

# PHIRI

Population Health Information  
Research Infrastructure

# Stakeholder dialogues

Meeting report 18.02.2022

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## Executive summary

PHIRI, the [Population Health Information Research Infrastructure](#), organized a series of stakeholder dialogues on February 18th (10:00-12:00 CET), in order to bring together, interact and/or exchange with relevant national and international stakeholders while promoting active discussions around three themes that are at the core of the PHIRI project: FAIR catalogues for health data, building a federated architecture and crisis preparedness. Several stakeholders and key persons of other European projects joined the 3 different panel discussions, moderated by PHIRI work packages leads.

Main takeaways:

### *FAIR catalogues on (population) health data*

- Metadata on health information data sources is important for discoverability
- We need incentives for data owners to provide proper documentations
- The EHDS is taking the first steps through the HealthDCAT-AP
- We need to increase the knowledge capability and expertise on metadata expertise

### *Building a federated infrastructure*

- The challenges of a federated approach are both legal/cultural and technical: the data governance, trust and harmonising heterogeneous data sources
- However, for now, the federated approach (instead of a centralized setting) is still the solution for analysing sensitive health data
- Options for federated learning methodologies are still being researched

### *Crisis Preparedness*

- Establishing cross-border exchanges of expertise and lessons learned in a secure environment was very important during the crisis; the projects have an important role as knowledge brokers.
- The challenges of being crisis-prepared is not only technical; the human resources are also important; workforce training and knowledge sharing can provide solutions.
- The [PREPARE cluster](#) can explore how they can complement each other's work, especially in this post pandemic era, in order to help Europe to be more prepared for future crises.

# PHIRI: Stakeholder Dialogues meeting report

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## About the Stakeholder Dialogues

PHIRI, the Population Health Information Research Infrastructure, organized a series of stakeholder dialogues on February 18th (10:00-12:00 CET), in order to bring together, interact and/or exchange with relevant national and international stakeholders while promoting active discussions around three themes that are at the core of the PHIRI project;

- Building **FAIR catalogues to describe population** health data sources in EU countries and the international level; the Health Information Portal;
- Creating and validating a **federated research infrastructure** that overcomes data reuse and data sharing hindrances for rapid, policy relevant, research response to the evolving pandemic;
- Building a sustainable infrastructure to support rapid exchange between actors from competent authorities, their advisors, researchers and stakeholders in the joint efforts to handle the COVID-19 pandemic and to **better prepared for future crises**.

The agenda:

Date: February 18 10:00-12:00 CET   Location: via Webex (online)			
Topic		Speaker	Time
1	Welcome	Petronille Bogaert <i>Sciensano Belgium / PHIRI coordination</i>	10:00
2	Fair catalogues on (population) health data	PHIRI representative: <b>Hanna Tolonen, THL Finland</b> 1. Henning Hermjakob, BY-COVID 2. Anastassja Sialm, SYNCHROS 3. Truls Korsgaard, Norwegian Directorate for e-Health	10:10
3	Building a federated infrastructure	PHIRI representative: <b>Enrique Bernal-Delgado, IACS Spain</b> 1. Ernestina Menasalvas, UnCover 2. Gergely Sipos, EGI-ACE 3. Salvador Capella-Gutierrez, ELIXIR-CONVERGE	10:45
4	Crisis preparedness: round table with the PREPARE cluster	PHIRI representative: <b>Claudia Habi, GÖG Austria</b> 1. Chaim Rafalowski, NO FEAR 2. Sofia Tsekeridou, STAMINA 3. Claudia Houareau, PANDEM-2 4. Anikó Balogh, CO-VERSATILE 5. Luis Rodríguez, COVID-X	11:20
5	Closing	Petronille Bogaert <i>Sciensano Belgium / PHIRI coordination</i>	11:55
END			12:00

Number of attendees: 74

# I. Panel I: FAIR catalogues on (population) health data

## Moderator

Hanna Tolonen – Finish Institute for Health and Welfare/PHIRI

## Panellists

Henning Hermjakob – [BY-COVID](#)

Anastassja Sialm – [SYNCHROS](#)

Truls Korsgaard – [Norwegian Directorate of eHealth](#)

Health data is a powerful tool; it can be used for research on new innovations, prevention and treatment and guides informed decision-making. This has been demonstrated clearly during the COVID-19 pandemic. As the population health information landscape is fragmented in Europe, it is difficult to find data for research and to support policy responses. It is urgent that we can enhance the value of the existing data by making it more visible, findable and more accessible. The role of the individual data owners is important: these data owners have the main responsibility to document the data and make it available. In PHIRI, we have taken the first step by establishing the [Health information Portal](#) with catalogues of health information sources. PHIRI relies on [its network of national nodes](#) to provide the metadata on health information sources.

Solutions to find incentives for data owners to document and standardize the data can include:

- working closely with journals, which can help you activate the discussion towards common standards and appeals to the research community;
- building knowledge and have metadata managers in all registries; individuals that are working on metadata management, can help building such skills in others. In Norway, they are working towards an expert enabler group, that will continuously improve the metadata;
- addressing the ‘federation fatigue’ (different standards can lead to incompatibility of (meta)data and discussions on who should change their format) by doing impact assessments; in publishing we want to know how much we are cited, but in the data field this is much less exploited as a motivator to get high-quality metadata. How often are data used? Which dataset has an impact? The use of persistent identifiers for each dataset can aid in these impact assessments.

Currently, the industry has much more detailed metadata descriptions for their datasets than we have in health data. How ‘deep’ should we go when it comes to describing our health data sources? The 1<sup>st</sup> ‘(international) layer’ should be minimal metadata, the barrier to entrance should be low. Of course, the more the metadata you provide, the chances are higher that the dataset has an impact! In addition, pure discoverability is not enough for domain specific metadata. The 2<sup>nd</sup> ‘(national) layer’ should contain more detailed descriptions of the data. In Norway, they have even created a 3<sup>rd</sup> ‘layer’, for example in their Cancer Registry, which is enriched with specific metadata on cancer treatments or diagnostics. Of course, these layers should be compatible.

The European Commission aims to establish a European Health Data Space (EHDS). In September, a pilot will start aiming to develop, explore, and analyse standards on data governance, data quality and data infrastructure for data-sharing between different participating countries across Europe. Part of this pilot project is the development of a health extension of the DCAT-AP metadata standard that is endorsed by the Commission.

Takeaways:

- Metadata on health information data sources is important for discoverability

- We need incentives for data owners to provide proper documentations
- The EHDS is taking the first steps through the HealthDCAT-AP
- We need to increase the knowledge capability and expertise on metadata expertise

## II. Panel II: Building a federated infrastructure

### Moderator

Enrique Bernal-Delgado – Instituto Aragonés de Ciencias de la Salud/PHIRI

### Panellists

Gergely Sipos – [EGI-ACE](#)

Ernestina Menasalvas – [UnCOVer](#)

Salvador Capella-Gutierrez – [ELIXIR-CONVERGE](#)

[PHIRI opted for a federated approach](#), because the data that it is managing, is personal, thus sensitive data. The GDPR as well as its local applications should be taken into account. The federated approach is better equipped to deal with differential privacy. Additionally, if PHIRI wants to enrich existing data sources with newly collected variables for prospective research, pseudonymisation is needed, which is difficult when data is transferred to a centralized data warehouse. PHIRI is dealing with real world, routinely-collected data, which is collected in a specific context, and a federated approach is much better equipped for working with these sensitive data.

There are several challenges to this federated approach. There are policy challenges that relate to legal or cultural barriers: the data owners might have fear that they ‘lose control’ over their data when they deposit their data or allow their data to be shared. Sometimes there is even an ‘overshoot’; when there is stricter control of data use in place in order to be on the safe side. In the [UnCOVer](#) project, one of the main barriers was convincing the DPO’s that their solution was compliant with the GDPR and that the connection to the central servers was stable and secure. In addition, the federated system comprises many data owners, which can lead to problems in communication (in a centralized setting, this might be less of an issue). The technical barriers include data harmonization, but also limited technical capabilities in the different nodes in the federation. In projects such as [HealthyCloud](#), the technical solutions and best practices that are already in place (for example on national or even institutional level) are mapped, aiming to deploy these at a larger (international) scale.

For now, across most domains and disciplines in health science, the federated approach is dominating, instead of a centralized setting. When storing massive amounts of big data centrally, you would need supercomputers to manage these data. It would be economically a more reasonable approach to have the data stored locally. However, in the long term there could be issues with the operational costs of such a federation: we would need strong computational units locally. In the future, we could move towards a more mixed approach.

Progress has been made in the [Global Alliance for Genomics & Health](#) (GA4GH) to advance on automatisisation for accessing datasets. If a user is compliant with the requirements, the process can be automatized. However, we should keep in mind that this is for genomics; for other types of health data such as electronic health records this could prove to be more difficult. For these types of data that are part of a federation, the only thing that can be automatized, is the access for analysis.

Finally, in the current computational infrastructure of [EGI-ACE](#), there is no support for federated learning beyond the border of an institute. Expanding the learning model across several institutes is not possible yet, as it is not mature enough (still in an explorative phase). Some of the problems are related to the data not being properly harmonised, with many inconsistencies.

Takeaways:

- The challenges of a federated approach are both legal/cultural and technical: the data governance, trust and harmonising heterogeneous data sources
- However, for now, the federated approach (instead of a centralized setting) is still the solution for analysing sensitive health data
- Options for federated learning methodologies are still being researched

### III. Panel III: Crisis Preparedness

#### Moderator

Claudia Hahl – Gesundheit Österreich GmbH/PHIRI

#### Panellists

Chaim Rafalowski – [NO FEAR](#)

Sofia Tsekeridou – [STAMINA](#)

Claudia Houareau – [PANDEM-2](#)

Anikó Balogh – [CO-VERSATILE](#)

Luis Rodríguez – [COVID-X](#)

PHIRI established a sustainable infrastructure to support and facilitate exchange between 1) competent authorities for pandemic response and their advisors, 2) researchers in the field and 3) stakeholders (EU networks, ECDC, JRC, WHO) in joint efforts to manage the COVID-19 pandemic. By doing so, PHIRI offers:

- rapid responses to research and policy questions that are raised in countries
- promptly disseminate internationally agreed guidelines, standards and reports
- exchange (best) practices among countries regarding COVID-19
- provide expertise to policy considering the shifting landscape of evidence

PHIRI organizes bi-weekly (every second Monday 10.00am-11.00am), 1-hour online meetings in a moderated, structured format answering pre-agreed urgent research and policy questions on COVID-19 (topics are contributed by the participating countries and chosen via a survey ex-ante to each meeting). Responses by countries (backed up by evidence like national reports, guidelines, etc.) are compiled and shared on the [Health Information Portal](#) and participants are encouraged to share them with their national crisis response teams.

This is the first time that all projects who are part of the [PREPARE cluster](#) are publicly discussing the topic of crisis preparedness. The PREPARE cluster (REparedness and resPonse for emergency situAtions in euRopE) is a cluster of twelve H2020 funded projects (with a combined funding of €72m) who are tackling challenges specifically looking at the preparedness and response phases of crisis management. Working together, they aim to achieve stronger results and greater impact for their cause. For example, the COVID-X and STAMINA consortia have overlapping partners and work together on the technical level and regarding the needs of their end-users.

Every country had a different timeline with regards to the crisis; in some countries the ‘waves’ of COVID-19 started later compared to other European countries. In order to ensure that experiences and lessons learned are exchange quickly, it is important to build strong networks, including not only public health professionals and decision makers, but also emergency medical care practitioners, suppliers and first responders.

We need to bridge the gaps in the different countries and projects. What can be the role of the PREPARE cluster in this? In PANDEM-2, they experienced very efficient exchange during the early

warning and response system for cross-border contact tracing. There is always room for improvement; all the projects have a different angle, but all focus on cross-border exchange of expertise and knowledge. For example, in NO-FEAR they experienced that in their network, they could share real time new phenomena and challenges that had an impact on the way patients are treated. There was a need to discuss some of the urgent questions in a safe environment. All projects have a role as knowledge brokers. We have to go beyond our usual ‘bubbles and circles.’

Unfortunately, the health systems are still facing many challenges. In the CO-VERSATILE project, they experienced that the human resources side is seriously impacted as well. The health workers are tired and infected and are leaving the workforce. Workforce training and knowledge sharing is very important.

How to overcome ethical issues in terms of crisis? You have to take into account that data belong to patients and they have the right to decide what the data is used for, for clinical follow up as well as for research purposes. There are also other limitations regarding the reuse of clinical data for research; for example, the data owner is the one who should provide access to data and is the gatekeeper. All the limitations are there for a purpose, but this does not mean that clinical data is not useful for research.

Takeaways:

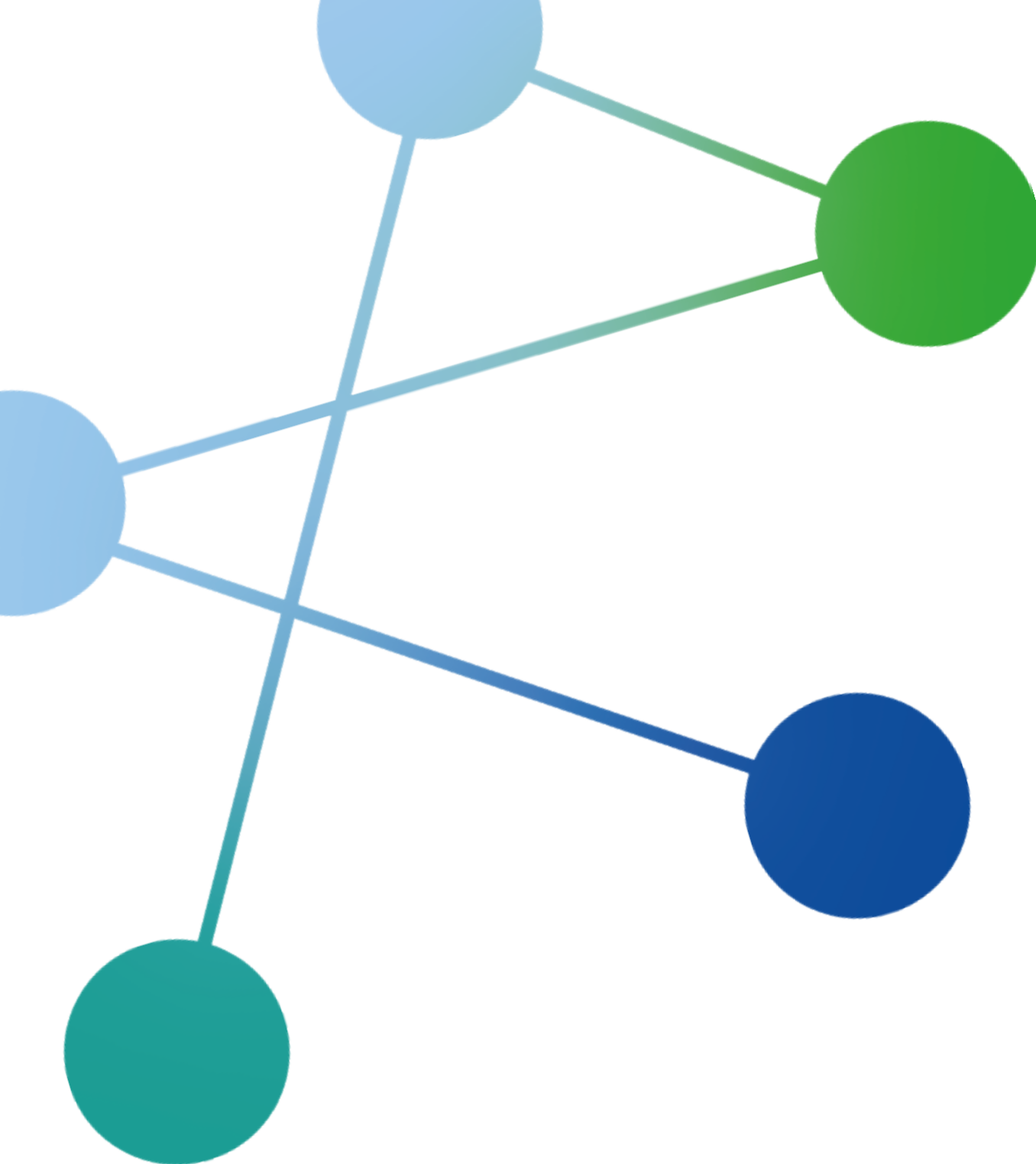
- Establishing cross-border exchanges of expertise and lessons learned in a secure environment was very important during the crisis; the projects have an important role as knowledge brokers
- The challenges of being crisis-prepared is not only technical; the human resources are also important; workforce training and knowledge sharing can provide solutions
- The PREPARE cluster can explore how they can complement each other's work, especially in this post pandemic era, in order to help Europe to be more prepared for future crises.

## Disclaimer

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