



# PHIRI

Population Health Information  
Research Infrastructure

# Sustainability Plan

D 3.3 – March 2023



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## Executive summary

This **sustainability plan** (Deliverable 3.3) outlines – based on the core achievements of PHIRI ([Population Health Information Research Infrastructure](#) project) – the potential of the project's outputs and outcomes to become an important building block for the future European Health Data Space (EHDS), especially regarding secondary use of data.

After a short outline of the **history and objectives of PHIRI** the report re-caps the most important activities and outcomes, which are summarised in seven **factsheets** and **main achievements**.

### Factsheets and contributions

- [Capacity building and European School on Health Information](#)
- [Rapid Exchange Forum](#)
- [Infodemic Management](#)
- [Health Information Portal and National Nodes](#)
- [Federated Research Infrastructure and Use Cases](#)
- [Foresighting](#)
- [COVID-19 Health Information System assessments](#)

### Main Achievements

PHIRI achieved significant milestones, including the development of a [European Health Information Portal](#) (HIP) to enhance accessibility to population health data and expertise throughout Europe or the establishment of a so-called [Rapid Exchange Forum](#) (REF) to promptly address urgent public health inquiries. The project partners further conducted comprehensive (COVID-19) health information systems assessments in eight countries, performed multiple literature reviews screening over 10,000 abstracts, created a federated research infrastructure to tackle diverse use cases utilising data from various European countries and sources, supported countries to perform foresight studies, created a training school for health information and successfully enhanced research capacity on these topics for researchers across Europe.

### Continuation

The report outlines options for continuing the cooperation **content-wise** (data management, capacity building, knowledge generation) and from an **organisational** (project-based work, creation of a legal entity) perspective. It is already ensured that the HIP, the REF and the Spring School on Population Health are maintained in 2024.

Moving forward, it is essential to carry on in supporting and expanding PHIRI as an element to further develop mutual learning and evidence generation in population health and to ensure a coordinated and effective joint response to future potential health crisis in Europe.

## Acronyms

GDPR	General Data Protection Regulation
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
EHDS	European Health Data Space
ERIC	European Research Infrastructure Consortium
ELSI	Ethical, Legal, and Social Implications
EPH	European Public Health
ERIC	European Research Infrastructure Consortium
ESHI	European School of Health Information
EU4H	EU4Health – 4 <sup>th</sup> EU Health Funding Programme
EUPHA	European Public Health Association
FAIR	Findable, Accessible, Interoperable, and Reusable (principles)
HIP	European Health Information Portal
PHIRI	Population Health Information Research Infrastructure (project and collaboration)
PREPARE	PREparedness and resPonse for emergency situAtions in euRopE Cluster of projects
REF	Rapid Exchange Forum
UNL	Universidade NOVA de Lisboa
WHO	World Health Organisation

## Disclaimer

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# List of Contents

- Executive summary ..... 2
- I. Background and Content ..... 5
  - 1. History ..... 5
  - 2. Content..... 6
- II. Achievements ..... 7
  - 1. Health Information Portal ..... 7
  - 2. Further main achievements..... 8
- III. Continuing the cooperation ..... 9
  - 1. Data Management ..... 9
  - 2. Capacity Building .....10
  - 3. Knowledge generation .....11
  - 4. Survey on sustainability of PHIRI .....13
    - 1. Methodology .....13
    - 2. Results .....13
  - 5. Future organisational and financial management.....15
    - 1. Project based-cooperation opportunities .....15
    - 2. Creating a legal entity .....21
    - 3. Membership fee .....22
    - 4. Other relevant activities.....22
- IV. Conclusions .....23

# I. Background and Content

Health is a cross-border issue, as recently demonstrated by the COVID-19 public health crisis. To make the most of health investments and to tackle public health threats like the COVID-19 pandemic jointly and in a meaningful way, health policies and decision-making need to be based on robust evidence from research on population health and health systems from high quality and timely data. International comparative research, data management and exchange of best practices is indispensable for strengthening the evidence base for national and international decision-making on health and health systems on a way to true European Health Union.

## 1. History

Caused by population health challenges (raising burden of disease caused by non-communicable diseases, ageing population, and social inequalities), European and national decision makers have expressed their need for comprehensive and sustainable health information from a public health perspective, i.e. trustworthy and comparable evidence, data, indicators and analysis. Consequently, besides activities of Eurostat and the Joint Research Centres, the European Health programmes funded several activities in the field.

In the 2<sup>nd</sup> Programming period 2008-2013 several actions on health monitoring and data were funded by the European Commission (EC), e.g., [Euro-Peristat](#), the European perinatal information system or the development of European Core Health Indicators for monitoring and comparing health outcomes between EU countries in support of policy-makers. The 3<sup>rd</sup> EU Health Programme allowed the creation of the [BRIDGE<sup>1</sup> Health](#) initiative with the aim to increase sustainability of the health systems for both public health and research purposes in 2015. BRIDGE Health assessed different structural and institutional options including a comprehensive European Research Infrastructure Consortium (ERIC) in health information and delivered a concept paper describing the scope, tasks, activities, and governance structure for a future EU-wide Health Information Service to be further developed and established. The mission of the following Joint Action [InfAct](#) (2018-2021) was to build the base for an EU health information system infrastructure and define its core elements, which where a one-stop shop for health information research, knowledge translation research for evidence-based decision making and technical infrastructure supported by national nodes and cooperation with European research networks.

InfAct thus pathed the way for the creation of the [European Health Information Portal](#) (HIP) which has all the above-mentioned core elements. When the COVID-19

pandemic hit Europe, partners of InfAct were asked to support efforts in tackling the disease by supporting a coordinated response to the crisis and being a place for evidence-based exchange of evidence and learning. This led into the creation of the [PHIRI consortium](#) and funding from the European Horizon2020 programme. PHIRI also became part of the [PREparedness and resPonse for emergency situAtions in euRopE \(PREPARE\) cluster](#) together with 12 other H2020 funded projects. Each of the projects (combined funding of €72m) is tackling challenges specifically looking at the preparedness and response phases of crisis management.

## 2. Content

This report, the **sustainability plan** (Deliverable 3.3) outlines – based on the core achievements of the PHIRI (Population Health Information Research Infrastructure project) – the potential of the project’s outputs and outcomes to become an important building block for the future European Health Data Space (EHDS), especially regarding secondary use of data.

It should be read in conjunction with the Technical Report published on the [PHIRI website](#) that describes the results, outputs, and outcomes of the project in great detail. This deliverable will focus on main achievements and will outline potential ways to continue and exploit results.

First, the report re-caps the most important activities and outcomes, which are summarised in seven **factsheets**:

- [Capacity building and European School on Health Information](#)
- [Rapid Exchange Forum](#)
- [Infodemics](#)
- [Health Information Portal and National Nodes](#)
- [Federated Research Infrastructure and Use Cases](#)
- [Foresighting](#)
- [COVID-19 Health Information System assessments](#)

Next, the report outlines the thematic **fields for continuation**, giving details on planned short-time activities and long-term objectives. The basis are moderated discussions of the group and a survey among PHIRI partners. The report also mentions concrete projects and activities where PHIRI partners continue to work together in population health and in pathing the way to the upcoming EHDS.

The sustainability plan is concluded with potential organisational **frameworks of cooperation**, namely plans to create a legal body for PHIRI.

## II. Achievements

PHIRI is a research infrastructure aiming to facilitate and support open, interconnected, and data-driven research through the sharing of cross-country population health information and exchange of best practices related to identification of data sources, access, risk setting and outcomes following Ethical, Legal, and Social Implications (ELSI) and FAIR (Findable, Accessible, Interoperable, and Reusable) principles.

### 1. Health Information Portal

One of the most important deliverables of PHIRI is the **European Health Information Portal, HIP** (<https://www.healthinformationportal.eu>), a one-stop shop that facilitates access to population health and health care data, information and expertise across Europe.

To ensure sustainability of the portal the PHIRI partners and national nodes **agreed to further maintain and update the website** and tools with new research items, data-catalogues, trainings, and initiatives.

An important change is that the focus of the HIP which was created in the light of the univocal need to tackle the COVID-19 pandemic is currently shifting to cover the **full spectrum of population health**, enforcing the original aim to be **the repository and infrastructure for international comparative research, data management and exchange of best practices**.

An important pillar to create the HIP were **National PHIRI nodes** who were in charge of providing information and input in a pre-determined way. The intention was to create a sustainable network of networks composed of National Nodes and Research Networks. National Nodes should bring together the key players in population health information in Member States, and Research Networks, or domain specific Nodes, should bring together experts in a specific health information field across European countries.

During the project it became obvious that these nodes are being transferred nationally because of the change in the ecosystem caused by the upcoming EHDS (e.g., demands for various roles, e.g. secondary data access bodies). So, the PHIRI partners as such continue to have an important role in sustaining PHIRI and being part of strong population health network even if they are not mandated as official national node.

As the Health Information Portal (HIP) is the brain and soul of PHIRI the project partners made a specific plan and **roadmap for continuation**.

The document features a comprehensive **sustainability assessment** of the Portal and outlines current efforts to secure financial support (e.g., the creation of a working group

of the PHIRI collaboration to explore national and EU-funding opportunities). It also stresses the imperative to maintain the accuracy and relevance of the existing information contained within the Portal. Furthermore, when necessary, the Portal must be updated by appending current information to its existing modules and sections, or through the creation of new modules and sections.

## 2. Further main achievements

Seven **factsheets** summarise key PHIRI activities and their main achievements and explain why it is necessary to continue with them.

- Capacity building and European School on Health Information  
European School on Health Information  
<https://zenodo.org/records/10579347>
- Rapid Exchange Forum  
Fast lane for decision making: The Rapid Exchange Forum  
<https://zenodo.org/records/10579318>
- Infodemic Management  
[https://www.phiri.eu/sites/phiri.eu/files/2024-02/PHIRI%20%26%20Infodemic%20Management\\_Sustainability.pdf](https://www.phiri.eu/sites/phiri.eu/files/2024-02/PHIRI%20%26%20Infodemic%20Management_Sustainability.pdf)
- Health Information Portal and National Nodes  
Gateway to Population Health Information. Health Information Portal  
<https://zenodo.org/records/10579394>
- Federated Research Infrastructure and Use Cases  
A federated research infrastructure to boost the reuse of health data in population health research  
<https://zenodo.org/records/10579426>
- Foresighting  
PHIRI Foresight: Modelling & Scenarios  
<https://zenodo.org/records/10579376>
- COVID-19 Health Information System assessments  
[https://www.phiri.eu/sites/phiri.eu/files/2024-02/T3.3\\_COVID-19%20Health%20Information%20System%20Assessment\\_26022024.pdf](https://www.phiri.eu/sites/phiri.eu/files/2024-02/T3.3_COVID-19%20Health%20Information%20System%20Assessment_26022024.pdf)

The final technical report that is published on the [PHIRI website](https://www.phiri.eu) in parallel to this document allows a complete and detailed overview of all achievements.



### III. Continuing the cooperation

Besides the HIP we identified the following main topics for continuation of the PHIRI infrastructure that will be in the focus of our road towards long term sustainability.

#### 1. Data Management

As data users (researchers, innovators, regulators and decision-makers) need high-quality data, PHIRI developed and tested tools to ensure that 1) existing data catalogues on national level (e.g., from sickness funds or mortality statistics) are collected in a common repository following the FAIR (Findable, Accessible, Interoperable, and Reusable) principles and adhere to existing metadata standards such as DCAT, Schema.org, DDI LifeCycle etc., 2) new research outcomes and data sets are added and that 3) a common technical infrastructure and platform to support researchers and advisors to decision-makers to make best use of these data is available.

These tools, i.e. **digital objects** that researchers can download, adapt, and apply cost-free for their own research questions are part of the HIP and are maintained and further developed by the PHIRI collaboration, e.g. via European projects like QUANTUM (HORIZON-HLTH-2023-TOOL-05) or activities related to the upcoming EHDS. These digital objects include [common data models, including synthetic data sets, quality assessment scripts and analytical algorithms](#) and the [PHIRI app](#).

PHIRI develops, implements and deploys a federated research infrastructure (RI) that leverages the reuse of real-world data to answer policy relevant research questions in population health, as has been demonstrated by [four research use cases](#). PHIRI partners are actively involved in the discussions on the proposed **European Health Data Space** (EHDS) to promote better exchange and access to different types of health data for health research and health policy making purposes (secondary use of data). PHIRI as a research infrastructure has a large added value to this data space. It will provide key services, such as federated analysis of sensitive data and real world data in virtual labs and computational environments and metadata as a service; and guidance and best practices for researchers on how to get the most out of the services and tools provided in the EHDS. Furthermore, PHIRI is one of the early adopters that will test the technical services provided by the [EGI-ACE](#)-project which main goal is to implement the compute platform of the European Open Science Cloud. Finally, several PHIRI collaborators play a vital role in the planned Joint Action TEHDAS 2 on preparatory activities for the reuse of data in the EHDS.

## 2. Capacity Building

Another core feature of PHIRI is the [Rapid Exchange Forum](#), that addressed urgent questions and current developments in population health during the COVID-19 pandemic and has developed beyond that. In one hour meetings, that still take place after the end of the project grant, the participants belonging to European public health institutes, Ministries of Health, research institutions and universities as well as EU-level stakeholders answer questions and discuss experiences from their own countries related to population health issues (e.g., the evolution of the MyHealth@EU services or Human Respiratory Syncytial Virus (RSV) induced hospitalisation rates of children) that require cross-country exchange and mutual learning. All results are available for the public [here](#).

There is a huge need to continue the REF or a REF-like structured platform for exchange, underpinned by the fact that also after the end of the project every month a meeting is taking place and that new delegates from the Netherlands and Sweden requested to be part of the REF Network to benefit from the exchange of information and expertise. Also, the ad-hoc question tool is frequently used, and all information is still uploaded by the REF Secretariat at GÖG to the devoted corner on the Health Information Portal.

The PHIRI School of Health Information is a further pillar of capacity building beyond the actual collaboration partners. Starting with the first pre-project session in summer 2020 (see [documents](#)) PHIRI's **European School of Health Information (ESHI)** has organised 15 training activities, involving more than 100 participants and collaborations with more than 21 countries in the project scope, for details see [here](#).

One highlight of ESHI was the online **Spring School 2023** organised by Universidade NOVA de Lisboa, UNL in Portugal. The curriculum on recent health information topics featured 27 speakers from 15 countries and international organisations, like World Health Organisation (WHO) and the European Centre for Disease Control and Prevention (ECDC). Almost 50 participants from 26 European and non-European countries attended and retrieved a certificate. Due the huge success, planning for the Spring School 2024 to be held on five Thursdays in March and April 2024 is ongoing and a small attendance fee will be requested, thus allowing a continuation of the ESHI. This will ensure the training materials available on the portal will continue to expand and remain relevant for its users.

PHIRI partners developed a [compact guide for foresighting](#) and taught it in a webinar series titled 'Develop your PHFS' which resulted in so far 11 country presentations of planned foresight studies from eight EU Member States. More and more countries are integrating foresighting in their national systems, and e.g., also ECDC introduced a new unit on foresighting in 2023.

### 3. Knowledge generation

PHIRI provides the **services and tools** necessary for researchers to link different data sources and to use pan-European data in a GDPR (General Data Protection Regulation) compliant, federated way. By doing so it is important for PHIRI to promote a consistent application of Ethical, Legal, and Social Implications (ELSI) principles within all partner organisations.

PHIRI emphasises **cooperation with fellow researchers and organisations** working in the field of population health also outside the collaboration. Good examples are that the REF has been opened to all interested researchers (since the end of the project representatives of three non-PHIR partners attended meetings) or that the PHIRI Glossary was updated jointly with the [HealthyCloud](#) consortium members.

Caused by the broad scope of activities of the members of the PHIRI collaboration the necessary steps towards sustainability and the resources needed differ considerably. The following documents allow an overview of **sustainability efforts and contributions** in the different work packages and thematic fields:

- Miriam Saso, Nienke Schutte, Petronille Bogaert, Marika Borg, Neville Calleja: **Country one pagers on European countries' health information systems monitoring the wider effects of Covid-19 on population health**  
<https://www.phiri.eu/sites/phiri.eu/files/2023-12/COVID-19%20Health%20Information%20System%20Assessment%20-%20Complete%20V1.pdf>
- Johannes Weiss, Claudia Habl, Anita Gottlob: **Rapid Exchange Forum (REF) Needs assessment summary**  
[https://www.phiri.eu/sites/phiri.eu/files/2023-12/WP8%20M53\\_Needs%20assessment%20summary\\_for\\_SC.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-12/WP8%20M53_Needs%20assessment%20summary_for_SC.pdf)  
<https://zenodo.org/records/10065942>
- Ernest Aigner, Christina Lampl, Andrea E. Schmidt, Willi Haas: **Integrating climate, health, and equity for a climate-resilient Europe**  
[https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4\\_Foresight\\_PolicyBrief\\_Integrating%20climate%2C%20health%2C%20and%20equity%20for%20a%20climate-resilient%20Europe.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4_Foresight_PolicyBrief_Integrating%20climate%2C%20health%2C%20and%20equity%20for%20a%20climate-resilient%20Europe.pdf)  
<https://zenodo.org/records/10559396>
- Mariana Peyroteo, Mélanie Maia, Marilia Silva Paulo, Luís Velez Lapão: **Unlocking the Future of Primary Health Care. The Digital Era Unleashed**  
[https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4\\_Foresight\\_PolicyBrief\\_Unlocking%20the%20future%20of%20primary%20health%20care%20the%20digital%20era%20unleashed.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4_Foresight_PolicyBrief_Unlocking%20the%20future%20of%20primary%20health%20care%20the%20digital%20era%20unleashed.pdf)  
<https://zenodo.org/records/10559435>
- Alexander Grabenhofer-Eggerth, Beate Gruber, Sophie Sagerschnig: **A pandemic's impact on mental health**

[https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4 Foresight PolicyBrief A%20pandemic%27s%20impact%20on%20mental%20health.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4_Foresight_PolicyBrief_A%20pandemic%27s%20impact%20on%20mental%20health.pdf)

<https://zenodo.org/records/10531978>

- Daniela Moye-Holz, Elizabeth N. Mutubuki, Marit de Vries, Henk Hilderink: **Foresight for policymaking. Preparing for challenges and promoting desirable futures**

[https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4 Foresight PolicyBrief Foresight%20for%20policymaking%20preparing%20for%20challenges%20and%20promoting%20desirable%20futures.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-11/WP9.4_Foresight_PolicyBrief_Foresight%20for%20policymaking%20preparing%20for%20challenges%20and%20promoting%20desirable%20futures.pdf)

<https://zenodo.org/records/10556668>

- Luís Velez Lapão, Marília Silva Paulo, Mariana Peyroteo, Johannes Weiss, Claudia Hahl: **Public Health and Social Measures in times of COVID-19 pandemic and beyond. Contributions to the Sustainability Plan**

[https://www.phiri.eu/sites/phiri.eu/files/2023-12/D8.6\\_PHSM%20in%20times%20of%20Covid-19%20pandemic%20and%20beyond\\_20231107.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-12/D8.6_PHSM%20in%20times%20of%20Covid-19%20pandemic%20and%20beyond_20231107.pdf)

<https://zenodo.org/records/10245154>

- Hanna Tolonen, Miriam Saso, Csaba Kiss, Brigid Unim, Luigi Palmieri, Pascal Derycke, Mariana Peyroteo, Luís Velez Lapão, Nienke Schutte: **A sustainability roadmap for the European Health Information Portal.**

<https://zenodo.org/records/10245154>

- Metka Zaletel, Hanna Tolonen: National Nodes. **A sustainability of the structure.**

<https://zenodo.org/records/10245179>

- Francisco Estupiñán-Romero, Javier González-Galindo, Natalia Martínez-Lizaga, Juan González-García, Carlos Tellería-Oriols, Martin Thissen, Enrique Bernal-Delgado: **Report on scalability, sustainability, and rapid cycle analysis requirements.**

[https://www.phiri.eu/sites/phiri.eu/files/2023-12/D6.6\\_report\\_on\\_sustainability\\_scalability\\_rapid\\_cycle\\_requirements Submitted.pdf](https://www.phiri.eu/sites/phiri.eu/files/2023-12/D6.6_report_on_sustainability_scalability_rapid_cycle_requirements_Submitted.pdf)

<https://zenodo.org/records/10579165>

- Henk Hilderink, Elizabeth Mutubuki, Daniela Moye Holz, Marit de Vries, Mariken Tijhuis: **The future of Foresight. Input for the PHIRI sustainability plan.**

<https://zenodo.org/records/10579165>

**All research outcomes**, deliverables developed by the project and the federated technical infrastructure (see [demonstrators](#) for testing) are **available to the public**, either via the project website <https://www.phiri.eu>, the online repository [Zenodo](#) or the [HIP](#).

## 4. Survey on sustainability of PHIRI

### 1. Methodology

An important question to be addressed in the beginning of sustainability planning was, which elements of PHIRI were particularly important for the project partners but also to stakeholders to maintain in the long term.

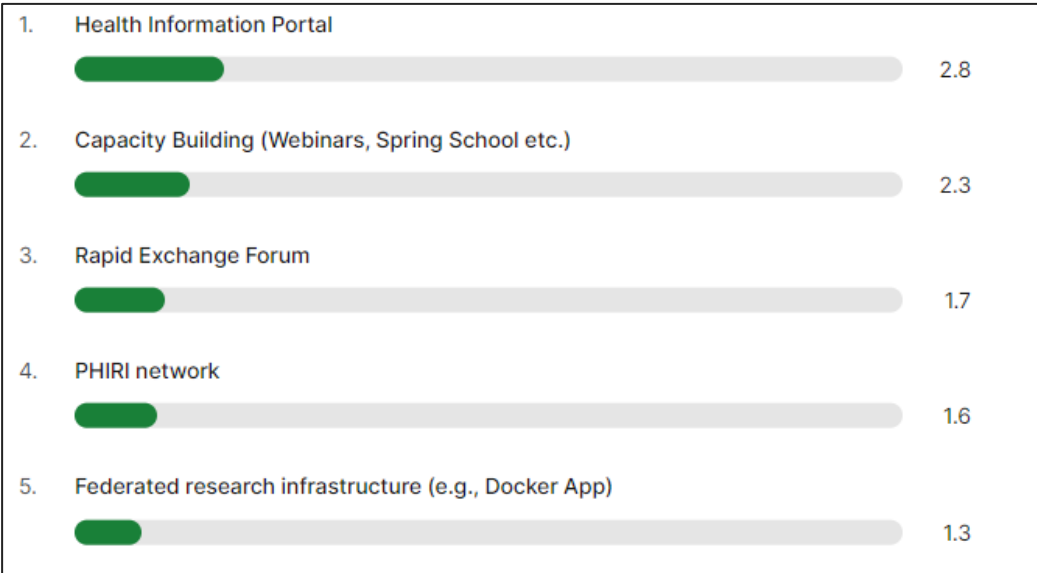
To identify these elements, a ‘PHIRI Survey on Sustainability’ was launched by the Task lead GÖG between 7 June and 16 September 2023. With kind support by Coordination the short survey was distributed per email as broadly as possible - not only among the project members and REF partners, but also stakeholders and newsletter subscribers.

The poll consisted of 4 questions: 2 ranking questions with 14 and 16 preselected topics, the 5 most important of which should be selected, 1 word cloud and 1 free text question with up to 300 characters. The survey was prolonged two times and generated 34 responses in total.

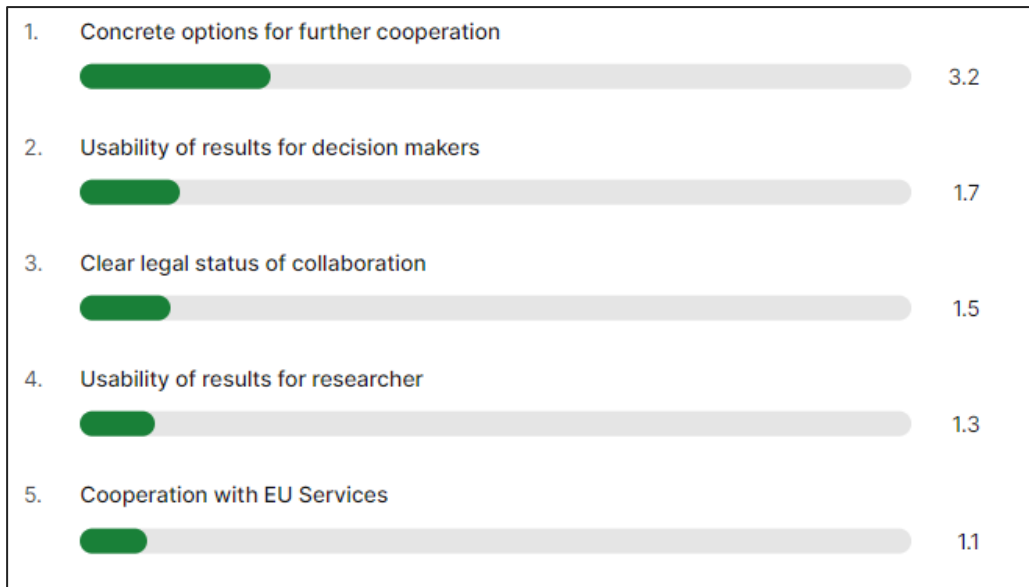
It yielded the following results, which were discussed at the final PHIRI Steering Committee XIII in September 2023.

### 2. Results

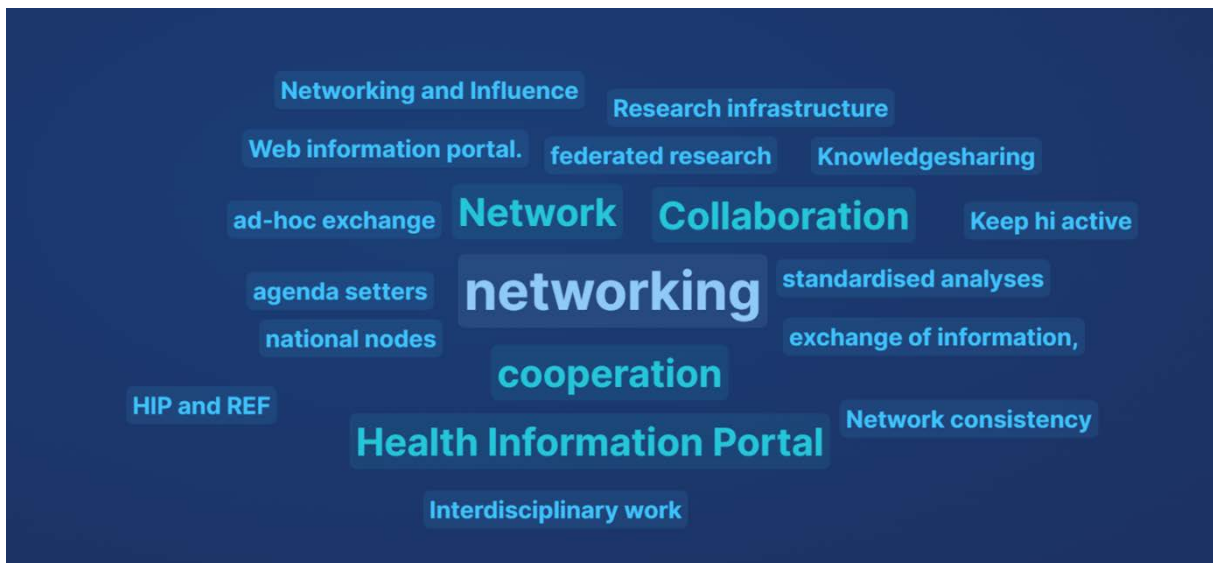
**Question 1:** What did you like best about PHIRI resp. what did you benefit most? Please select and rank 5 topics.



**Question 2:** What should/could be improved? Please select and rank five topics.



**Question 3:** What do you think is PHIRI's biggest value and achievement (please reply in one single word or in one short 3-word sentence)?



The survey showed clearly that PHIRI partners and nodes see the most value in the networking activities and exchange of information followed by the created federated research infrastructure.

In final “open” question, if and how partners would like to continue working together as PHIRI collaboration there was a collective agreement to this idea. The replies included comments such as “Explore EU funding opportunities”, “Does PHIRI need a legal



personality?”, “We could ask for fees”, “We had done research together and will do in future” and “We should lobby to have PHIRI in the Health Programme”. Surprisingly no one relied to mere national funding, e.g. as some of the national nodes will need to prepare and maintain, e.g. the metadata catalogues in the light of the upcoming EHDS regulation anyhow.

## 5. Future organisational and financial management

### 1. Project based-cooperation opportunities

As suggested by partners and following the tradition of the collaboration (see Background section) WP 3 leads explored opportunities of the following EU funding programmes for their suitability of a continuation of PHIRI’s work.

#### **HORIZON – Health Cluster**

Horizon Europe is the EU’s key funding program for research and innovation, with a substantial budget of around EUR 95.5 billion. The programme fosters collaboration, strengthens research and innovation impact and supports the creation and dissemination of excellent knowledge and technologies. The Health Cluster within Horizon Europe aims to advance health research, improve healthcare systems, and enhance public health across the European Union. PHIRI’s objective to strengthen population health research especially in the light of the upcoming EHDS nicely relies to the Programme’s areas such as disease prevention, personalised medicine, digital health, and healthcare innovation.

It is a suitable option as all current partners are eligible for the programme and the current project was funded under HORIZON as well. Funding is usually 100% of the gross salaries of staff and direct cost (e.g., travels) complemented by 25% overheads, which makes it attractive but also very competitive.

The downside is that our topic falls more under the responsibilities of EU’s DG SANTE, whereas HORIZON is managed by RTD. We explored options for complementary funding from SANTE and RTD (instead of sequential funding) but so far failed to identify the way to make it possible. There are several challenges to this, including the variable funding rates, non-coordinated timeline, and the complexity of the legal aspects. There are initiatives at the DG level to synchronize efforts in order to avoid the silo-fication of programmes, we keep a close eye on the evolutions to stay up to date on any funding possibility for our initiative.

Still the project partners made effort to apply in smaller cooperation groups to calls, e.g. HORIZON-HLTH-2023-TOOL-05-0.

## EU partnerships

An interesting arm of EU's HORIZON funding programme are so-called EU partnerships, as they allow the integration of private, also commercial, partners into research projects with the common goal to address pressing challenges through concerted research and innovation initiatives in many thematic fields, among them health and care.

There are basically three types of such partnerships: 1) co-funded, 2) co-programmed and 3) institutionalised partnerships.

The current most interesting partnership programme is the **European Partnership on Transforming Health and Care Systems (THCS)** which e.g., 1) aims to fill knowledge gaps and produce evidence for health system transformation, 2) develop new solutions to support and maintain people's health, 3) strengthen the research and innovation community in health and care systems and 4) establish a platform for scaling up successful innovations across different health systems.

The PHIRI partners will explore opportunities to apply in the next call scheduled for spring 2024.

<https://www.thcspartnership.eu/>

## EU4HEALTH (EU4H) including Health Emergency Preparedness and Response Authority (HERA)

The programme aims to improve health, protect against cross-border health threats, and enhance crisis preparedness thus making HERA a vital element. In the light of the COVID-19 pandemic the budget was increased, making it almost EUR 753 million in 2024 (whole funding period 2021-2027 is EUR 5.3 billion).

The objectives are very broad, e.g., the programme aims to enhance health outcomes, promote well-being, and address health inequalities across the European Union. It shall strengthen health systems, making them more resilient, efficient, and accessible to all citizens. Furthermore, it shall enhance preparedness and response to health emergencies, including pandemics and other health crises and ensure access to medicines and medical devices. EU4H explicitly encourages research, innovation, and collaboration to advance medical knowledge, technologies, and healthcare practices.

In summary, EU4H strives to create a healthier and more resilient Europe by addressing critical health challenges and fostering collaboration among member states.



PHIRI nicely fits into these objectives and partners have been part of current EU4Health projects and have great interest in carrying on with it. Funding is up to 80% of the gross salary of staff plus an 7% overhead allowance which makes it economically less attractive than HORIZON. On the positive side, there are programme strands called “Joint Actions” where the main barrier is that an institution must be nominated by the appropriate national authority to become eligible for partnerships but there is no competition in this segment. So, to convert PHIRI into a Joint Action or to bring in elements of PHIRI’s activities like the metadata catalogues or foresighting into Joint Actions was agreed in the last Steering Committee to be a good way forward.

## **COST Actions**

A COST Action is an interdisciplinary research network that allows researchers, innovators, and public institutions to investigate a topic of their choice for four years. The programme usually does not fund staff resources but covers travels, study visits and all other sort of networking activities but it allows to join existing actions at any time. Thus, it is well suited to explore further options for cooperation of the bodies.

Interested PHIRI partner institutions may apply for a COST action to increase the community of population health research networks and projects (e.g., those funded under HORIZON programme), and e.g. to further develop the HIP to give shape to continuous support to research and policy making.

The following services (work packages in a COST action) were discussed in the Steering Committee:

- Horizon scanning (topics in the pipeline and who is who in terms of research and innovation capacities)
- Cataloguing those digital objects not covered under dataset: for example, training materials and research tools
- HealthData@EU navigation services (legal and ethical counselling, for example)
- Foresight analysis - preparedness for future policy needs
- Training and capacity building
- Playgrounds for the development and implementation of analytical workflows

## **ESFRI (ERIC)**

Another potential, and on the first view obvious funding source, is to establish PHIRI as a formal European Research Infrastructure Consortium, a so-called ERIC. To make this happen the undertaking has to be listed at the European Strategy Forum on Research Infrastructures (ESFRI) Roadmap. Some project partners prepared an application back in September 2020 in the grant preparation phase for PHIRI but failed despite the team haing collected 12 Memorandum of Understandings, 10 letters of

political support and three intentions to finance from national Ministries of Health and/or Science.

Three major barriers hindering success were that the ESFRI roadmap was very full, that the project was considered on the verge between Health and Research and that a legal body would be useful. The latter issue is on the way to being solved and the fact that the project involves Health and Research could be seen as an asset and not a liability after Europe experienced a pandemic.

The consortium is still considering a re-application, but only once the legal body is created and there are clear signals from at least five to seven country representatives in ESFRI.

### **a) *Actual Cooperations of PHIRI partners***

At the time of finalisation of this Deliverable in January 2024, members of the PHIRI consortium are engaged in the following already ongoing or future cooperative activities which are partly funded by EU Programmes like EU4Health including **HERA**, **HORIZON**, **COST** or similar. The selected projects align with PHIRI's commitment to strengthening research-based knowledge and generation of evidence in population health and healthcare system resilience especially in the light of the upcoming EHDS regulation.

#### **QUANTUM**

Overall, QUANTUM (HORIZON-HLTH-2023-TOOL-05-0) aims at providing guidance on a quality and utility label, out of the testing of a data quality, utility and maturity labelling mechanism in a substantive number of data holders. Ideally, this labelling mechanism could be adopted in the HealthData@EU as foreseen in Article 56 in the current legislative European Health Data Space for secondary use proposal.

[www.quantumproject.eu](http://www.quantumproject.eu)

#### **JACARDI - Joint Action on cardiovascular diseases and diabetes**

JACARDI (EU4H-2022-PJ-11) aims to support EU countries to reduce the burden of cardiovascular diseases and diabetes mellitus and related risk factors, both at individual and societal level, while assuring health systems sustainability and equity.

<https://www.sciensano.be/en/press-corner/21-european-countries-unite-eu-joint-action-jacardi-reduce-burden-cardiovascular-diseases-and>

## **UNITED4Surveillance (Union and National Capacity Building for Integrated Surveillance)**

The focus of this Joint Action is integrating existing and new data sources for more comprehensive EU/EEA infectious disease surveillance, prevention and control. In doing so, it will contribute to surveillance capacity-building within Europe and beyond, working to improve global health security.

UNITED4Surveillance will propose a Roadmap to implement integrated surveillance at the European Member State and Union level which will 1) analyse gaps and needs, 2) integrate national and international policies, 3) identify promising approaches and conduct pilots, 4) disseminate best practices and 5) share experiences and knowledge through capacity-building.

<https://united4surveillance.eu/>

## **EU-HIP - EU interoperability with HERA's IT platform**

The EU-HIP program develops new IT systems as well as strengthens and enhances existing national IT systems for improving health threat assessment in European countries. This is in parallel with the objective of interoperability of EU-national IT systems and the new HERA's IT platform for intelligence gathering in the field of medical countermeasures.

<https://zenodo.org/communities/eu-hip/?q=&l=list&p=1&s=10&sort=newest>

## **HealthData@EU Pilot**

This project intends to build a pilot version of the European Health Data Space (EHDS) infrastructure for the secondary use of health data which will serve research, innovation, policy making and regulatory purposes: The project will connect data platforms in a network infrastructure and develop services supporting the user journey for research projects using health data from various EU Member States. It will also provide guidelines for data standards, data quality, data security and data transfer. The HIP catalogue of datasets can feed in to the planned HealthData@EU cataloguing mechanism.

<https://ehds2pilot.eu/>

## **BY-COVID**

BeYond-COVID (BY-COVID) project, funded under the EU4Health Programme, is a significant initiative aimed at making infectious disease data, including COVID-19, openly accessible to scientists, medical professionals, and policymakers. A strong emphasis is placed on mobilizing raw viral sequences to identify and monitor the spread of SARS-CoV-2 variants. PHIRI expertise is especially helpful in two fields:

connecting data (i.e., linking infectious disease data, including clinical and virus data) and standardising data, namely providing good practices and standards for data description as learned in setting up the federated research infrastructure.

<https://by-covid.org/>

### **Joint Action Xt-EHR: Extended EHR@EU Data Space for Primary Use**

This EU4Health Action enhances cooperation among EU member states regarding the interoperability and exchange of healthcare data. It will contribute to improved primary use of electronic health data and empowers individuals to control their health data.

### **JAPreventNCD: Cancer and other Non-communicable-diseases (NCDs) prevention – action on health determinants**

NCDs like cancer constitute two-thirds of the disease burden in Europe, with significant variations among different population groups based on factors like socioeconomic status, geographical area, and gender.

With over 90 million Euro this Joint Action is one of the biggest ever in the history of EU Health Programmes. It shall investigate the prevention of cancer and other non-communicable diseases by influencing risk factors like smoking habits or nutrition of European citizen. A significant aspect is the rigorous evaluation of existing practices to assist authorities in prioritising the most effective prevention strategies.

Several PHIRI members are engaged in this Joint Action and will make use of established tools such as foresighting or will make use of the Rapid exchange forum.

#### ***b) Planned cooperations***

PHIRI partners are involved in the following project activities which are in a proposal or preparation phase:

#### **EUCanScreen – Joint Action on Implementation of cancer screening programmes**

This Action (EU4H-2023-JA-06) is one of several initiatives launched for the implementation of Europe's Beating Cancer Plan taking the latest EU recommendations on cancer screening of September 2022 (<https://cancer-screening-and-care.jrc.ec.europa.eu/en>) as important population health measure into account.

#### **Joint Action for secondary data use under the EHDS**

The main aim of this planned joint action (EU4H-2023-JA-03-IBA) is to prepare ground for harmonised implementation of the EHDS on secondary use of health data and develop collaboration between all key stakeholders. It will provide guidelines and

technical specifications which will guide Member States and the Commission in developing solutions and operationalising cross-border collaboration.

## European Partnership on Transforming Health and Care Systems (THCS)

The upcoming Call for proposals, scheduled for end February 2024 will aim to support the implementation of innovative person-centred health and care models addressing prevention strategies, with the key help of existing IT and digital technologies and services. As this topic is very much into the core of PHIR we will explore opportunities to apply.

### 2. Creating a legal entity

Already in the proposal phase, the PHIRI consortium decided to explore options to ensure the sustainability of PHIRI and the created infrastructure. After careful analysis that included the exchange with similar structures at the EU level (e.g., Euro-Peristat or the European Observatory on Health Systems and Policies) the PHIRI partners concluded that setting up their own legal structure could be an important step in building a sustainable future for PHIRI.

Setting up a legal structure allows

- to set up a formal governance and management structures,
- to develop of services for users and cost models,
- to facilitate requests for EU-funding (DG-Research, DG Connect, DG Sante, ...) as an official consortium,
- to support the (re)application to the ESFRI roadmap, if decided it is still an option of added value,
- to receive funding from national and EU programmes not only on project basis but from direct management funds,
- to establish collaborative agreements or partnerships with other initiatives, research infrastructures and organisations in the field and
- to carry out PHIRI core activities jointly in future.

PHIRI opted for an international non-profit organisation under the Belgian law<sup>2</sup>. The basic characteristics of the International non-profit organisation in Belgium are 1) activities of the organisations have an international character; 2) there will be a royal decree recognising the entity; 3) there is some flexibility regarding internal organisation; and 4) there is a wider choice for the form of general assembly and internal governance.

The aim of the international non-profit organisation will be to catalogue and curate knowledge generated by a critical and growing mass of European researchers and

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 <sup>2</sup> <https://uia.org/belgianlaw>  
Population Health Information  
Research Infrastructure

their international networks, and to facilitate and stimulate the population health research across Europe. The organisation works towards facilitating the reuse of population health data and reducing the health information inequity across Europe. The association ensures research is interoperable and in line with ethical and legal requirements.

Members can be research organisations (governmental and non-governmental), population health institutes, and data access providers under the condition of being qualified and able to provide either access to relevant data and/or relevant expertise for population health and health data research. Sciensano, the Belgian-based coordinator of PHIRI is currently working on drafting the statutes and the bylaws.

This legal entity allows for the set-up of a PHIRI secretariat, that is the main point of contact, oversees the communication and outreach, scanning the funding schemes and maintaining a ready-to-apply consortium. In addition, it will continue the PHIRI newsletters, X (previously Twitter), LinkedIn etc.

As PHIRI has presented itself as a trustworthy and strong brand, we will choose 'PHIRI' as name for the legal entity. Partners who want to be part must sign joint articles of association (currently under revision of Sciensano's legal team) and to contribute to the funding of the body with in-kind or cash contributions.

### **3. Membership fee**

Linked to the above-mentioned planned PHIRI legal body, the collaboration discussed the option to collect an annual fee from the partners to stay operational. However, aside from potential initial payments to create the legal body, no partner was able to secure funds to contribute cash toward the sustainability of the undertaking.

Nonetheless, some participants volunteered to continue selected elements of PHIRI by in-kind contributions: Sciensano (Belgium) is maintaining the technical functionality of both the HIP and the project website, while also working on the foundation of the legal body. GÖG (Austria) is still running the REF and hosting the Secretariat. UNL (Portugal) is organising the annual Spring School on Health Information. DoH Malta remains active in preparedness planning and keeping an ear to the current policy developments. THL (Finland), IACS (Spain), RKI (Germany) and NIJZ (Slovenia) keep monitoring and maintaining the data catalogues and inputs on the HIP and the federated infrastructure.

### **4. Other relevant activities**

#### **a) Cooperation with WHO**

PHIRI also commenced a successful cooperation with WHO, especially in the field of Infodemics and overall preparedness planning. For instance, our Portuguese task

leader Prof. Luís Velez Lapão was appointed member of the Technical Advisory Group on the development of the Strategy and Action Plan on health emergency preparedness, response, and resilience (Preparedness 2.0) in the WHO European Region. The aim of the Preparedness 2.0 TAG is to provide expert recommendations to the Member States in the Region in the development of a new regional strategy and action plan on the strengthening of health emergency preparedness, response, and resilience for the 74th session of the Regional Committee in 2024. Members of this network (e.g., Dr. Gerald Rockenschaub) consequently will be lecturing in the upcoming spring school.

PHIRI and WHO also joined efforts in tackling infodemics, i.e. the overabundance of information (some accurate and some not) that occurred during the pandemic and is a growing problem for all fields of health care. It spreads between humans in a similar manner to an epidemic, via digital and physical information systems. There have been several workshops (e.g., at the European Public Health (EPH) Conference) or Rapid Exchange Fora on this together and the cooperation will be continued, e.g. in the upcoming PHIRI spring school.

### ***b) Cooperation via European Public Health Alliance (EUPHA)***

Already during the project PHIRI was actively engaged with the European Public Health Alliance (EUPHA), given that many PHIRI partners are members. PHIRI partners organised numerous sessions, pre-conferences, and workshops, gave speeches and pitches and presented posters at the annual EPH Conference of EUPHA in autumn but also during the annual European Public Health week in spring.

In the future, PHIRI will continue to be active on the EPH conference and intends to make use of the fact that four of the current 26 sections of the European Public Health Alliance (EUPHA) are headed by PHIRI partner institutions.

- Foresight
- Global health – initiative
- Public health monitoring and reporting and
- Digital health

There are plans at EUPHA to set up an exchange platform of public health researchers and public bodies that has a strong potential for synergies with the REF. The WP 3 team intends to set up a call with the newly appointed EUPHA Executive Director to explore and materialise these synergies.

## **IV. Conclusions**

The PHIRI collaboration created a base for interdisciplinary and decision-making oriented population health research through mutual exchange, use of up-to-date



technology and modern forms of knowledge presentation and dissemination. The PHIRI partners, potentially under the umbrella of an own legal body as explained in section 5.2 will continue to facilitate data collection in population health, will bring together research networks in Europe, link researchers, policy advisors and decision maker and will ensure that generated tools and knowledge are robust and accessible.

The implementation of PHIRI opens promising opportunities for researcher to develop effective public health and social measures and actions to positively influence population health in Europe. It supports accessibility to health data and information at national and international level, facilitates close monitoring of population health trends, particularly by offering a federated research infrastructure and enables the access to useful data and information that is not accessible via already established tools (e.g., PubMed or ECDC databases), fully compliant with and complementary to the European Health Data Space.

A small working group will be established from PHIRI partners willing to continue to follow-up the progress of the Health Information Portal and to screen the potential funding sources based on this Sustainability Plan.