medical staff and healthcare workers
	+ Telemedicine
* Information on quarantine and asymptomatic patients
* Data on MSs public health measures (diagnostic tools: PCR testing and serology testing, intervention measures, materials, logistics, hospital capacities, movement and location, protective gear, criteria for lockdown and exit strategies, contact tracing)

**Added value for MS**

* Easily findable data and information needed for research and to underpin policy decisions
* Facilitate exchange and access to real time data
* Rapid response to research and policy questions
* Access to a network of Covid-19 health information experts to retrieve information from and feed international agreed standards to
* Quick wins by identifying good practices in countries and exchanging approaches between countries such as sharing key indicators, protocols and tools to monitor the Covid-19 pandemic
* Overview of available training materials and training staff
* Pragmatic support to countries in preparing for potential upcoming Covid-19 waves or other epidemics

**The DIPoH consortium and international actors**

DIPoH builds on a strong consortium of health information specialists currently working at the forefront of the Covid-19 pandemic. The consortium is unique building on a foundation of National Public Health Institutes. Besides having the expertise, partners have been working closely together, through projects such as the BRIDGE Health project and InfAct made possible by SANTE, fostering a trusted environment for exchange. The DIPoH consortium is a quickly mobilizable group. The consortium consists of:

* National health information authorities that manage the Covid-19 data, coordinate the research and provide the scientific evidence for policy makers in countries
	+ Statistical offices, national public health institutes, Ministries of Health and other health information data holders and curators
* European research networks that monitor the impact of Covid-19 in different population health and non-health domains
	+ Networks on types of data sources (e.g. examination and interview surveys)
	+ Networks on specific population groups (e.g. perinatal health)
	+ Networks on specific topics (e.g. cancer, heart infarction, NCDs, environment)

It will contribute to the European Health Data Space and link through EOSC to relevant data resources available in other research infrastructures or ERICs such as:

* Pathogen information : genomic profiling
	+ ENA Archive, Elixir, Federated European Genome-phenome Archive (FEGA)
* Biobanks: e.g. virology, serology
	+ BBMRI
* Experimental: treatments and vaccine development
	+ ECRIN (clinical trials research), EATRIS (translational medicine)
* Big data analytics: geographical contextual factors - dynamics of epidemics - forecasting

The consortium interacts with Covid-19 stakeholders including labs, hospitals, elderly and care homes, prisons, asylum centers etc. to feed the data flow. Most of the consortium partners do so routinely.

In addition, the consortium is also well known among key actors at European and international level (e.g. ECDC, EFSA, OECD, WHO, Eurostat, JRC, EEA, European Observatory on Health Systems and Policies, IANPHI, EUPHA, ASPHER). It has worked in synergy with these in the past and during this crisis. Here are some examples of activities that have been carried out in the past weeks with regards to international organisations:

* Share with consortium ongoing initiatives or networks operating.
	+ Promoting the work of the Health System Response Monitor (HSRM). A joint undertaking of the WHO Regional Office for Europe, the European Commission, and the European Observatory on Health Systems and Policies. <https://www.covid19healthsystem.org/mainpage.aspx>
	+ IANPHI platform for exchange
* Share requests from international organisations to MS to complete surveys, participate in webinars and provide expert advice in new reports.
	+ Share request for expert advice from the WHO Europe European Health Information Initative report on “Measuring population health after the first phases of the COVID-19 pandemic”
	+ Invitation to WHO ad hoc consultation on infodemic management (7-8 April 2020)
	+ Provide overview of countries carrying out covid-19 Health Interview surveys with OECD
* Share internationally agreed standards and protocols.
	+ WHO ICD coding for covid-19 and ECDC reports on masks.