



# PHIRI

Population Health Information  
Research Infrastructure

# Final report

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Miriam Saso

Nienke Schutte

Barthélémy Moreau de Lizoreux

PHIRI Steering Committee Members



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## I. Disclaimer

Disclaimer excluding Agency and Commission responsibility.

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## II. Introduction

The Final Report (Deliverable 1.3) describes the achievements of PHIRI, the [Population Health Information Research Infrastructure](#), and it provides an overview of the financial statements of the different partners who participated in the project for the period 01/05/2022 to 31/10/2023.

This report takes into consideration the feedback received in the Mid-term PHIRI review meeting (2nd of September 2022) and the written evaluation of the reviewer Guido Bertolini.

## III. Summary of the context and overall objectives of the project

Health is a cross-border issue, recently demonstrated by the COVID-19 public health crisis. A structured European mechanism for exchange to organize and share information for critical population health issues is urgently needed, especially in population health. [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 the identification of data sources, access, risk setting and outcomes following ELSI (Ethical, Legal and Societal Implications) and FAIR (Findable, Accessible, Interoperable and Reusable) principles. PHIRI has the following objectives:

1. Provide a [Health Information Portal](#) with FAIR catalogues on health and healthcare data for structured information exchange across European countries. 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.

2. Provide structured exchange between countries on population health best practices and expertise. PHIRI shares public health and clinical management information and methodologies identified and allows researchers and policy-makers to provide relevant and evidence-based information ready for use in research and decision-making processes.
3. Promote interoperability and tackle health information inequalities by providing capacity building and training.

Over the project's duration, PHIRI achieved significant milestones, including the development of a Health Information Portal to enhance accessibility to population health data and expertise throughout Europe, established and sustained a [Rapid Exchange Forum](#) to promptly address urgent public health inquiries, conducted comprehensive COVID-19 health information systems assessments, performed multiple literature reviews screening over 10000 abstracts, created a federated research infrastructure to tackle diverse use cases utilizing data from various European countries and sources, supported countries to perform foresight studies, and fostered capacity building on these topics for researchers across Europe.

#### **IV. Work performed from the beginning of the project to the end of the period covered by the report and main results achieved so far**

PHIRI launched its Health Information Portal in May 2021: a one-stop-shop facilitating access to population health and health care data, information and expertise across Europe. For the first time, catalogues of population health data sources from national and international organizations (350+), health information projects within countries and across Europe (170+), training materials (190+) and research networks (15) are findable through one single Portal. PHIRI maintains a strong network of National Nodes (27 and growing): organisational entities that function as a national liaison and bring together relevant national stakeholders in the country in a systematic way.

PHIRI adopted a federated architecture, that is piloted by 4 research use cases of immediate relevance on COVID-19 impacts (on vulnerable populations, on perinatal health, on mental health and delayed cancer care). In 20+ datahubs, data was mobilized and analysed in a distributed manner. The same methodology has now been successfully adopted in other projects such as [BY-COVID](#).

PHIRI developed a consolidated framework to assess the direct and indirect impacts of COVID-19 on population wellbeing, morbidity and mortality. Over 10.000 abstracts were scanned and indicators extracted.

PHIRI's Rapid Exchange Forum offers a structured and highly needed platform for regular quick exchange between countries, policy advisors, commission services and researchers in the joint efforts to manage the COVID-19 pandemic. Until the end of the project, almost 60 bi-weekly meetings have been organized and 180+ urgent

research and policy questions answered. Such meetings are now continuing on a monthly basis after the ending of the project.

PHIRI supported European countries in developing scenarios to gain insights in possible future health impacts of the COVID-19 outbreak for national situations. After an advanced course, 8 countries performed their own foresight study, supported by PHIRI experts.

PHIRI reached out to the diverse stakeholders in the health data field, by organizing several inclusive and targeted stakeholder meetings, discussions and dialogues.

PHIRI mapped the health information systems in 8 European countries that monitor the effects of COVID-19 on population health through virtual country visits.

PHIRI organized trainings and workshops to strengthen the public health workforce in Europe and overcome health information inequalities and shared best practices regarding infodemic management.

PHIRI established an External Scientific Advisory Board: a cross-domain group of independent scientific experts that provides advice on several issues (quality of deliverables, ethical issues, direction of the project, corrective measures etc.).

PHIRI is 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.

PHIRI is actively involved in the discussions on the 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).

## **V. Progress beyond the state of the art, expected results until the end of the project and potential impacts**

The Coordination Team (WP1) continued to ensure the smooth running of the project covering administrative and financial aspects of the project.

The Communication Team (WP2) strengthened dissemination and engagement with key stakeholders to amplify the reach and impact of the PHIRI-outputs.

The Outreach and Sustainability Team (WP3) performed additional COVID-19 Health Information System Assessments. PHIRI is actively investigating routes for sustainability to ensure the work performed within the project will be integrated in a more permanent population health research infrastructure.

The Health Information Portal Team (WP4) continued the enrichment and standardization of the information provided on the Portal to further facilitate the use and access of population health information for researchers and policy makers across Europe.

The Team working on research methodologies to assess the impact of COVID-19 (WP5) completed the screening of the identified papers for systematic reviews contributing to the understanding of the impact of COVID-19 on population wellbeing and health.

The research use cases and the PHIRI research infrastructure Teams (WP6-7) published the use case results with additional data from the PHIRI partners contributing to the building of a federated research infrastructure for rapid policy response.

The Rapid Exchange Forum Team (WP8) continued to host meetings to help tackling emerging public health research and policy questions in a fast and effective manner. The Foresight: Modelling and Scenarios Team (WP9) hosted policy workshops with key experts in the field and policy makers and supported researchers across Europe in performing foresight studies in their own countries.

Finally, PHIRI prepared 11 scientific publications that will be part of a special issue of the European Journal of Public Health to be published early 2024.

## VI. Explanation of the work carried out by the beneficiaries and overview of the progress

### A. Objectives

PHIRI, the [Population Health Information Research Infrastructure](#), has the following objectives:

1. To provide a [Health Information Portal](#) with FAIR catalogues on health and health care data for structured information exchange across European countries. It facilitates access to and use of relevant population health (health status and determinants of health) and care data provided by European countries' public health bodies represented in the PHIRI consortium and beyond. It provides the services and tools necessary for researchers to link different data sources and to use Pan-European data in a GDPR compliant, federated way.
2. To provide [structured exchange between countries on COVID-19 best practices and expertise](#). PHIRI shares public health and clinical management information and methodologies identified at national and international level. It allows researchers to provide relevant and evidence-based information ready for use in research, and decision-making processes by citizens, clinicians, public health practitioners and policy makers. To avoid duplication of work, PHIRI regularly organizes meetings to exchange expertise and information with European projects, (inter)national organizations and other key health stakeholders in the field (e.g. [Rapid Exchange Forum \(REF\) – Special Edition](#)).

3. To promote interoperability and tackle health information inequalities. PHIRI supports researchers and public health bodies to research queries in FAIR and ELSI compliant manners. It provides [capacity building for management of 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.

While initially its work was focused on COVID-19, PHIRI soon expanded beyond it, providing support and performing research on multiple urgent public health topics.

### **Objective One**

PHIRI has launched its [Health Information Portal](#) in May 2021. Since the mid-term report of the project, the content and the visibility of the Portal have increased greatly. In addition to the metadata catalogues of population health data sources from national and international organisations (now containing 350+), health information projects within countries and across Europe (170+) and training material and courses (190+) and research networks (15), the Portal hosts a new section dedicated to the services PHIRI can offer as a research infrastructure. These include: material on [federated demonstrators](#), [health information system assessments](#) and an upcoming ELSI (Ethical, Legal and Social Implication) toolbox. Many of the partners, across almost all PHIRI Work Packages (WP), continue to be actively involved in all the steps related to the design, development, promotion and maintenance of the Health Information Portal.

The PHIRI Technical working group, started in January 2021 to discuss the implementation of new developments on the Portal, provides feedback to the ICT team and discusses the next steps for improving the Portal, continued to meet on a weekly base until the end of the project. Currently, the working group meets once a month on a voluntary base to maintain and update the content of the Portal. All the WPs remained active throughout the project for the development of different sections of the Portal and for the provision of new content. Finally, several meetings have been organised to promote the Health Information Portal to its potential users and increase collaboration with other key organisations in the field (e.g. WHO European Observatory, ECDC, European Commission).

Furthermore, another important pillar of the research infrastructure is the federated architecture. This architecture is supported by a containerised reproducible solution for data analysis to be deployed on premise by each participant partner, the PHIRI APP. This solution (a Docker image) constitutes a prototype that includes all the pipeline components required to carry out the research queries in WP6 ([Research Use Cases measuring the impact of COVID-19 on population health](#)) and the demonstration pilot in order for the federated architecture in PHIRI to be sustainable and accommodate for future research questions. PHIRI investigated upgrading options for this PHIRI federated analysis approach, including lessons learned from the



use cases, in-depth analysis of the IT requirements of the favoured options in order to formulate one vision towards the development of a research infrastructure for population health research in the European health data sharing ecosystem.

### **Objective two**

Since the start of the project, PHIRI organises biweekly the [PHIRI Rapid Exchange Forum](#). In this one-hour meeting, 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 urgent policy and research questions related to the COVID-19 pandemic and beyond. The PHIRI partners actively participated in the meetings by providing valuable information on their own countries and by involving different experts across key national and international health players depending on the topic discussed. In the second part of the project, 24 REF meetings have taken place and more than 100 urgent policy & research questions have been answered. A lot of attention has been given to the promotion of the Rapid Exchange Forum outside PHIRI by organising meetings with external stakeholders, by hosting promotional events, by dedicating a page to the Rapid Exchange Forum on the Health Information Portal and by promoting its open events on social media (e.g. [Twitter](#)) and on the [PHIRI website](#).

To contribute further to the Rapid Exchange Forum, PHIRI continues to maintain a strong network of [National Nodes](#) (27 nodes and growing): national organisational entities, often linked to a national institution or governmental unit that function as a national liaison and bring together relevant national stakeholders in the country in a systematic way.

Furthermore, PHIRI organised anniversary events and stakeholders' events to bring together, interact or exchange with relevant national and international players while promoting active discussions around themes that are at the core of the PHIRI project such as metadata catalogues, the federated infrastructure, crisis preparedness, foresight and research methodologies. Finally, to avoid duplication of work, PHIRI organized additional meetings to exchange expertise and information with international organisations (e.g. [Rapid Exchange Forum \(REF\) – Special Edition](#)) to shed some light on the international activities and expert groups that are already in place or that have been set up during the pandemic to exchange information on research and policy questions that require rapid action.

### **Objective three**

PHIRI developed a vast variety of [capacity building activities](#) to decrease health information inequalities targeting the PHIRI partners and beyond. One of the key activities performed was the Spring School on Health Information, featuring lectures from different public health institutes in Europe, encompassing a vast range of topics from data collection methods to data analysis, interoperability and GDPR insights. Furthermore, PHIRI concluded the [COVID-19 Health Information System](#)



[assessments in 8 European countries](#). These assessments aim to identify the strengths and weaknesses of the different data flows across the health information system, whilst monitoring broader COVID-19 effects. They provided opportunities for other countries to learn from the experiences and build on them when assessing own health information data flows, and contribute to capacity building across Europe, which in turn can contribute towards reducing health information inequalities within and between countries. Finally, these assessments allowed the formulation of key recommendations for resilient health information systems across Europe, increasing the countries' preparedness for future crises.

As mentioned by the reviewer "The project was managed according to the planned actions. Appreciably, more activities were carried out than initially envisaged, following the needs of some target groups". The PHIRI partners have been working together since 2015 with the start of [BRIDGE Health](#), followed by the [Inf-Act Joint Action](#) and PHIRI, and they are deeply committed in the work performed in the project. This is showcased by all the extra activities they engaged themselves with to achieve the objectives of the project.

## B. Explanation of the work carried out per WP

### 1. Work Package 1

The aim of [Work Package 1 \(Coordination and Management\)](#) is to efficiently manage the project and to systematically monitor its activities in order to support the construction of the Population Health Information Research Infrastructure (PHIRI). More specifically, within WP1 the following actions were taken in the second part of the project:

- To facilitate and ensure convergence between WPs in the roll out of PHIRI's activities, six additional [Steering Committee](#) meetings were organised to discuss the achievements of the project, the planned activities and the strategic direction of PHIRI. To increase exchange between the WPs, the frequency of the Steering Committee meetings was kept to around every three months instead of every six. Additionally, one [General Assembly](#) has been organised with all Consortium Partners to inform them about the different financial reports necessary to be delivered and updates of the project.
- To support consortium networking among (research) institutions, research networks and international organisations, multiple meetings have been organised with the specific WPs and the interested stakeholders.
- To increase the quality of the outputs produced by the project, an [External Scientific Advisory Board](#) (ESAB) composed by the following experts Martin McKee (London School of Hygiene & Tropical Medicine); Louise Potvin (University of Montréal); Howard Needham (European Centre for Disease Prevention and Control) and Christian Wimmer (European Commission - HERA) was appointed.

The PHIRI coordination team continued to meet with the members of the ESAB formally and informally.

- To further increase the quality of the outputs produced within the project, a peer-review system in which all the deliverables and (almost all) milestones produced in one WP are reviewed by other partners in another WP continued to be successfully implemented within the project. All PHIRI deliverables were made publicly available on the [PHIRI website](#).
- As the PHIRI consortium is composed of 40 partners across 31 countries, a lot of time had to be spent on collecting and organising all the information from the different partners for the writing and finalisation of the Consortium Agreement and final report.

This was achieved through a strong collaboration between all the PHIRI partners and coordinated by Sciensano. The partners actively contributed to the smooth running of the project by organising meetings within their WPs, by reviewing other partners' work and by complying to the Sciensano Coordination team's requests.

## 2. Work package 2

The aim of [WP2 \(Communication and Portal Development\)](#) is to establish and implement effective communication channels within and outside PHIRI to ensure that information is available to the Consortium Partners, population health and COVID-19 research networks, relevant stakeholders in European countries, international organisations and the general public. The following goals have been achieved:

- A visual identity was established at the beginning of the project and maintained through its duration. This includes the selection of a recognizable logo and colour scheme (via a subcontract) and the development of multiple and new templates for presentations, reports, email signatures, meetings agendas, meetings minutes and all the other outputs of the project. The active engagement of PHIRI on social media, online and in person events and the consistent use of its visual identity made the PHIRI logo and its work more and more recognisable over time.
- The PHIRI website was established at [www.phiri.eu](http://www.phiri.eu) and it continued to be updated and managed in the second part of the project to ensure all the events and content produced by PHIRI would be easily findable and accessible by the visitors.
- An internal workspace (SharePoint) has been opened and updated. Such platform allowed all the PHIRI partners to safely share and work together on PHIRI documents.
- A [communication and dissemination strategy](#) has been elaborated (with subcontracted support) and updated throughout the project to remain relevant.
- Several videos have been made and published:
  - [PHIRI introduction video](#) (subcontract)

- PHIRI anniversary and outcomes videos ([PHIRI achievements #PHIRI3years anniversary 22.09.2023](#); [PHIRI 2 Years anniversary - Project's latest outcomes](#); [PHIRI mid project achievements](#))
- Additional activities have been conducted on infodemic management in the second part of the project:
  - [Round table: Experiences on infodemic management in public health authorities in Europe and internationally - European Public Health Conference, 12th November 2022](#)
  - [Oral presentations: Health information and infodemic management - PHIRI Rapid Exchange Forum \(REF\): A key tool for cross-country exchange in times of crisis - European Public Health Conference, 12th November 2022](#)
  - [Webinar - The change in demand and consumption of health information - 27th January 2023](#)
- Social media accounts have been created, managed and maintained throughout the life course of the project. Currently, [Twitter/X](#) counts 675 followers and 1,167 posts and [LinkedIn](#) 460 relations
- Between, May 2022 and October 2023, [13 newsletters](#) were prepared and sent out to 707 subscribers.
- The WP supported the organisation and participation of PHIRI in more than 83 events (workshops, webinars, trainings, conferences...).
- The team supported of all the PHIRI partners in the creation and publications of infographics, deliverables, one-pagers, reports, scientific posters, promotion material for social medias, web and printed flyers and brochures specific to the different outcomes of the PHIRI WPs.
- Maintenance (Sciensano ICT) and promotion of the <https://www.healthinformationportal.eu/> which has reached its monthly record in terms of visitors in November 2023: 2594.

This was achieved through a strong collaboration between all the PHIRI partners and coordinated by Sciensano. The partners actively contributed to the activities in this WP by providing valuable content to be promoted throughout all the PHIRI channels i.e. social media platform, newsletters, websites and public events.

### 3. Work Package 3

The aim of [WP3 \(Outreach, Engagement and Sustainability\)](#) is to reach and engage key research infrastructures, stakeholders at national and international level to ensure the sustainability of the project's actions. More specifically, within WP3 the following actions were taken in the second part of the project:

- To have a comprehensive view of the developments and state of play of health information systems that monitor the wider effects of COVID-19 on population health at national level and international level, [COVID-19 Health Information System assessments](#) were performed in 3 additional countries interviewing more

than 30 experts across Netherlands, Hungary and Belgium. The results of such activities were presented at:

- the Special Committee on the COVID-19 pandemic (COVI) of the European Parliament,
  - the World Congress of Public Health 2023,
  - the European Public Conference in 2022 and 2023 and
  - at one of the PHIRI Rapid Exchange Forum – Special Edition.
  - Additionally, one publication on the findings titled “COVID-19 health information system assessments in eight European countries: identified gaps, best practices and recommendations” is ready to be published at the European Journal of Public Health.
- Additional bilateral meetings have been organised with international stakeholders and other European projects to increase PHIRI’s engagement with other key health players in the field.
  - 2 additional [Rapid Exchange Forum \(REF\) – Special Edition](#) have been organised where key guests of international organisations laid out the main COVID-19 activities and boards/expert groups performed by their organisations.
  - Contributions to several international conferences and support of consortium members when submitting abstracts for presentations on such conferences, such as the European Public Health Conference 2022 and 2023 and the World Congress of Public Health 2023.
  - To investigate routes for economic sustainability, brainstorming and meetings were organised in the second part of the project to discuss with the different WPs effective ways to increase the reach and sustainability of the project. A working group focused on the sustainability of PHIRI continued to meet through the project to bring forward the work to obtain the status of iVZW (Belgian international non-profit association). As one of the key deliverables of the project, a [sustainability plan](#) was developed delineating the services PHIRI could offer as a research infrastructure beyond its current financial period.
  - PHIRI and multiple of its partners continued to be involved in other EU initiatives such as [EU-HIP, BY-COVID, HealthyCloud, unCoVer, TEHDAS, ELIXIR, EGI ACE, HealthData@EU Pilot](#) and the upcoming QUANTUM to avoid duplication of work and share expertise on e.g. innovative solutions for federated research.

This was achieved through a strong collaboration between all the PHIRI partners and coordinated by Sciensano. The partners actively contributed to the activities in this WP by promoting, identifying, contacting and organising the COVID-19 health information system assessments in multiple countries, by identifying key stakeholders relevant for the work performed within WP3 and by brainstorming together on potential routes of sustainability for the project. The colleagues from GÖG took the lead and brought forward the work related to the PHIRI Sustainability plan.

## 4. Work Package 4

The aim of [WP4 \(Health Information Portal\)](#) was to build the Health Information Portal on health and health care data to support structured information exchange between European countries, to promote and coordinate the sustainable network of national nodes, to prepare an overview of population health studies and capacity building activities in European countries and to prepare guidelines and recommendations for legal and ethical issues. More specifically, within WP4 the following actions were taken:

- The Health Information Portal was established at <https://www.healthinformationportal.eu/> following the FAIR (findable, accessible, interoperable and reusable) principles and actively maintained in the second part of the project:
  - Metadata catalogues for health data, population health studies (national and international), publications, and capacity building and training activities were developed and maintained on the Health Information Portal.
  - For each catalogue, a metadata template was developed to organise and describe the information available in the different European countries in a standardized format. These metadata catalogues followed existing metadata standards (DDI Lifecycle, DCAT-AP, Dublin core). In the second part of the project, small adaptations were made based on the feedback of the users.
  - Work is ongoing to align the current data sources metadata template to the upcoming Health DCAT-AP metadata standard in collaboration with the EHDS-2 Pilot.
  - Schema.org was implemented on additional pages of the Portal further enhancing the machine readability and findability of the materials.
  - The [PHIRI National Nodes](#) continued to support in the provision of information to the Portal through these metadata templates.
  - Regular Questions & Answers meetings continued to be organised to receive feedback on the developments of the Portal and provide support to the users. In combination with the weekly internal meetings for developing the Health Information Portal, a set of tasks were developed and communicated to the ICT team to improve further the Portal (further implementation of metadata standards such as [Schema.org](#) and [DCAT](#), export function of metadata records, more advanced search functions, provision of an API for the Portal for sharing information, etc.).
  - The users of the Health Information Portal continued to be monitored through analytics tools.
- Promote and coordinate the sustainable network of national nodes:
  - In the second part of the project, 2 National Nodes meetings were organised to increase their involvement in the project, to keep them informed on the

PHIRI developments and discuss relevant topics on which cooperation at the European level is key. In the life course of the PHIRI, the metadata for National Nodes has been developing and widening; therefore, National Nodes had to add some additional information on their activities and on data sources. This was communicated either in the meetings or via e-mail messages.

- The catalogue of National Nodes was prepared to inform all the National Nodes about the structure of necessary information and shortages of information in some parts, namely a few countries with missing information.
- [Up-to-date information on National Nodes](#) was maintained and published in the Health Information Portal.
- The [sustainability document for National Nodes](#) was prepared to expose forerunners with excellent solutions in organisation of National Nodes and to describe the necessary steps to follow the forerunners.
- Prepare an overview of COVID-19 population health studies in European countries:
  - A review (literature and web) on population health studies on COVID-19 was conducted excluding clinical trials and surveillance systems which have already been summarised elsewhere. Originally, the plan was to upload this information on the Portal in a searchable format using one of the metadata templates. Toward the end of the project, when the review was ready, it was thought that this type of information would become out of date fast and therefore, it might not be suitable for the Health Information Portal. Results were then published as a WP4 milestone on the PHIRI website.
  - As part of the National Node description, countries have also listed their national projects on population health. This information can be found through each National Node under tab 'National projects'.
- Preparation of an overview of capacity building activities in European countries:
  - A section on [capacity building activities](#) was established on the Portal. This section has three parts: 1) Activity catalogue, 2) PHIRI School on Health Information, and 3) Upcoming events.
  - A web search was conducted regularly to population activity catalogue and list upcoming events which now contains more than 190 activities.
  - PHIRI School on Health Information is a collection of training events organized by different WPs during the PHIRI to enhance national capacities on infodemic management, organization of foresight studies, conducting peer review studies, burden of diseases topic etc.
- Preparation of guidelines and recommendations for legal and ethical issues
  - An [ELSI \(Ethical, Legal, and Social Issues\) Toolbox](#) was developed to guide researchers on existing practices and guidelines on ethical and legal aspects of handling and exchanging health information. The Toolbox was built based on outcomes from studies and reports produced under grant and



service contracts with CHAFEA and DG SANTE regarding possible differences between Member States' rules governing processing of health data and identifying elements (e.g. through code of conduct) that might affect the cross-border exchange of health data in the EU.

- A survey among WP6 partners who conducted Use Cases was conducted to collect more detailed information about national regulations, practices and experiences on use and sharing of health data. In total of 12 countries responded to the survey and results are published as part of the ELSI Toolbox on the PHIRI website. This is being achieved through a strong collaboration between all the PHIRI partners and coordinated by THL and co-coordination by NIJZ.
- Presentations and publications about WP4 in May 2022-November 2023:
  - EHMA Conference, Brussels, Belgium, June 2022: Oral presentation on building joint platform
  - 54th days of preventive medicine – International Congress – Serbia, 27-30 September 2022: The Health Information Portal for better health research and policy decisions
  - Poster on the 2<sup>nd</sup> Annual Summit of the Comprehensive Health Research Centre, Évora, Portugal: Peyroteo, M., Paulo, M. S., & Lapão, L. V. (2022). PHIRI: Contributing for the deployment of the European Health Information Portal in time of COVID-19. 2nd Annual Summit of the Comprehensive Health Research Center, Évora, Portugal. Zenodo. <https://doi.org/10.5281/zenodo.6642586>
  - EUPHA Public Health Week, May 2022: Portal used as an example
  - ELIXIR Belgium: FAIR data for Life Sciences Research, May 2022, Brussels, Belgium: Presentation on the PHIRI building blocks including the Health Information Portal
  - European Public Health Conference, November 2022, Berlin, Germany:
    - Pre-conference on ‘What is metadata? Common standards and properties?’ - Why we need metadata for public health data sources? Illustrated with the European Health Information Portal
    - Mentioned in several PHIRI presentations
  - Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (COVI) – Workshop on EU crisis preparedness and response, March 2023, Brussels, Belgium: The Population Health Information Research Infrastructure – example of the catalogues on the Portal
  - Better statistics for better health for pregnant women and babies, Euro-Peristat Meeting, March 2023, Amsterdam, Netherlands: The Population Health Information Research Infrastructure – example of the catalogues on the Portal
  - EUPHA public Health Week, April 2023: Fantastic Data and Where to Find them



- Research to policy DG RTD (7<sup>th</sup> COVID-19 research to policy action dialogue: Post COVID-19 condition, May 2023, Brussels, Belgium: The Population Health Information Research Infrastructure – example of the catalogues on the Portal
- Radical Health Festival, Helsinki, Finland, June 2023: Code meets Data – Overcoming data sharing hindrances in Europe. Presentation focusing on federated demonstrators on the Portal
- 1<sup>st</sup> National Public Health Conference – Health as a Source of Prosperity, 3 October 2023, Portorož, Slovenia: The Population Health Information Research Infrastructure – focus on the Portal
- EC Workshops –Landscaping data driven projects and initiatives in cancer–rationale and directions for better collaboration and integration Introduction and landscaping of data-driven projects in cancer 26 October 2023 WebEx: The Health Information Portal, a one-stop shop for health information – focus on data sources and metadata standards
- World Congress of Public Health 2023, May 2023, Rome, Italy: The HIP was presented in two sessions:
  - Saso M, Bogaert P, Schutte N, Tolonen H. The Health Information Portal for better health research and policy decisions. 17th World Congress of Public Health, 2-6 June 2023, Rome, Italy. *Popul. Med.* 2023;5(Supplement):A1650. DOI:10.18332/popmed/164091
  - Bogaert P, Tolonen H, Lapão L, Habl C, Calleja N. PHIRI Rapid Exchange Forum (REF): a key tool for cross-country exchange in times of crisis and beyond. 17th World Congress of Public Health, 2-6
- European Public Health Conference, November 2023, Dublin, Ireland: The Health Information Portal (HIP) was presented during the pre-conference on
  - Reuse of sensitive individual data – Methods and tools for a federated approach
  - Better public health: a data centered approach to interoperability, with international information standards
  - Additionally in many of the PHIRI presentations HIP was mentioned as a source of information.
- The Portal was also presented at multiple PHIRI events such as the PHIRI 2 year anniversary (April 2022, Online), the Spring School on Health Information (March 2023, Online), PHIRI 3 year anniversary (Brussels, Belgium, September 2023), multiple National Nodes meetings, Q&A sessions on the Health Information Portal for PHIRI partners.
- Multiple publications were also prepared as part of WP4:
  - Metadata templates for the HIP are published in Zenodo: Tolonen, H., Mäkinen, M., Bogaert, P., Daubresse, P., Lang, R., Lapão, L., Palmieri, L., Peyroteo, M., Saso, M., Schutte, N., Unim, B., & Zaletel, M. (2022). Documentation and user guide for the Health Information Portal. Metadata description. (1.01). Zenodo. <https://doi.org/10.5281/zenodo.6413408>

- An article "European Health Information Portal – a one-stop-shop for health information" has been accepted for the PHIRI Special issue of the European Journal on Public Health
- A sustainability report of the HIP has been in Zenodo: Tolonen, H., Saso, M., Kiss, C., Unim, B., Palmieri, L., Derycke, P., Peyroteo, M., Lapão, L., & Schutte, N. (2023). A sustainability roadmap for the European Health Information Portal. Zenodo. <https://doi.org/10.5281/zenodo.10021129>
- A National Node sustainability report published on Zenodo: Zaletel, M., & Tolonen, H. (2023). National Nodes - sustainability of the structure (October 2023). Zenodo. <https://doi.org/10.5281/zenodo.10245179>

This was achieved through a strong collaboration between all the PHIRI partners and coordinated by THL.

## 5. Work Package 5

The aim of [WP5 \(Research Methodologies to Assess the Impact of COVID-19\)](#) is to support European countries to understand the impact of COVID-19 on population well-being and health, morbidity and mortality using a multidisciplinary approach in order to be better prepared for current and future crises. In the second part of the project, the following [results](#) were obtained:

- 11 presentations (oral or poster) in the following scientific events: Spanish Society of Epidemiology 2022 (San Sebastian, Spain) and 2023 (Porto, Portugal); European Public Health Conference 2022 (Berlin, Germany) and 2023 (Dublin, Ireland); International symposium on multimorbidity 2021 (Amsterdam, the Netherlands); World Congress of Public Health 2023 (Rome, Italy)
- 2 Capacity building activities: a workshop on Learning from journeys in literature reviews of COVID-19 research (October 2022, Online) and a lecture on Innovative COVID-19 technology research and challenges” as part of the PHIRI Spring School on Health Information (March 2023, Online).
- 3 papers under review at the European Journal of Public Health, special issue: “Identification of methodological issues regarding direct impact indicators of COVID-19: a rapid scoping review on morbidity, severity and mortality”, “Measurement of the disruption on healthcare services caused by the COVID-19 pandemic: a narrative review”; “The Role of Digital Tools and Emerging Devices in Covid-19 Contact Tracing during the First 18 Months of the Pandemic: A Systematic Review”.
- Four publications:
  - “Aetiological and prognostic roles of frailty, multimorbidity and socioeconomic characteristics in the development of SARS-CoV-2 health outcomes: protocol for systematic reviews of population-based studies” <https://pubmed.ncbi.nlm.nih.gov/36414309/>;
  - “Innovative Methods Used in Monitoring COVID-19 in Europe: A Multinational Study” <https://pubmed.ncbi.nlm.nih.gov/36612884/> ;

- “Multimorbidity and frailty are associated with poorer SARS-CoV-2-related outcomes: systematic review of population-based studies” (accepted by the journal *Aging Clinical and Experimental Research*).
- “Etiological and prognostic roles of socioeconomic determinants in the development of SARS-CoV-2 health outcomes: systematic review of population-based studies” (currently under review).

The COVID-19 pandemic originated an extensive body of literature, which has provided valuable insights to (quickly) understand this unknown disease. A systematic approach and text-mining methods were employed to identify and describe methodologies and data pathways used in these studies investigating the direct and indirect impacts of COVID-19, aiming to provide a representative snapshot of the research landscape. A systematic review of the literature complemented the research on approaches and tools used for COVID-19 monitoring by highlighting the pros and cons of the emerging contact tracing devices during the first 18 months of the pandemic.

## 6. Work Package 6

The aim of PHIRI [WP6 \(Research Use Cases Measuring the Impact of COVID-19 on Population Health\)](#) is to demonstrate how a broad variety of secondary data (e.g. administrative and survey data) can be pooled and/or reused in a distributed way across Europe. WP6 has 4 use cases on the impact of COVID-19:

1. Use Case A - Vulnerable populations, inequalities and risk factors with direct or indirect impact on COVID-19 outcomes
2. Use Case B - Delayed care in cancer patients
3. Use Case C - Effects of the COVID-19 pandemic on maternal and new-born health
4. Use Case D - COVID-19 related changes in population mental health

The PHIRI Federated Research Infrastructure (FRI) is supported by a containerized reproducible solution for data analysis to be deployed on-premises by each participant partner (PHIRI-app). In order to perform these use cases in the PHIRI partner countries, the following actions were taken:

- Potential data sources have been identified by the PHIRI data hubs by means of the use cases’ common data models. The common data models and analytical pipelines for reporting FAIR rapid cycle outputs were created by the Use Case Leads in collaboration with the orchestrator in PHIRI’s federated infrastructure (IACS) and were published on Zenodo. The work package lead (RKI) and the orchestrator, followed up on the status regarding the transformation of the data at each local hub to the common data schema, the running the analyses and the sending of the results to the orchestrator. In total 13 releases of PHIRI WP6 & WP7 including all digital objects are published and persisted in Zenodo ([here](#)), an Open Aire initiative under a creative common’s international attribution 4.0 license ([D6.5](#)).

The PHIRI Federated Research Infrastructure including Common Data Models and R-Markdown scripts has 2,400 views and was downloaded 292 times.

- The help desk, based in IACS, supported this whole process during the project by opening 45 tickets (i.e. update the data model, update the scripts, or new version or correction of the PHIRI app, etc.), including 278 conversations (each conversation/thread involves a few emails totalling more than 900 emails) and conducting 27 meetings (video conferences) of at least 1 hour each.
- Two workshops were organized by PHIRI to inform the European Commission on the progress of these use cases and their role in implementing the federated architecture of PHIRI.
- As part of the harmonization and standardization effort, WP6 checked with partners participating in all use cases the availability and accessibility of both the data sources and the concrete data required for each of the use cases through several surveys (i.e. data availability and accessibility survey and 4 specific common data model availability surveys). Resorting to common data models mitigates semantic incongruences across data sources and information biases although, for some research queries, for example, those that aim causal inference, this approach may not prevent from confounding. In addition, the workflow implemented includes quality checks on the original datasets built upon the common data model which, on the one hand, reduces the risks of inaccurate information, and the other hand, may help to the proper interpretations of the results. The interpretation and contextualisation of the use case results is carried out in close collaboration with the data contributing institutions (data hubs). To offer a platform for discussion and collaboration three data hub meetings including use case leads and co-leads, data contributing colleagues, orchestration representatives as well as WP lead were conducted.
- As an important output, four case study reports ([D6.1-D6.4](#)) were drafted focusing on methods and research results. In total, data was mobilized and analysed in 15 data hubs in a distributed manner across Europe whether the PHIRI-app Docker was deployed and tested in 14 data contributing nodes.
- In [D6.6](#) (Report on scalability, sustainability and rapid cycle analysis requirements) the lessons (positive and negative) learnt in the deployment of the use cases. This report aims to reflect on how scalable the design and implementation of the PHIRI research infrastructure has been, and discuss elements around sustainability, specifically the implementation of rapid cycle analysis.
- As part of the activities of the WP, multiple publications were prepared:
  - Has the COVID-19 pandemic changed existing patterns of non-COVID-19 health care utilisation? A retrospective analysis of 6 European regions
  - Delayed treatment in breast cancer patients during the COVID-19 Pandemic: a population health information research infrastructure (PHIRI) case study

- Socioeconomic disparities in population changes to preterm birth and stillbirth rates during the first year of the COVID-19 pandemic: a study of 21 European countries
- COVID-19 related changes in population mental health
- PHIRI Federated Research Infrastructure: implementation lessons and preparedness for the future of population health research

Finally, table 1 shows the WP6 dissemination activities performed in the second part of the project.

Table 1: WP6 dissemination activities performed in the second part of the project

Event	Date/Location	Type	Title	Content/Aim
<b>European Public Health Week</b>	19.05.2022 virtual	Presentation	Research Use Cases Measuring the Impact of COVID-19 on Population Health	Introducing the PHIRI federated approach and the four research use cases measuring the impact of COVID-19 on population health
<b>15th European Public Health Conference</b>	10.11.2022 Berlin	Workshop	Showcasing PHIRI use case results measuring the impact of COVID-19 on population health	Ensure a better understanding of COVID-19 impacts in specific subgroups and risk settings by conducting research through real-life use cases of immediate relevance
<b>17th World Congress on Public Health</b>	05.05.2023 Rome	Workshop	Research use cases measuring the impact of COVID-19 on population health feeding into a federated research infrastructure	Measuring COVID-19 impacts by conducting research through four use cases to provide actionable outcomes to guide policy makers in preparedness and response scenarios
<b>16th European Public</b>	08.11.2023 Dublin	Pre-conference	Reuse of sensitive individual data – Methods and	Cover the PHIRI federated research infrastructure achievements

<b>Health Conference</b>			tools for a federated approach	consisting of three main elements: <ol style="list-style-type: none"> <li>1. an introduction to the PHIRI story as well as the Health Information Portal being a one-stop shop</li> <li>2. a presentation on the federated approach to enhance interoperability and a section on four real-life research use cases</li> </ol> an interactive hands-on session on how to replicate a use case in a federated infrastructure
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## 7. Work Package 7

Building on InfAct's achievements, PHIRI has implemented a large-scale federated multipurpose research infrastructure involving multiple population health researchers and multiple data sources hosted in various European countries. As an overarching goal, PHIRI [WP7 \(Building a Federated Research Infrastructure \(FRI\) for a Rapid Policy Response\)](#) aimed at creating and validating a federated research infrastructure that, overcoming data reuse and data sharing hindrances in public health research, could prepare for rapid response in future pandemics.

Specifically, WP7 has developed the methodological and technological substrate for implementing an FRI that allows mobilising potentially sensitive data hosted by several data holders from multiple countries in a handful of research queries while preserving GDPR principles. In figure 1, it is shown a representation of the master-worker topology design to serve this purpose.



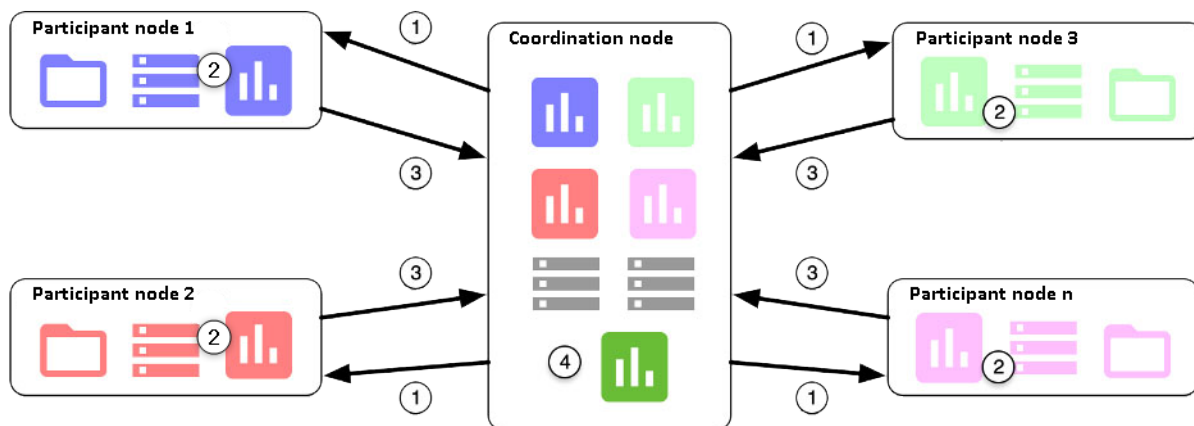


Figure 1. Master-worker topology in PHIRI FRI

Upon this topology, figure 2 summarises the methodological workflow implemented to back the deployment of the use cases. The workflow represents a solution to comply with the different layers of interoperability -legal, organisational, semantic and technical - in federated multi-country research that uses potentially sensitive data.

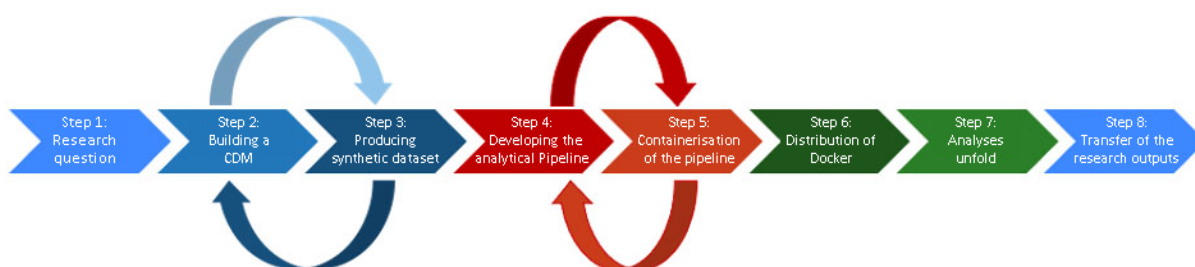


Figure 2 Methodological workflow in the deployment of the use cases

**Deliverable 7.1** (13/05/22) described the features of the midsize prototype of the FRI. This prototype could already serve the four use cases carried out as part of WP6. Building blocks in this midsize FRI were the development of the common data model for each use case, the implementation of scripts for data quality assessment and analyses, containerisation of the script and technological stack within a Docker Image (secured environment for the implementation of the FRI across nodes); and the GUI for deployment of the use cases.

*FAIR outputs:*

The Docker image was published in ZENODO (<https://doi.org/10.5281/zenodo.5729310>). It constitutes a fully operative prototype that includes all the pipeline components required to carry out the research queries foreseen in WP6 and the demonstration pilot (Version 2.3.0).



The latest versions of the algorithms for data analysis scripts for the PHIRI use cases A to D which were run to produce the actual research results can be found separately here:

- WP6 – Use Case A scripts (R Markdown) <https://doi.org/10.5281/zenodo.6359850>; (v1.1.2)
- WP6 – Use Case B scripts (R Markdown) <https://doi.org/10.5281/zenodo.6359892> (v4.0.1)
- WP6 – Use Case C scripts (R Markdown) <https://doi.org/10.5281/zenodo.6380733>; (v2.0.1)
- WP6 – Use Case D scripts (R Markdown) <https://doi.org/10.5281/zenodo.6359904>; (v1.1.1)
- WP7 – Pilot scripts (R Markdown) <https://doi.org/10.5281/zenodo.7092521> (v1.0.0)

**Deliverable 7.2** (09/06/23) reported the enhancement of the midsize version of the FRI with the implementation of a demonstrator that piloted the human-to-machine interface. While in the first version, comparative analysis across participant nodes required sending the local results to the coordination hub via email, this pilot would allow local outputs to be pulled to software that triggers the analytical scripts, produces the local results and automatically updates the comparative report built in QUARTO.

In addition, the deliverable explored how to use the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) to represent the information requirements specified to the PHIRI use cases. Mappings from use cases A, B and D standard data models to [OMOP v5.3 CDM](#) were included as part of the update of the PHIRI app to a mid-size prototype (check at <https://doi.org/10.5281/zenodo.5729310>).

**Deliverable 7.3** (29/09/23) provided the final developments for a fully operable FRI. Specifically, the implementation of a technological stack that enables user authentication within the EGI AAI platform (PHIRI collaborated with the EGI-ACE project as an early adopter of the EGI services and solutions for the project; in particular, the EGI offers the possibility of creating EGI communities and registering applications using EGI-ACE services). The AAI system would allow pulling the outputs of interest to trigger the analysis and produce joint results as in deliverable 7.2, but using a secure authenticated access.

A demonstration can be accessed via links in the Health Information Portal' (<https://www.healthinformationportal.eu/services/federated-demonstrators>) or directly at a) <https://phiri.iacs.es/upload> for the 'Upload' interface to upload new aggregated outputs from the local analysis produced by a partner participating in use case B; b) at <https://phiri.iacs.es/report> for the 'Interactive report' on international comparison analysis of participants in use case B; and, c) at <https://phiri.iacs.es/> for an interactive mock-up of the web application interface enable upon PHIRI app local deployment in a partners' systems.

As part of the activities of the WP7, interaction with developers and users was formalised through a survey (21/02/23) covering the experience with the PHIRI App as well as the experience in a number of topics specific to the use cases, namely, accessing the required data, transforming the input data to the common data model (ETL), deploying the container and using the GUI application. The results of the survey were included in Deliverable 7.4.

**Deliverable 7.4 (29/09/23)** presented the result of the assessment carried out around the future directions that PHIRI FRI should take, according to not only the technical aspects but also the regulatory requirements, semantic elements and its location in a rapidly changing environment. There were also elements for the interaction with the European Commission's European Health Data Space regulation, EOSC, as well as with other data-sharing infrastructures currently under development, such as the Genomics Data Infrastructure or the European Cancer Image Infrastructure.

### Relevant activities during this 2<sup>nd</sup> reporting period

- 1) The community of IT experts in the participant nodes advanced ideas on developing the FRI. In this regard, two IT developers' meetings (27.10.22 and 14.03.23) were conducted.
- 2) In addition, the help desk, both for Technical and Implementation issues (bugs, etc.) and for Domain issues (research questions, data model, etc.), continued to provide support to the WP6 use cases during the 2<sup>nd</sup> reporting period. During PHIRI, the Help Desk issued 45 tickets, drafted 278 conversations (over 900 emails) and had 27 meetings with WP6 FRI users.
- 3) Meanwhile, the PHIRI WP7 core team explored upgrading options for the PHIRI research infrastructure, evaluating advanced distributed analysis techniques and assessing the potential need for increasing computational and storage capacity (e.g. using the [services provided by EGI-ACE](#) such as cloud computing services)
- 4) A workshop on "options for a future PHIRI infrastructure" with experts from outstanding projects (VIB / LIXIR-BE, BSC, Sciensano/ BY-COVID, EGI Foundation, Swansea /Data Shield, Erasmus MC / EMA Darwin, KNAW-DANS, IACS/BIGAN) was convened; the workshop served as an external consultation opportunity for PHIRI to examine options for a future PHIRI infrastructure (26/06/23). Summary of the workshop is available at the [PHIRI workspace](#).
- 5) A publication on "PHIRI: lessons for an extensive reuse of sensitive data in federated health research" is about to be published in the European Journal of Public Health. This paper describes the design principles and the different building blocks that have supported the implementation and deployment of PHIRI, the strengths and challenges of the approach and some future developments.

- 6) During the European Public Health Conference in 2023 a pre-conference titled “*Reuse of sensitive individual data – Methods and tools for a federated approach*” was organized to showcase the work performed within PHIRI.

## 8. Work Package 8

WP 8 (Rapid Exchange Forum) aims to establish 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. While initially its work was focused on COVID-19, the Rapid Exchange Forum soon expanded beyond it, providing support and performing research on multiple urgent public health topics. In order to achieve that, the following activities have been performed in the second part of the project:

- Maintenance of regular bi-weekly meetings named Rapid Exchange Forum (REF). In this one-hour meeting, the participants belonging to European public health institutes, Ministries of Health, research institutions and universities as well as EU-level stakeholders and international organisations (e.g. WHO, OECD) answer questions and discuss experiences from their own countries related to the COVID-19 pandemic and beyond. Between May 2022 and October 2023, 24 regular meetings, 2 special edition meetings with guest speakers and 2 REF webinars in the course of the European public health week (EUPHW) 2022 took place. The REF network includes 31 countries (thereof 28 PHIRI partners: Austria, Belgium, Bosnia And Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Finland, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, Moldova, The Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, United Kingdom, and additionally Albania, Denmark and Cyprus) and 11 organisations (ECDC, EUPHA, European Observatory on Health Systems and Policies, CPME, OECD, WHO, EMA, EC, DG SANTE, DG RTD and ELIXIR – see Figures 3 & 4)
- In the first year of PHIRI, a Limesurvey was employed to prioritize topics for the REF meetings. Partners, including EC services like ECDC, proposed topics, and the preferred ones were chosen for the following REF meeting. In the second year, the approach was modified for faster information exchange. Ad-hoc questions were introduced, allowing structured partner responses within 7-10 days. Additionally, the topic selection process evolved, with topics decided in the current session for the next, forming a continuous "pipeline." However, changes in pandemic management structures in 2022 led to a drying up of the pipeline, prompting the secretariat to actively call for topics during meetings. The absence of topics could result in meeting cancellations. Responding to these shifts, Steering Committee VIII expanded the REF's scope to include population health issues beyond COVID-19, initiated in mid-2022 and fully implemented in 2023.

- Maintenance of a dedicated page to the [Rapid Exchange Forum on the Health Information Portal](#). Selected results of non-confidential nature of each REF were uploaded immediately, making them freely available to the public. Based on the feedback received during the PHIRI Review meeting, the following functionalities are added to the search function of the Rapid exchange Forum page on the Health Information Portal:
  - The REF content is added to the main search function of the homepage of the Portal;
  - Two new fields are added in the template of the REF: keywords and topics. For the topics, a pre-set list of terms is created while the key words are complementary to the topics;
  - Boolean operators improve the search function (AND, OR, NOT).
- Maintenance of a page dedicated to the [COVID-19 policy measures](#) on the Health Information Portal which provides an overview of the key policy measures implemented throughout Europe for the management of the pandemic. Currently this information is provided by more than 20 countries. The content was last updated and the policy measures adapted in order to better map the COVID policy measures in place in different European countries only recently when the project ended at the end of October. Several bilateral meetings with ECDC have also been organised until September 2022 to support their work on the [Response Measures Database \(RMD\)](#) website as long it was maintained.
- Development of a needs assessment survey for evidence-based policy support among health policy makers to identify the gaps between research and policy involving 24 European countries. The [results of the survey](#) have been used to guide the topics to address within the Rapid Exchange Forum and the key COVID-19 policy measures to which the different countries were encouraged to provide information in the Health Information Portal.
- Fine-tuning of the [mapping exercise of sources of population health information on COVID-19](#) to provide relevant population health guidelines, standards, and reports with the aid of web scraping. Building on the mapping, this task created a catalogue of existing international initiatives and projects on COVID-19 related diagnosis, treatments, interventions and measures (except policy measures) conducted in European countries. Such information is uploaded on the Health Information Portal.
- Enlargement of a network of experts and expertise that can easily be approached for the purpose of information exchange and review of evidence-based policy support information. List of experts available on SharePoint for the PHIRI partners and it is widely consulted by all PHIRI partners.
- Leveraging the information collected and shared by the participants during the Rapid Exchange Forum meetings, a literature review was performed to investigate the evidence surrounding public health and social measures implemented during the COVID-19 crisis. The review was published at Frontiers in Public Health as “Impacts of public health and social measures on COVID-19 in Europe: a review and modified Delphi technique”.

This is being achieved through a strong collaboration between all the PHIRI partners and coordinated by GÖG. The partners actively contributed to the activities in this WP by meeting bi-weekly for the PHIRI Rapid Exchange Forum, by collecting relevant information for answering the urgent research and policy questions broadcasted in the Rapid Exchange forum Network and by filling in the information on their own country on the Health Information Portal related to the pages developed within this WP.

A retrospectively Needs Assessment Summary (M53) at the end of the project analysis this baseline methodology of the Rapid Exchange Forum, which necessarily turned out to correspond to pandemic evolution across Europe. It reflects on REF’s methodology over four phases and showcases main topics and modifications to the processes as well as the progress of topics over time.

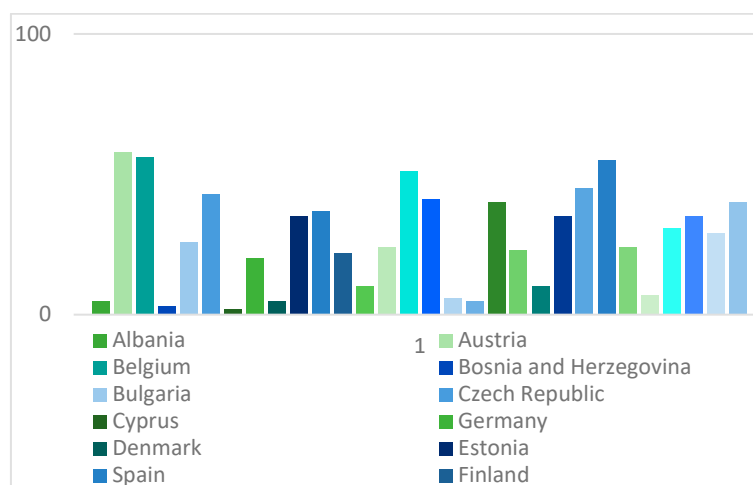


Figure 3: Aggregate number of session participation by country  
Source: PHIRI Needs assessment summary

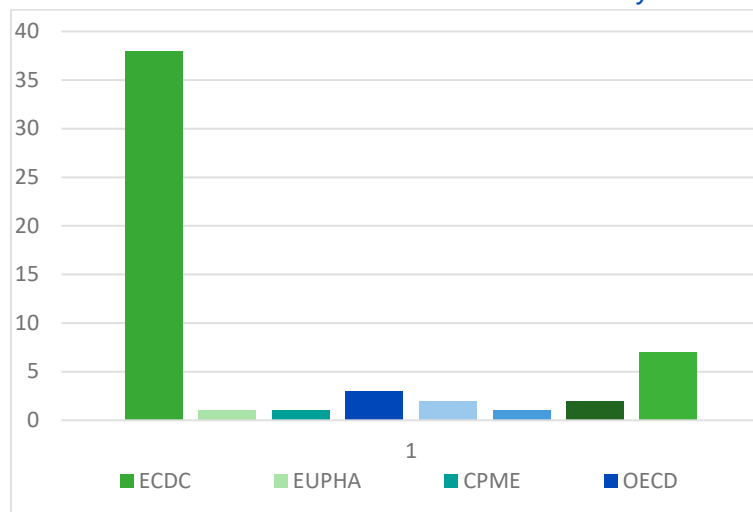


Figure 4: Aggregate number of session participation by institutions and organisations  
Source: PHIRI Needs assessment summary

## 9. Work Package 9

The overall aim of [WP9 \(Foresight: Modelling and Scenarios\)](#) is to gain insights into possible future health impacts of the COVID-19 outbreak, by developing scenarios. Within WP9, various activities have been undertaken to support the objective to strengthen the knowledge, expertise and applications of foresight in the field of public health. However, most of them took place in the first part of the project including a literature review and a [survey to identify current foresight activities and knowledge regarding foresight capacity](#), the building of a foresight network and the organisation of [a foresight capacity building course](#).

- The capacity-building activity "[Develop your Public Health Foresight Study](#)" was developed, wherein participants from European countries conducted their own foresight study with support from PHIRI. This activity and the support provided spanned throughout 2022, comprising 12 guided sessions and resulting in 11 country presentations of planned foresight studies from 8 European countries. This activity provided [insights into challenges encountered during the planning and development of a foresight study and strategies for addressing such challenges](#).
- A policy workshop was organized to get a better understanding how to improve the provision of public health foresight information to policy makers. In addition, based on the lessons learnt from the previous tasks, four policy briefs ([Foresight for policymaking: preparing for challenges and promoting desirable futures](#); [Integrating climate, health, and equity for a climate-resilient Europe](#); [Unlocking the future of primary health care: the digital era unleashed](#); [A pandemic's impact on mental health were developed](#)). These policy briefs focused on the use of foresight in policy making and aimed to communicate to public health experts and policy makers on how foresight can provide a platform to explore the future and discuss possible solutions to address present and future challenges towards desirable futures. Three policy briefs provided specific examples on the use of foresight and resulting policy recommendations in mental health, climate and healthcare, and digitalization of healthcare. Several of these studies were presented and discussed at European Public Health conferences from 2022 to 2023.
- One scientific publication titled "Foresight in public health: application and challenges" is ready to be published at the European Journal of Public Health as part of the PHIRI Special Issue.

### C. Impact

The information available on section 2.1 of the DoA is still relevant. PHIRI's vision is to set up a research infrastructure to generate the best available evidence for research on health and well-being of populations as impacted by COVID-19 and beyond.



In the table below we have listed the expected impacts and the implementation through the PHIRI projects and targets as have been presented in the DoA. The final column discusses the status as of October 2023.

We would like to draw attention to the role that PHIRI plays in the current European landscape: together with other large research infrastructures on health, such as ELIXIR, ECRIN and BBMRI, PHIRI is looking for opportunities to mobilise and expose human infectious disease data and population health data in a FAIR and GDPR compliant way according to the ELSI principles, for example in the BY-COVID project and contribute to the Horizon Europe European Open Science Cloud (EOSC) Partnership & European Health Data Space (EHDS). As multiple of the PHIRI partners are also involved in the mentioned initiatives, work is be aligned and stronger contributions can be provided.

Expected impacts	Benchmarks	Status October 2023
<p>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</p>	<p>PHIRI delivers a FAIR Health Information Portal for COVID-19 in close interaction with key stakeholders in the health information landscape, cataloguing population health data sources, studies and capacity building exercises in EU countries.</p> <p>Target: Health Information Portal set up after 6 months and filled in metatemplates added for 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36.</p> <p>PHIRI develops a Health Information Portal for COVID-19 that provides the services and tools necessary for researchers to link different data sources and to use Pan-European data in a GDPR compliant, federated way.</p>	<p>The Health Information Portal was launched in May 2021. The number of countries that are listed on the Portal is 28; they have provided information on their national health information system and have appointed a contact person for the Health Information Portal. Of these 28 countries, 22 of them have actively used the metadata templates that are designed to create a FAIR metadata catalogue on their health information sources.</p> <p>In the second part of the project, two meetings with the National Nodes in PHIRI have been organised to engage them in the PHIRI network and to support them in adding information to the Health Information Portal. In the</p>



	<p>Target: Engage and inform MS/AC's national health information system stakeholders through country visits, Stakeholder Meetings and national nodes: 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36.</p> <p>PHIRI promotes interoperability and tackle health information inequalities by providing capacity building for management of COVID-19 relevant population health and healthcare data.</p> <p>Target: Provide capacity building exercise to minimum 10% of EU 13 MS in first training, a cumulative of 50% of MS by the second and third training and a cumulative of 95% of EU 13 MS by the remaining training exercises.</p>	<p>first meeting, 18 countries participated and in the second meeting 24 countries participated. Two anniversary events have been organised and numerous bilateral meetings. Finally, the COVID-19 health information system assessments, including interviews with the national stakeholders, took place in 3 additional countries.</p> <p>An overview of the capacity building activities of 2021, 2022 and 2023 can be found on the <a href="#">Health Information Portal</a>. In 2023, PHIRI organised a European School on Health Information, to train young professionals and students in health information in the latest developments in digital health, data management, health informatics and European initiatives.</p>
<p>Identification of best practices for handling the COVID-19 epidemic at public health and clinical management level</p>	<p>A Rapid Exchange Forum will provide structured exchange between countries on COVID-19 best practices and expertise: a Portal for evidence, experts documents and information on competent authorities, as well as communication and dissemination to and with project partners and</p>	<p>From May 2022 until October 2023, 24 Rapid Exchange Forums were organised. All questions and answered that were discussed are uploaded onto the Health Information Portal:</p> <p><a href="https://www.healthinformationportal.eu/rapid-exchange-forum">https://www.healthinformationportal.eu/rapid-exchange-forum</a></p>

	<p>other collaborators and networks.</p> <p>Target: Provide onto the Health Information Portal proof of 10% of structure exchanges provided by M12, 50% of structure exchanges provided by M24 and 95% of structure exchanges provided by M36</p> <p>Swift responses to research and policy questions that are raised in countries by policy-makers, research communities and other stakeholders in the joint efforts to handle the COVID-19 pandemic can be established.</p> <p>Target: Address within two weeks a minimum of 50% of enquiries put forward to the Rapid Exchange Forum.</p>	<p>The Rapid Exchange Secretariat allows for ad-hoc questions to be sent over the Rapid Exchange Forum email list or to be discussed at the end of each biweekly meeting, allowing all questions to be put forward; either on the Forum itself (biweekly meeting) or via email.</p> <p>Currently, the reach of the Rapid Exchange Forum is expanded to allow stakeholders outside PHIRI to attend and propose the question(s) to be circulated within the Rapid Exchange Forum.</p>
<p>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</p>	<p>The use cases demonstrate how a broad variety of secondary data can be pooled and/or reused in a distributed way across Europe to produce actionable insights.</p> <p>Target: Open-source codes for four data models from the Use Cases published by M9.</p> <p>The outputs of the use cases are processed by formalising data models, data management processes and analytical</p>	<p>The first reports were published in M18, including data from over 20 PHIRI data hubs; these reports were updated in the second part of the project as more and more data hubs made their data available for meta-analysis. Even now, it is possible for data hubs to join the use cases, as all common data models and the PHIRI app is publicly available, supporting the open science principle.</p> <p>The Health Information</p>

	<p>pipelines in an interoperable way to feed in the federated research infrastructure</p> <p>Target: For each use case, out of those hubs expected to participate, the percentage fully applying the scripts and deliver the results: 10% in the first 6 months, 40% from month 6 to month 12, and 80% in month 18.</p> <p>The Portal allows researchers to provide relevant and evidence-based information ready for use in research. PHIRI supports researchers and public health bodies with research queries related to COVID-19 in FAIR and ELSI compliant manners.</p> <p>Target: Health Information Portal set up after 6 months. Public health bodies completed metatemplates and researchers accessed the Health Information Portal aiming for a coverage of 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36.</p> <p>PHIRI works towards full synergy with different types of actors and initiatives such as European research networks in the domain of population health; relevant national population data</p>	<p>Portal (launched in early 2021), lists over 390 metadata records describing population health data sources. Over the last year, the number of people who visited the Health Information Portal increased, reaching its monthly record in terms of visitors in November 2023: 2594.</p> <p>Two anniversary events have been organised and numerous bilateral meetings, including, but not limited to WHO Europe, DG SANTE, DG RTD, DG CONNECT, ECDC, JRC, Eurostat, OECD, The Observatory, ELIXIR, BBMRI-ERIC, ECRIN, BSC, CESSDA, DANS, EATRIS, EMBL-EBI, EHDEN, STRATEGY, EUPHA, IAPNHI, ETHEL, EUR3KA, STAMINA, COVID-X, COVERSATILE, RISKPACC, LINKS, PathoCERT, PANDEM-2, PERISCOPE, COVINFORM, NO-FEAR. EGI-ACE, UnCover, TEHDAS, CHAIN, SHARE, EpiPose, BY-COVID, VACCELERATE, EU-HIP, EHDS-2 Pilot and upcoming QUANTUM and X-Share projects.</p>
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	<p>owners/curators.</p> <p>Target: Overall average participation of 2/3 of selected stakeholders in bimonthly Stakeholder Meetings</p>	
<p>Contribute to the formation of a true European Health Data Space thus responding to the EU's Digital Health agenda</p>	<p>PHIRI will provide support towards the development and use of large-scale, integrated and sustainable data services for population health and health services research.</p> <p>Target: National nodes participation for 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36.</p> <p>Multiple domains are integrated for monitoring and assessing the long term effects of COVID-19 on the health of European populations.</p> <p>Target: Identifying research methodologies and innovative methods to assess the impact of COVID-19 and, digital tools for contact tracing of COVID-19 patients for a coverage of 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36.</p> <p>Researchers and experts can participate in ever stronger international health research networks, with a broader and more</p>	<p>Systematic reviews were conducted to arrive at robust indicators and research paths on the impact of COVID-19 and multiple papers have already been published or are currently under review.</p> <p>The bi-weekly 1 hour online meetings of the Rapid Exchange Forum (REF) have 2 parts: 1 pre-agreed urgent policy or research question on population health (topics are contributed by the participating countries and chosen via a survey ex-ante to each meeting) and ad-hoc questions. It is also possible to send urgent questions directly to the REF mailing list. Responses by the countries (backed up by evidence like national reports, guidelines, etc.) are compiled and shared via a devoted platform immediately after the meeting. This ensures that almost all questions are processed, answered and published.</p>

	<p>sustainable flow of research data and health information available for benchmarking, policy evaluation and implementation research</p> <p>Target: Health Information Portal set up after 6 months. Public health bodies completed metatemplates and researchers accessed the Health Information Portal aiming for a coverage of 10% of MS by M12, 50% of MS by M24 and 95% of MS or AC by M36. Address within two weeks a minimum of 50% of enquiries put forward to the Rapid Exchange Forum.</p>	
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## 2. Update of the plan for exploitation and dissemination of result (if applicable)

The main PHIRI communication and dissemination plan is still relevant and available here on the PHIRI website: <https://www.phiri.eu/sites/phiri.eu/files/2021-10/D2.1%20Communication%20and%20Dissemination%20Plan%20V3%20%28revised%29.pdf>

### D. Update of the data management plan

The PHIRI Data Management Plan has been delivered by IACS in M06 of the project: [https://www.phiri.eu/sites/phiri.eu/files/2021-10/PHIRI\\_Data%20Management%20Plan\\_D1.1.pdf](https://www.phiri.eu/sites/phiri.eu/files/2021-10/PHIRI_Data%20Management%20Plan_D1.1.pdf)

### E. Follow-up of recommendations and comments from previous review

Based on the mid-term review that PHIRI undergo in September 2022, the following recommendations were given by the reviewers concerning the first reporting period:

- The minutes of the Rapid Exchange Forum – Special editions were not found on the PHIRI website
- The results of the survey used to guide the topics to address within the Rapid Exchange Forum and the key COVID-19 policy measures was not found on the PHIRI website

The coordination team, responsible for the management of the PHIRI website, immediately took action and made the documentations requested more easily found on the PHIRI website. A dedicated page to the Rapid Exchange Forum – Special editions can now be found [here](#) while all the outputs of PHIRI, the results of the survey used to guide the topics to address within the Rapid Exchange Forum and the key COVID-19 policy measures, are available [here](#).

Regarding recommendations concerning future PHIRI work, the following comments were provided by the reviewer:

- A truly federated research infrastructure should be finalized, able to perform different pooled analyses without transferring raw data.
- It would be great to have an advanced search engine for the many topics covered by the rapid exchange forum. The one implemented now is quite basic.
- A detailed analysis of the effectiveness of all the communication and dissemination activities that were implemented would be very helpful.

For the first comment, PHIRI materialized the prototype as stated in the Grant Agreement, the building blocks of the PHIRI infrastructure are: 1) Common Data Models; and 2) Synthetic datasets; 3) Data quality assessment scripts; 4) Algorithms for data analysis; 5) Demonstrator of the human-to-machine interface (see <https://www.healthinformationportal.eu/services/federated-demonstrators/phiri-use-case-b-demonstrator>). These building blocks are known as the 'PHIRI pipeline'(figure 2). Supporting the open science principles, all common data models and the PHIRI app are publicly available (on Zenodo), allowing any data holder to map their data to the common data model, run the analysis and compare outputs. This pipeline has been adopted by other large projects to operationalise research questions: Beyond-COVID (BY-COVID, <https://by-covid.org/>) and the HealthData@EU Pilot Study ([www.ehds2pilot.eu](http://www.ehds2pilot.eu)). Currently PHIRI is exploring collaborations with large cancer projects and the upcoming reference network on Long-COVID to apply the PHIRI pipeline.

Regarding the second comment, detailed plans were made and implemented on the [Health Information Portal](#) to strengthen the search function for the Rapid Exchange Forum material. Now the content can be filtered by free text search of the questions addressed in each meeting, free keywords and a predefined list of topics. The terms used for the search are then highlighted in the text to allow the visitor to understand the context in which the term was used. Additionally, the introduction presentation on

the topic addressed during the meetings have been added to the Portal to provide the users additional background information.

For the final comment, the PHIRI team increased the monitoring of the statistics of the PHIRI website, the Health Information Portal and all the PHIRI social media channels. Monthly reports on the Health Information Portal's users' analytics are published on the PHIRI SharePoint. Updates were presented at each Steering Committee meeting on dissemination and dissemination KPIs. KPIs are monitored as much as technically possible: social media posts, followers, impressions, website and Portal's visitors, videos viewers, events' attendees, newsletter's subscribers... Improvements were set-up and assessed such as the implementation of Schema.org (a metadata standard for the indexation of web pages) on the Health Information Portal, which insured a better findability of the Portal's content on search engines such as Google, which has been monitored through specific dashboards.

## F. Deviations from Annex 1 and Annex 2

Since the start of the project, the deliverables presented in the table have been uploaded on the ECAS Portal however, with a delay. A justification for such delays is presented.

Deliverable	Title	Responsible partner	Deadline	Upload on ECAS	Justification Delay
D5.3	Report on innovative approaches for health impacts assessment in Europe: the role of digital tools and emerging devices	ISS	31-10-22	29-11-22	The short delay was caused by the review process performed within PHIRI to ensure a high level of quality in the report.
D6.5	Software publication in public repositories	IACS	31-10-22	03-01-23	Overall delay in running WP6 use cases. Hence, delays in both the common data model and the implementation of the pipeline for the analysis.



D5.2	Roadmap on indicators, methodologies, data pathways and needs across Europe for research on health outcomes, gap analysis and monitoring COVID-19 impacts assessment.	ISCII I	31-10-22	31-10-23	D5.2 builds upon the previous draft report (milestone 5.1) and involves four subtasks, including a review of methodologies and data pathways based on 20 thousand PubMed records. The team, comprising three full-time staff members and collaborators from 11 institutions, had some delays in hiring research assistants, leading to a request for an extension of the deadline of the task.
D5.4	Report on contribution of Artificial Intelligence on assessing the impact of COVID-19, including ethical and legal key considerations and recommendations	EOP YY	31-10-22	31-10-2023	Due to health reasons, the Greek Team has contacted both the WP5 leaders and the Coordination Team to ask for an extension on the mentioned deliverable. The need of an extension was communicated by email and approved during one of the PHIRI Steering Committee. To ensure the quality of the deliverable met the rest of the PHIRI outcomes, this deliverable was delayed multiple times to undergo multiple revisions.
D9.3	Presentations by countries, Synthesis scenario report	RIV M	31-01-23	09-05-23	An extension for this deliverable was requested by email and approved at the PHIRI Steering Committee. On January, the participants of the task presented the work done in their studies developed within the task. Based on the presentation, they received feedback from the RIVM team and reported back a summary sheet with the main findings of their studies. These summary sheets were used for the Report part of the D9.3. In order to complete all these activities and give the participants

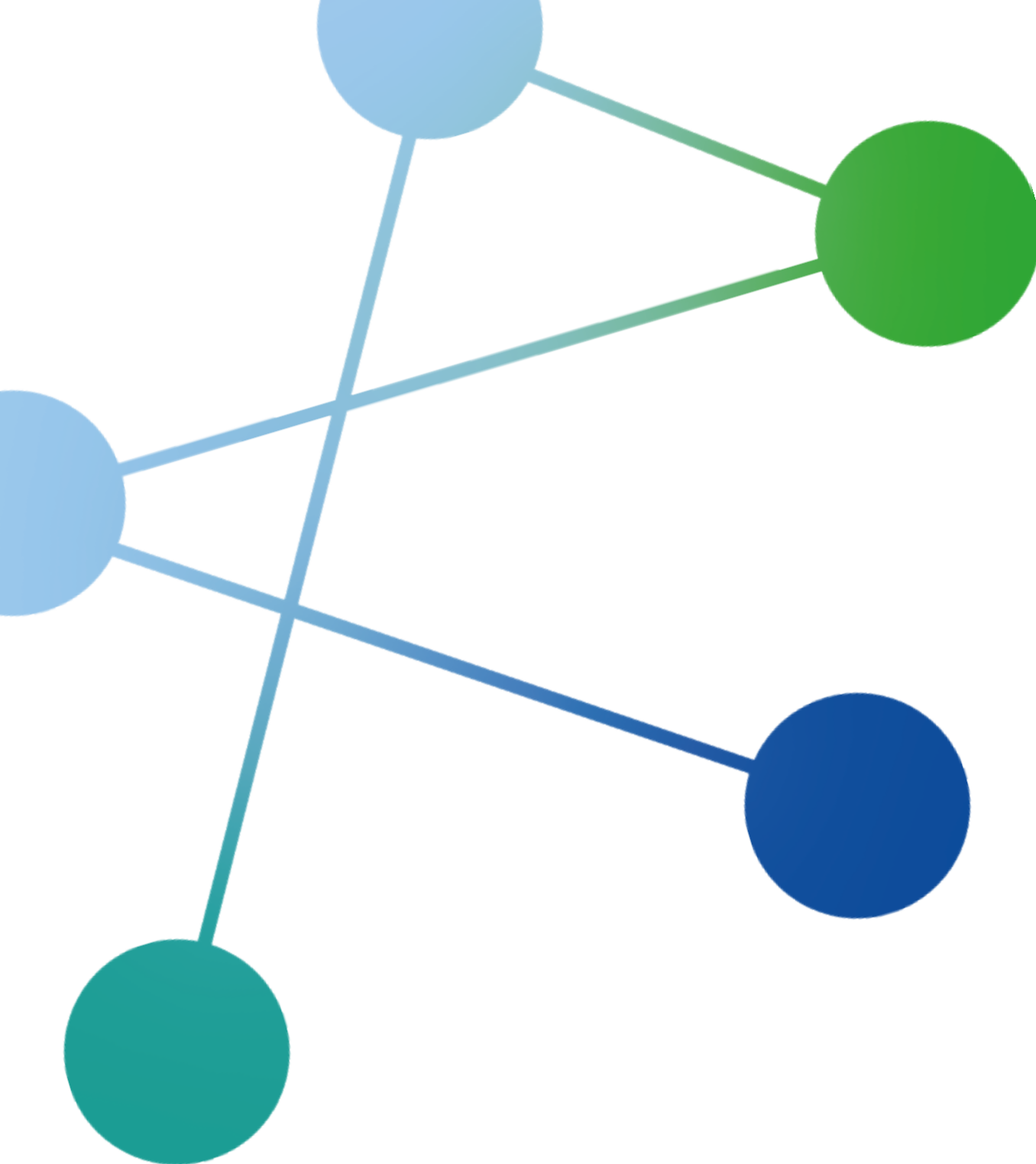
					sufficient time to provide their summary sheets, they requested an extension.
D7.2	Mid-size prototype of PHIRI federated infrastructure	IACS	28-02-23	09-06-23	Due to decision to include in D7.2 both the Human to Machine Demonstrator with the new version of the Docker and scripts as part of the mid-size prototype and the contents on the OMOP mapping 3 additional months were needed for finalising D7.2 expected.
D8.6	Contribution to the Sustainability plan	UNL/DGS	30-04-23	04-12-23	The delay occurred because we aimed to integrate both our review paper and the information available on the page dedicated to this topic on the Health Information Portal into the deliverable. Most of the delay was related to the support from informatics. The paper was published at frontiers in public health.
D9.4	Factsheet with main outcomes for policy making	GÖG	31-07-23	18-09-23	All policy briefs were completed in the predefined timeframe. However, some additional work on the layout was performed over summer to give the same look and feel to the documents.
D1.3	Final report	Scien nsan o	31-10-23	05-03-2024	To be able to publish the final report, all the information from the technical and financial reports of PHIRI needs to be ready. For this reason, this causes a delay in the publishing of the PHIRI Final report.
D3.3	Sustainability plan	GÖG	31-10-23	05-03-2024	The sustainability plan is one of the key outcomes of PHIRI as it provides a direction for the continuation of the project and its activities. In this regard, it takes the support of all the PHIRI partners

					and it is currently requiring some additional time to include all the key findings.
D4.5	A toolbox how to transfer existing practices and guidelines on ethical and legal aspects	OFK O	31-10-23	24-11-23	The toolbox on how to transfer existing practices and guidelines on ethical and legal aspects was developed on time. However, as PHIRI focuses a lot of attention on the reviewing process to increase the quality of its outputs, the review process took longer than anticipated.
D3.1	Country one pager on EU countries' health information (HI) systems on monitoring the wider effects of COVID-19 on population health	Scie nsan o	31-10-23	01-12-23	The content of the Deliverable 3.1 was ready on time however, the multiple in person events that took place between October and November caused some delays in the combining of all the findings and the reviewing process of the deliverable.
D6.6	Report on scalability, sustainability and rapid cycle analysis requirements	IACS	31-10-23	04-12-23	The drafting took longer than expected. Besides, approval & uploading into the EC participants portal also contributed to the delay.
D3.2	Stakeholder meeting report	Scie nsan o	31-10-23	19-12-23	Similarly to D3.1, the content of the D3.2 was ready on time however, the multiple in person events that took place between October and November caused some delays in the combining of all the findings and the reviewing process of the deliverable.

D5.1	Report on the identification on determinants and risk settings associated with COVID-19 and prevention and intervention strategies	SpFrance	31-01-22	31-01-23	This Deliverable was already granted an extension (from January 2022 to April 2022). However, the team considered it important to keep a systematic review approach instead of a scoping or rapid review – as the best choice to provide in-depth information, which took more time than anticipated. Therefore, they are asking for a 2-month extension (June 2022). The deliverable was uploaded on the ECAS Portal only at the end of the project due to the timeline of the scientific publication associated with the deliverable.
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## VII. Overview Deliverables

All Deliverables can be found on the PHIRI website: <https://www.phiri.eu/outputs>



## SCIENSANO

Rue Juliette Wytsmanstraat 14  
1050 Brussels | Belgium  
[phiri.coordination@sciensano.be](mailto:phiri.coordination@sciensano.be)

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

 [@PHIRI4EU](https://twitter.com/PHIRI4EU)