Population Health Information Research Infrastructure (PHIRI)

First General Assembly/ Kick-off Meeting

Minutes

19th November 09:30-12:30 via Webex (online)

Contact: phiri.coordination@sciensano.be

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

I. Participants

Alan Cahill, Alba de Martino, Alberto Cusinato, Aleksandar Medaveric, Alex Patak, Alfonso Valencia, Amalia Munoz Pineiro, Amparro Laurarri, Andrea Faragalli, Andreas Holtel, Angela Fehr, Anna Wallace, Annapina Palmieri, Anne Cody, Arshiya Merchant, Ashley Akbari, Asuncion Diaz, Athanasios Thanos Kakarount, Ausra Zelviene, Aziz Naji, Bangin Brim, Brecht Devleesschauwer, Brigid Unim, Cap Jan, Carlos Luis Parra Calderon, Carmen Rodriguez-Blazquez, Christian Ohmann, Christian Leonard, Claudia Dima, Claudia Habl, Claudius Griesinger, Clemens Wittwehr, Daniela Moye, Diane Whitehouse, Dimitra Lingri, Dimitrios Sarikizoglou, Dorita Buttigies, Elena Petelos, Elke Hanssens, Els Plettinckx, Enrico Ben, Enrique Bernal Delgrado, Esmond Urwin, Fabienne Lefebvre, Florence Bietrix, Francisco Estupinan, Francois Domergue, Frederik Coppens, Gergely Sipos, Gianmario Candore, Hanna Tolonen, Henk Hilderink, Herman Van Oyen, Howard Needham, Ilze Burkevica, Imane Zidi, Inmaculada Leon, Irisa Zile, Istvan Csizmadia, Jane Idavain, Janis Misins, Javier Gomez-Arrue, Jelena Dimnjakovic, Jennifer Zeitlin, Jillian Oderkirk, João Forjaz, Johannes Klumpers, Jordi Rambla, Juan Gonzale- Garcia, Karin De Ridder, Karin Smets, Karolina Wegrzyn, Katie O'brien, Kim Deruyck, Kim Vyncke, Laure Carcallion, Leone Flikweert, Leonor B Nicolau, Licinio Kustra Mano, Lies Gremeaux, Linda Abboud, Linda Berger, Louisa Stüwe, Luciana Neamtiu, Luigi Palmieri, Luis Lapao, Maddalena Querci, Mari Mäkinen, Marianne Philibert, Marie Delnord, Marie Guichardon, Marieke Verschuuren, Mariken Tijhuis, Marina Karanikolos, Marta Marin, Martha Purcell, Martin Thissen, Matej Vinko, Maura Hiney, Mauro Petrillo, Merike Ratsep, Metka Zalatel, Miguel Penalver, Mihaela Matei, Miriam Saso, Neville Calleja, Nicklas Blomberg, Nienke Schutte, Ondrej Majek, Patricia Clarke, Paulo Nogueira, Petr Holub, Petronille Bogaert, Ramon Launa, Richard Pentz, Rodrigo Sarmiento, Romana Haneef, Ronan Lyons, Rosa Cano, Rosalyn Keys, Rosita Claesson Wigand, Rebeca Ramis, Sabine Drieskens, Sandra Caldeira, Sandra Garcia Armesto, Sarah Glaveys, Sarka Dankova, Seila Cilovic, Sharon Kappala, Sherry Merkur, Simona Parvu, Spiros Georgakopoulos, Stefan Mathis Endenhofer, Stefanie Seeling, Szabo Mihaly, Szymon Bielecki, Tadek Krzywania, Tatjana Kofol, Teresa Lopez Cuadrado, Tina Lesnik, Tomasz Wisniewski, Toni Andreu, Toni Suutari, Tugce Schmitt, Zeljka Drausnik, Zuzana Nordeng.

II. Welcome session – Petronille Bogaert, Principle Investigator, Sciensano

a) Overview of the agenda and aims of the meeting

b) Permission to record

c) Welcoming words

PHIRI builds on two consecutive projects in health information: BRIDGE Health and on the Joint Action on Health Information (InfAct). They led to the development of the concept of a research infrastructure for population health information. In these projects it was already clear that there is a need to address fragmentation of databases and to address inequalities in health information across Europe. COVID-19 exacerbated some of these issues and exposed gaps in (inter)national health information sources. The aim of PHIRI is to address these now and overcome some of these issues also for the future. This is reflected in PHIRI's activities covering immediate needs and setting this up in a way to be able to also address future crises and needs. It is with pride I can introduce you to the people working at the forefront of the COVID-19 crisis. They have understood and experiences the advantages of sharing information and expertise across borders. This project has been developed during challenging times and with short deadlines, but a comprehensive and strong set of activities have been put together and will be presented today. Colleagues leading the work are experiencing on a day to day the struggles with health information and COVID-19. This experience is reflected into the activities in PHIRI that we have put together and we believe will strengthen our approach to overcome the crisis whilst developing methodologies, expertise, infrastructure and a network for years to come. Finally, a research infrastructure is nothing without its users and without being strongly embedded in the current landscape. Therefore I want to encourage you to talk about PHIRI and to make use of what PHIRI can offer you. I know for a fact our colleagues will do their very best to carry out their tasks and make this a successful project.

III. Introductory Speech of Johannes Klumpers - Head of Research and Industrial Infrastructures Unit at the Research and Innovation DG of the European Commission.

a) Apologies from his colleague who could not join

b) Strengths of the project: Impressive how quickly the project was started. Great example of joint efforts between the European Commission (EC) and the Member States (MS). PHIRI will help to create new links and collaborations across the European Union (EU) and be a cornerstone of the European Health Data Space. Interested to see how the information gathered in the project will contribute to help address fear and misinformation in the EU.

c) Concluding remarks: Be aware of the difficulties and congratulations for the large and quick collaboration started.

Picture 1: Johannes Klumpers – DG RTD

IV. PHIRI overview - Petronille Bogaert - Sciensano

a) See presentation slides

b) Timeline: Attention was brought to the timeline of PHIRI focusing on producing a bulk of the work in the first year and a half. It is important to react quickly.

V. WP 1 - Coordination and management - Petronille Bogaert - Sciensano

a) See presentation slides

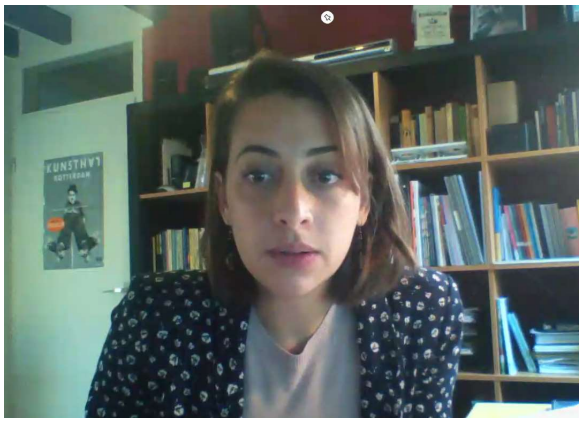
VI. WP 2 - Communication and Health Information portal development - Petronille Bogaert and Linda Abboud - Sciensano

a) See presentation slides

b) Create awareness of PHIRI and disseminate messages

c) Preparation of Health Information portal

d) Address Covid-19 population health infodemics through workshop and training in collaboration with WHO Europe



Picture 2: Linda Abboud - Sciensano

VII. WP 3 - Outreach, engagement and sustainability

a) See presentation slides

b) What are the struggles experienced by countries in monitoring of the effects of COVID-19? This will be captured through the country visits.

c) Stakeholders meetings: key to interact with national and international stakeholders to inform them and create collaboration and avoid duplication.

d) Aiming to create synergies through three long meetings and two shorter meetings every two months.

e) Integrate knowledge into policy through facts sheets. Important to summarize the main findings to key stakeholders.

Picture 3: Nienke Schutte and Petronille Bogaert – Sciensano

VIII. WP 4 - Health Information portal for COVID-19 – Hanna Tolonen - THL

a) See presentation slides

b) Questions

Andreas Holtel: Is there a formal recognition of National Nodes by countries? Will they work only on COVID-19 or will the collaboration persist beyond?

- **Hanna Tolonen**: No formal recognition at this stage, but hopefully in the future.
- **Herman Van Oyen:** the concept of National Nodes comes from previous projects so it goes beyond COVID-19. Available almost in 20 countries.
- **Sandra García Armesto**: the Joint Action TEHDAS (to develop the EHDS) will benefit from the PHIRI experience for COVID-19 and it will expand it beyond to tackle these issues.

Picture 4: Hanna Tolonen - THL

IX. WP 5 - Research methodologies to assess the impact of COVID-19 - Paulo Noguiera - Universidade de Lisboa

a) See presentation slides

b) Questions

Anna Wallace: What is the role of Cochrane, the WHO evidence synthesis effort?

- **Paulo Noguiera:** Looking at it, but not yet found the definitive synthesis. However, there are connections.

Aziz Naji: Does the data refers to health alone of individuals or is there a link to socioeconomics data linked to health data? Is this link already present or foreseen with other data providers?

Picture 5: Paulo Noguiera – Universidade de Lisboa

X. WP 6 - Research use cases measuring the impact of COVID-19 on population health - Martin Thißen - RKI

a) See presentation slides

b) Questions

Romana Haneef: Do you think there will be synergies between use case A and task 5.2 for determinants?

- **Martin Thißen:** Yes, it will be very important to share the experiences.

Andreas Holtel: Is the mode of operations to develop common data models for each individual research query?

- **Martin Thißen**: Yes this is the idea.

Carlos Luis Parra-Calderon: Will you try to index your data sets and analytics services in EOSC?

- **Petronille Bogaert**: We are exploring EOSC modules and are collaborating in the EGI-ACE project.

XI. WP 7 - Building a federated research infrastructure for a rapid policy response – Enrique Bernal Delgado - IACS

a) See presentation slides

b) Questions

Petr Holub: How will you handle data quality (implementation of quality control)? This is really critical point given how the data is produced in this domain.

Carlos Luis Parra-Calderón: Have you taken into account privacy aspects when doing data analysis in the federated infrastructure, applying the principle of Privacy Preserving Distributed Data Mining?

- **Enrique Bernal Delgado**: Data will not be moved, the scripts will. Data will be kept in hubs, to make sure they will stay in the countries. They are many solutions to reduce the risk of tracking patients. The different hubs have to ensure anonymity following their national regulations.

- **Juan Gonzalez-Garcia**: We are researching in Privacy Preserving Distributed Data Mining, but initial algorithms to be used do not require sophisticated AI, DM techniques.

Romana Haneef: How are "open source dashboards with trends..." different from the current available dashboards on COVID-19?

Andreas Holtel: Variables mapping for CDMs needs resources, is that catered for?

- **Enrique Bernal Delgado:** Limited time, so we have to be humble. The idea is to have concrete results.

- **Herman Van Oyen:** Main aim is that other researchers will be able to use what we develop.

Mauro Petrillo: Do you imagine a sort of "certification authority" process for the final deployment of the software? And a registry for storing/keeping the formulated questions?

- **Enrique Bernal Delgado**: All the analytical pipeline will be open source under creative commons attribution-non-commercial share. All the pipeline will be FAIR open access in PHIRI.

Alan Cahill: Synergies between this WP and TEHDAS, particularly around the legal aspects.

- **Petronille Bogaert**: Our colleagues from IACS are also leading WP6 and 7 in TEHDAS which is an advantage to make synergies between the two projects. Sciensano is also leading a workpackage and a task in TEHDAS.

Petr Holub: Do you aim to reuse some of the existing solutions to this federated computations sent to hubs? Like DataSHIELD or similar things developed in IMI ConcePTION (similar work was done in several EU-Canada related projects) this also links to the IMI ConcePTION. Plus from already existing RI perspective (BBMRI): we need to think not [only] about establishing new data hubs - but rather about defining/standardizing interfaces that existing data hubs can implement to participate in such an endeavour. Because otherwise it will be a lot of duplication at the national level.

- **Juan Gonzalez-Garcia**: What you have defined is exactly what is going to be designed in TEHDAS Joint Action: the APIs for a P2P EHDS

- **Enrique Bernal Delgado**: On using existing solutions. Assessment of potential solutions will be carry out in task on validation and upgrading.

Petr Holub: Same things are being defined in different projects and then it starts to become a nightmare for the datahubs. You should aim for upfront alignment and minimization of standards.

- **Juan Gonzalez-Garcia**: TEHDAS is a JA, leaded by DG Sante and will support a legislative initiative to be published by EOF 2021, so it can be a good forum.

- **Sandra García Armesto**: the key is building synergies and aligning strategies. We have a good set of tools and channels in our hands to work in this direction. The explicit interlink across initiatives we already profit from and are willing to strength is from my point of view quite reassuring as to avoid duplication or contradiction.

Andreas Holtel: Does any legal responsibility (GDPR) rest with 'owners' of transnational access platform, or is this legal responsibility exclusively with local data hosts?

- **Dimitra Lingri**: GDPR is responsibility also for transnational exchanges rel. Shrems II decision. Certified DPO, interested in further discussing the topic for WP4.

- **Enrique Bernal Delgado**: Work will be done along with WP4 in these details. For example, whether a DPO in the coordination hub is needed.

Picture 6: Enrique Bernal Delgado – IACS

XII. WP8 - Rapid exchange Forum – Claudia Habl – GÖG

a) See presentation slides

b) Rapid exchange, success stories

c) Call for everyone interested in the topic to join the bi-weekly meetings

d) External Inputs

Howard Needham: ECDC would be keen to join the biweekly meeting, as it can provide important resources for the understanding of emerging evidence on important areas, but also improve our "intelligence" on current policy issues in MS; obviously we can then promote these at EU level, and try to address those issues that are common to several MSs

XIII. WP9 – Foresight: Modelling and scenarios – Mariken Tijhuis - RIVM

a) See presentation slides

Picture 7: Henk Hilderink - RIVM

XIV. Panel Discussion

a) Impact: Giving the current pandemic, it is really important for countries to collaborate, exchange knowledge and identify gaps. Is the importance of media/ infodemia tackled?

- **Joao Forjaz**: Infodemics will be tackled.

- **Neville Calleja**: Courses are an essential part of the project. Especially with the upcoming vaccine, the use of infodemics will be essential. As part of preparation of PHIRI, there was a liaison with WHO Geneva for running an infodemic management course.

- **Claudia Habl**: Focus on active collaboration to exchange experiences. How did they tackle a specific issue corona related in other countries? Answer came really quickly. Positive effects in the long run to have this type of network

- **Herman Van Oyen**: the main aim is to make health information sustainable for researchers and policy makers. This type of collaboration started already in 2013 with many members. Discussion on how to provide researchers with access, reuse, skills on data. Decision to apply distributed way of working, already implemented in other sciences. The main aim is to build in this crisis to show the feasibility of the project and build further with other research infrastructures to achieve the EOSC and EHDS.

b) Sustainability:

- **Hanna Tolonen**: PHIRI is 3 year project with focus on COVID-19 but what is done does not only focus on COVID-19, the focus is on Health Information. The infrastructure will help many other activities performed at the EU level. Regarding ESFRI: Distributed Infrastructure on Population Health (DIPoH) proposal is one step forward to make it sustainable.

- **Sandra Garcia Armesto**: It is the correct moment to make use of all the initiatives coming up as a result of the crisis. And also building on the work already done. It is not only for this pandemic. Knowledge, population data coming from all the experts across the EU could be reused for multiple purposes. Building capacity.

- **Andreas Holtel**: it is crucial to see how much interest this project has already raised. ECDC, TEHDAS, preparedness for pandemics, new partnership in the making. PHIRI should be a key player to and stay on top of the initiatives. There is high interest at all levels, new partnerships where PHIRI can be a key player.

    (1) Develop smart task force to coordinate all these initiatives. Contact point between the EC and PHIRI.

Picture 8: Andreas Holtel - DG RTD

XV. Concluding remarks - Christian Leonard – Sciensano

a) Ensure that the source of information is of high quality and that data is collected in the same manner. Different ways of counting things across countries. What does it mean to be in good health? A lot of different definitions. A qualitative approach should be used to complement quantitative data.

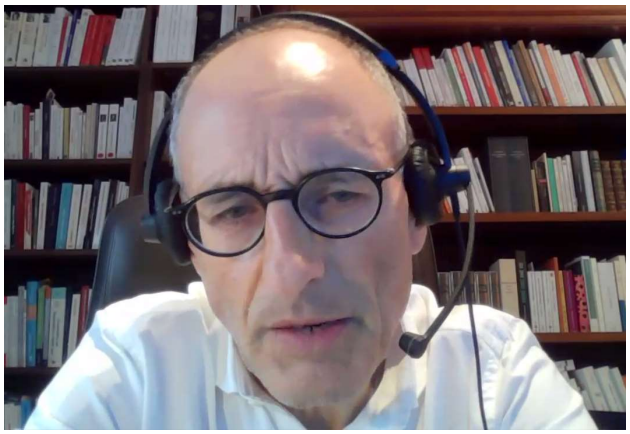
   - **Ronan Lyons**: Agrees with Christian Leonard. A lot of work needs to be done on definitions/standardisation before analysis and comparisons are made.

b) Avoid utilitarian approach: Give a broad vision of the health status. Regarding inequalities, a pure economic/ financial aspect cannot compensate the social aspects. Do not oversimplify.

c) Fight conspiracy theories by providing good data

d) Act together in the future

e) Conclusion on the utility of the project: Great for scientists and policy makers but also for the positive impact of high quality information on fake news at the international level.



Picture 9: Christian Leonard - Sciensano

XVI. Wrap-up and conclusions – Herman Van Oyen -Sciensano

a) Need to remain humble: Work with experienced colleagues (other RIs , EU institutions, international organisations).

b) Working together to build a sustainable infrastructure and minimize health information inequalities.

c) Attention towards capacity building to minimize the health information inequalities we are facing. Ensure PHIRI WPs pay enough attention to capacity building (horizontal activity). This started already in WP6 in Infact (school on health information).

d) Be involved as a group in the upcoming activities at EU level (TEHDAS, Healthy Cloud). Effective way to make this work sustainable.

e) Focus on facilitating research. However, close interaction with policy/ foresight is essential. Tool to interlink data science with other contextual information to support policies for the future. In the 4th pillar of DIPoH the aim is to strengthen research oriented to translate knowledge in different levels of intervention.

f) Data is evolving rapidly in the EU: higher need for cooperation with other initiatives.

Picture 10: Herman Van Oyen - Sciensano

XVII. Participants interested in being involved in PHIRI

a) **Christian Ohmann**: ECRIN-ERIC, the European Infrastructure for clinical trials. ECRIN is developing a COVID-19 repository for clinical trial data, which could be of interest for PHIRI.

b) **Jordi Rambla**: ELIXIR and the Federated European Genome-phenome Archive.

c) **Toni Andreu**: EATRIS happy to join the SG and share their experience on COVID-19, in particular related to Personalized-targeted approaches.

d) Aziz Naji: Looking forward on how we could use this research infrastructure in the frame of our next call for proposals.

e) **Petr Holub**: BBMRI-ERIC European Research Infrastructure. Interested in being included in the data sources - because we have already established data sources in most of European countries. Aggregated view of the COVID data sources in our RI: https://web.bbmri-eric.eu/Directory-files/directory-global-covid-map-5-0-big-nolabels.png.

- **Martin Thißen**: Dear Petr, happy for your offer of collaboration. It would be great if we can discuss the topic within the stakeholder meeting in December and more in depth in our WP meetings.

XVIII. Annexes

a) Agenda of the meeting

AGENDA
Kick off meeting

Population Health Information Research Infrastructure [PHIRI] for COVID-19

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

Nr	**November 19** 09:30-12:30 via Webex (online)	Speaker	Time
1	Welcome	Johannes Klumpers *Head of Unit for Research & Innovation Infrastructures - European Commission / DG RTD*	09:30
2	Introduction of PHIRI	Petronille Bogaert & Nienke Schutte *Sciensano, Belgium*	09:40
3	WP 1 - Coordination and management WP 2 - Communication and portal development WP 3 - Outreach, engagement and sustainability	Linda Abboud & Petronille Bogaert *Sciensano, Belgium*	10:00
4	WP 4 - Health Information portal for COVID-19	Hanna Tolonen *THL, Finland*	10:15
5	WP 5 - Research methodologies to assess the impact of COVID-19	Paulo Noguiera *DGS/FMUL, Portugal*	10:30
6	WP 6 - Research use cases measuring the impact of COVID-19 on population health	Martin Thißen *RKI, Germany*	10:45
BREAK			11:00
7	WP 7 - Building a federated research infrastructure for a rapid policy response	Enrique Bernal Delgado *IACS, Spain*	11:15
8	WP 8 - Rapid Exchange Forum	Claudia Habl *GÖG, Austria*	11:30
9	WP 9 - Foresight: Modelling and Scenarios	Mariken Tijhuis *RIVM, The Netherlands*	11:45
10	Panel discussion	All WP leaders, moderated by Nienke Schutte	12:00
11	Concluding remarks	Christian Léonard *General director - Sciensano, Belgium*	12:20
12	Wrap up	Herman Van Oyen *Scientific director - Sciensano, Belgium*	12:25
END			12:30

b) Slides from the Work Packages´ presentations

Population Health Information Research Infrastructure (PHIRI)

19/11/2020 Kick off Meeting

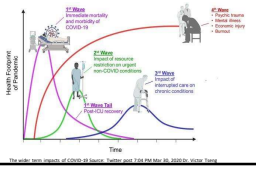
Name: Petronille Bogaert, Nienke Schutte, Linda Abboud, Miriam Saso and Herman Van Oyen
Email: phiri.coordination@sciensano.be

This project is funded by the Horizon 2020 - Research and Innovation Framework Programme of the European Union

Welcome

PHIRI Overview

- Name: Population Health Information Research Infrastructure (PHIRI)
  - Timeline: 1 November 2020 - 3 years
  - Financing: DG RTD - 4M€
  - Coverage: 41 partners in 30 countries
  - Structure: 9 workpackages and 3 transversal topics



The wider term impacts of COVID-19 Source: Twitter post 7:04 PM Mar 30, 2020 Dr. Victor Tseng

Map with PHIRI Partners. Source: http://philarcher.org/diary/2013/euromap/

PHIRI for Covid-19

- Population Health Information Research Infrastructure (PHIRI) aims
  - the identification, access, assessment and reuse for research,
  - population health and non-health data in MSs and across MSs
  - that can underpin public health policy decisions relevant to Covid-19.

In close interaction with key stakeholders in the health information landscape, in particular with ECDC, EUROSTAT, JRC, OECD, and WHO.

PHIRI for Covid-19

Objectives?

1. To provide a **Health Information portal** for COVID-19 with FAIR catalogues on health and health care data for structured information exchange across European countries. 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**. It allows researchers to provide relevant and evidence based information ready for use in research, and decision-making processes.
3. To promote **interoperability** and tackle health information inequalities. PHIRI supports researchers and public health bodies to research queries related to COVID-19 and provides **capacity building** for management of COVID-19 relevant population health and healthcare data

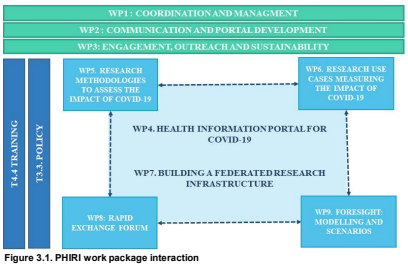


Figure 3.1. PHIRI work package interaction

Timeline

PHIRI timeline

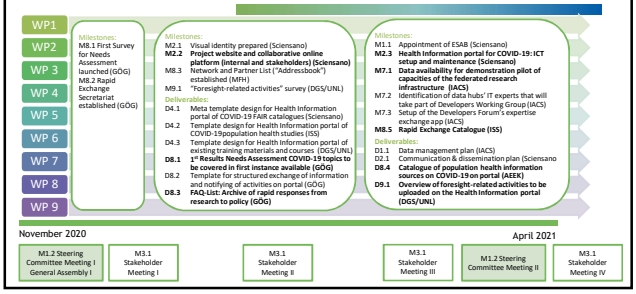
- November 2020 – October 2023 (3 years)
- Biannual Steering Committee meetings
- Yearly General Assemblies
- Bimonthly Stakeholder Meetings

Phase 1	Phase 2	Phase 3
Design & Pilot	Validation	Implementation

Date	Meeting
19 November 2020	General Assembly I – Kick off
15/16 November 2021	General Assembly II
24/25 November 2022	General Assembly III
28/29 September 2023	General Assembly IV (final)

Date	Meeting
December 2020	Stakeholder Meeting I
February 2021	Stakeholder Meeting II
April 2021	Stakeholder Meeting III
June 2021	Stakeholder Meeting IV
etc	

PHIRI timeline



WP1 – Coordination and management

Aim

To manage the project and to systematically monitor its activities in order to support the construction of the *Population Health Information Research Infrastructure*

To coordinate the day-to-day follow-up of the scientific, administrative and financial aspects.

Activities WP1

1. Represent PHIRI
2. Provide support to all WPs
3. Develop data management plan
4. Oversee peer review evaluation process
5. Prepare interim, final reports and financial reporting

WP2 – Communication and Portal Development

Aim

To establish PHIRI communication and dissemination tools and channels within and outside PHIRI

Activities WP2

1. Create more awareness for PHIRI
2. Disseminate with targeted messages to wide audience
3. Prepare the backbone for the Health Information Portal
4. Address COVID-19 population health infodemic through workshop and training

Communication tools and dissemination channels

- www.phiri.eu
- @PHIRI4EU
- PHIRI
- www.HealthInformationPortal.eu
- Logo
- Newsletters
- PHIRI.coordination@sciensano.be

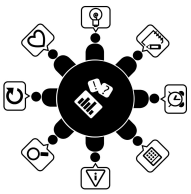
WP3 – Outreach, engagement and sustainability

(Virtual) country visits

- Mapping the state of play to monitor the wider effects of COVID-19
- Collaboration WHO Europe

Stakeholder meetings

- National stakeholders:
  - Ministry of Health
  - Ministry of Research
- International stakeholders:
  - Notably ECDC, JRC, EEA, ESAF, EOSC, Eurostat, EU COVID-19 Data platform, WHO, OECD and other Research Infrastructures



Knowledge translation

Integrating knowledge into policies

- Transversally oversee PHIRI's policy activities and support their
- Fact sheets and sustainability plan

phiri.eu @PHIRI4EU
phiri.coordination@sciensano.be

This project is funded by the Horizon 2020 - Research and Innovation Framework Programme of the European Union

PHIRI WP4 Health Information Portal for COVID-19

Kick-off meeting, 19th November 2020

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

Health Information Portal for COVID-19

- To build the Health Information Portal on health and health care data for COVID-19 to support structured information exchange between EU countries.
- Would cover not only patient data but population level data as well.

Input to the health information portal

Catalogue of national nodes

Catalogue of existing training materials and courses

Catalogue of COVID-19 data sources incl. also population health studies

Legal and ethical toolbox

What is a National Node?

- A network of national stakeholders working with the health information and being owners/controllers of health and health care data
- During the InfAct, several countries have already established their national node
  - Format and composition varies between countries. No one-fit-for-all model.

Role of national nodes in PHIRI

Provides for NNs

Possibility to increase national collaboration between relevant stakeholders.

Knowledge of HI related actions in other countries, benchmarking of own activities.

National Nodes

WP4 organizes NN meetings to facilitate interaction between NNs and coordinates information requests

Provides to PHIRI

Information about data sources, capacity building activities, legal and ethical aspects of data exchange etc. in the country

Capacity building in PHIRI

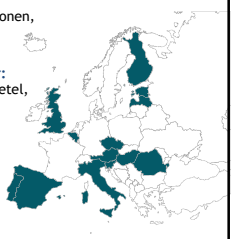
- Different WPs generate guidelines, methodologies, tools etc., and provide different kinds of capacity building activities to promote them among MSs.
- WP4 will coordinate these activities and supports organization of required capacity building activities.

WP4 Organization

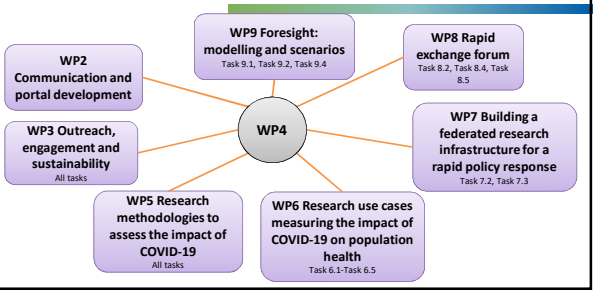
Partner	Task				
	4.1	4.2	4.3	4.4	4.5
Sciensano, BE					
GÖG, AT					
UZIS, CZ					
NIHD, EE					
THL, FI					
AEEK, HU					
ISS, IT					
CDPC, LV					
DGS/UNL, PT					
INSP, RO					
NIJZ, SI					
ISCIII/CNE, ES					
IACS, ES					
SU, UK					

Leader:
Hanna Tolonen,
THL, FI

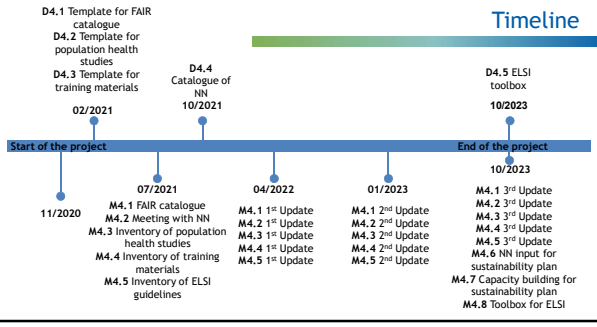
Co-leader:
Metka Zaletel,
NIJZ, SI



Interaction with other WPs



Timeline



Thank you!

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

PHIRI for Covid
WP5 Kick-Off meeting
19/11/2020

Research methodologies to assess the impact of COVID-19

Population Health Information Research Infrastructure (PHIRI)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101016317

Partners

Work package number	5			**Lead beneficiary**			DGS/FUML (co-lead: ISCII)				
Work package title	Research methodologies to assess the impact of COVID-19										
Participant number	1	2	3	5	6	7	9	11	12	13	15
Short name of participant	SCIENSANO	GAG	FBiH	CPH	UZIS	NIHD	SpFrance	RKI	EOPYY EOPYY / UTH	AEEK	ISS
Person-months per participant:	2.1	0.8	2	1.7	2.5	1.2	9.1	2	1.8	2.5	5.2
Start month	1			**End month**			36				
Participant number	16	24	25	28	29	32					
Short name of participant	CDPC	DGS DGS / FMUL DGS /UNL	INSP	NLZ	ISCIII	SU					
Person-months per participant:	2.1	20	2.1	1.7	15	0.4					
Start month	1			**End month**			36				

Objectives

The aim of this work package is to support European countries to understand the impact of COVID-19 on population wellbeing and health, morbidity and mortality using a multidisciplinary approach, under the umbrella of a COVID-19 impact framework and population science, in order to be better prepared for current and future crises.

The specific objectives

O5.1. To map and synthesize the methodologies, determinants and risk settings to foster research on the impact of COVID-19 on wellbeing, morbidity and mortality across European countries at subnational, national and European Level.

O5.2. To identify useful innovative promotion, prevention and care indicators and methods to characterize effects of COVID-19.

O5.3. To gather information about indicators, and its variability, used by different countries and other organisations such as WHO, and propose harmonization.

O5.4. To synthesize research and data pathways for analyzing impact of COVID-19.

Tasks

Task 5.1: COVID-19 impact indicators and methodologies

(lead:DGS/FMUL, ISCIII/CNE ; Partners: RKI, ISS, UZIS, CDPC, AEEK, INSP, NIJZ, GOG, FBiH, CIPH, NIHD; Months 1-36)

Task 5.2: Exploring the determinants of the severity of long-term health outcomes of SARS-COV2 infection

(lead:SpFrance ; Partners: ISS, FMUL, ISCIII/CNE, UZIS, AEEK; Months 1-36)

Task 5.3: Efficacy of new digital tools for COVID contact tracing and assessment of its impact on health and social behaviors

(lead: ISS; Participants: FMUL, CDPC, INSP, DGS/UNL, NIHD, EOPYY, EOPYY/UTH; Months 1-24)

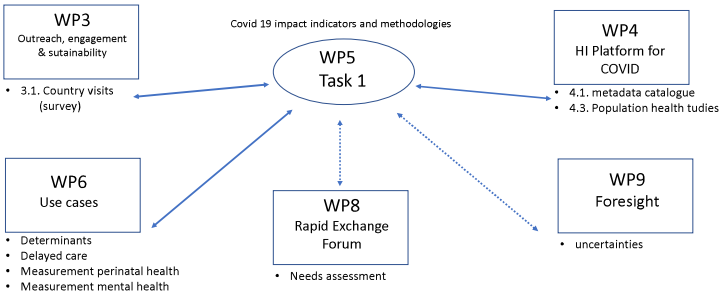
Task 5.4: Capacity building exercises on COVID-19 impact assessment.

(lead: Sciensano ; Partners: DGS/FMUL, ISCIII/CNE, ISS, SW, DGS/UNL, FBiH; Months 1-24)

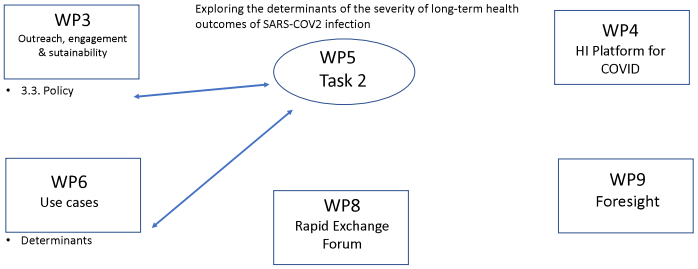
Deliverables

- **D5.1:** Report on the identification on determinants and risk settings associated with COVID-19 and prevention and intervention strategies (M15) Responsible: SpFrance
- **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. (M24) Responsible: ISCIII/CNE
- **D5.3:** Report on innovative approaches for health impacts assessment in Europe: the role of digital tools and emerging devices (M24), Responsible: ISS
- **D5.4:** Report on contribution of Artificial Intelligence on assessing the impact of COVID-19, including ethical and legal key considerations and recommendations (M24) Responsible: EOPYY/UTH

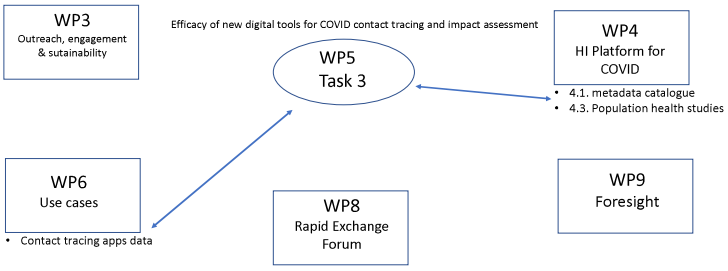
WP5 - Research methodologies to assess the impact of COVID-19 – Relation with other WPs



WP5 - Research methodologies to assess the impact of COVID-19 – Relation with other WPs

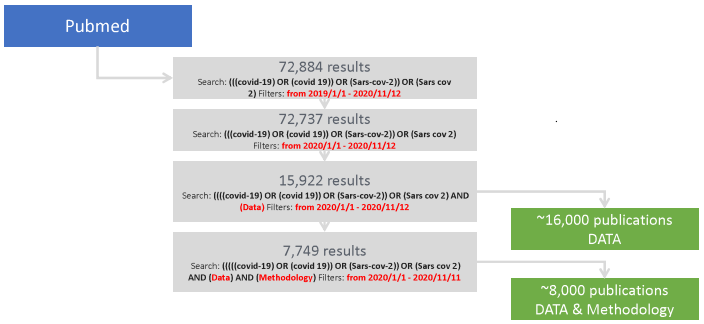


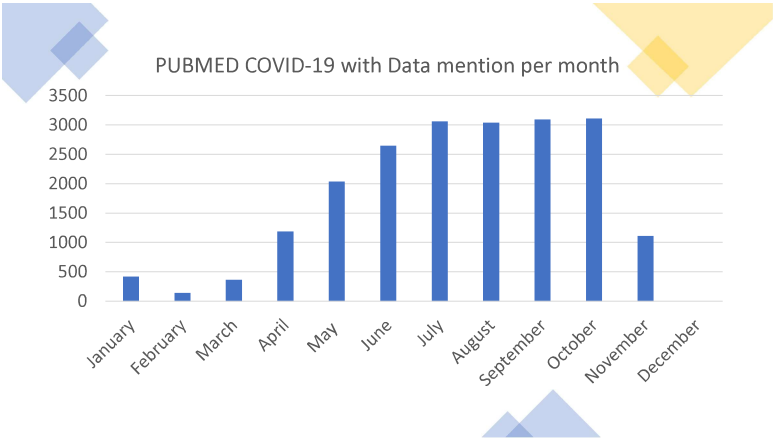
WP5 - Research methodologies to assess the impact of COVID-19 – Relation with other WPs

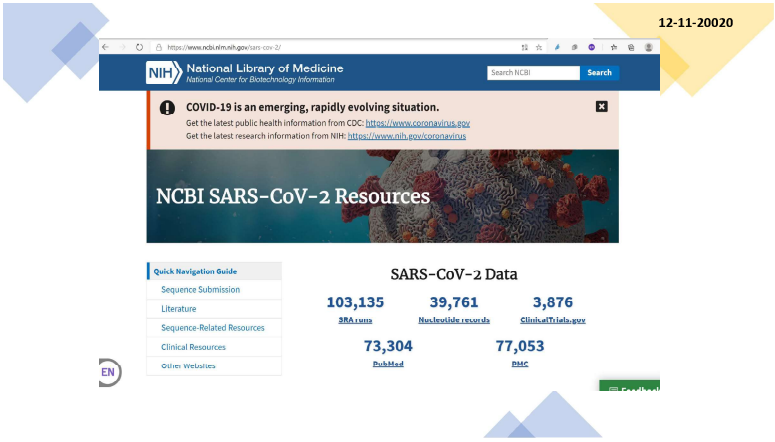


A 1st scientific literary search

On the 12/11/2020







Strategy/Workplan

- Literary review
- Conceptual approach
- Interaction with country visits
- Surveys
- Case studies

- Strong planning and interaction with tasks and subtasks
- Interaction with all WPs

Comunication plan

- Monthly WP5 Partners meetings
- Subtasks 5.1. meetings every two weeks
- Other subtasks specific plans

Population Health Information Research Infrastructure (PHIRI) — WP6

19/11/2020 General Assembly Kick-off Meeting

Name: Martin Thißen, Stefanie Seeling, Thomas Ziese
Email: PHIRI-Germany@rki.de

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

WP6 — Objectives

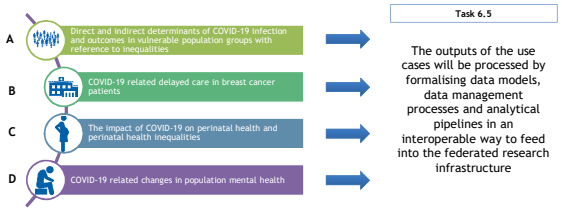
Research use cases measuring the impact of COVID-19 on population health

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:

1. Conduct research through use cases of immediate relevance on the consequences of the COVID-19 pandemic on European population health
2. Pilot activities for the benefits and added value of a research infrastructure by bringing together data from different European countries and feeding the results into the federated research infrastructure

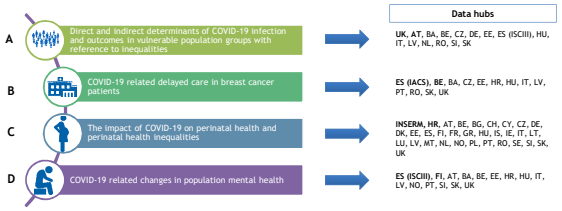
WP6 — Tasks

WP6 will look at COVID-19 impacts in specific subgroups by conducting research through real life use cases of immediate relevance

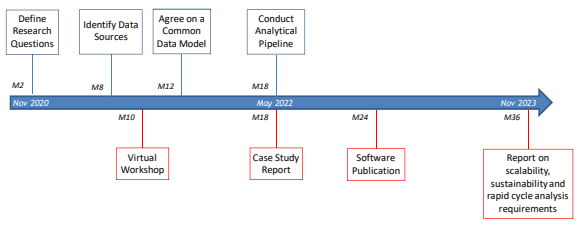


WP6 — Tasks

WP6 will look at COVID-19 impacts in specific subgroups by conducting research through real life use cases of immediate relevance



WP6 — Timeline



WP6 — Expected outcomes

1. WP6 facilitates research by making scalable, reproducible methods available (WP5)
2. WP6 outputs feed into the federated research infrastructure (WP7)
   - Data models, analytical pipelines and reporting solutions published in a public open access repository
3. WP6 FAIRified use cases analysis results publication in the data portal (WP4)
   - Aggregated data and metadata, for the development and the analysis results of the use cases
4. WP6 provides outcomes to guide policy makers in preparedness and response scenarios (WP9)
5. WP6 will ensure the development of a format for the timely dissemination of use case results to the targeted groups, e.g. through fact sheets (WP2, WP3) and via webinars (WP8)

WP6 — Interaction with international organisations

- Technical support and experiences
- Support knowledge translation
- Soft skills capacities to reach out to data providers

- Integrate surveillance data to respond to specific queries and investigate the added value

JRC and ECDC will be invited to participate in the use case meetings

Thank you very much for your attention!

WP7 Building a federated research infrastructure for a rapid policy response

Kick-off meeting November 19th, 2020

Enrique Bernal-Delgado, Juan González-García, IACS, ES
Ronan Lyons, Swansea University, Wales, UK

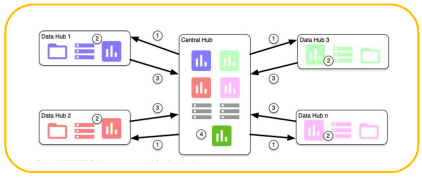
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101016317

Outputs

1) A federated demonstration pilot on rapid cycle analysis on COVID19
   - Open source dashboard with trends and predictions on a number of measures
2) Validated solutions for a federated research infrastructure on COVID19
   - Based on use cases WP6 & and demonstration pilot 7.1
   - Feeding PHIRI portal
3) A network of IT developers capable of sustaining and upgrading the FRI
   - Those technical people in the data hubs
   - Linked to capacity building activities in WP4

Developing a research infrastructure based on the secondary use of routine data

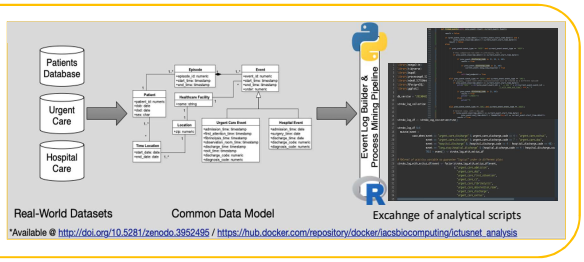
THE ARCHITECTURE



Privacy and safety by design
No data motion across the FRI - just scripts move
Data hubs host and curate data and/or have "easy" access to data
Coordination hub: develops code, coordinates code exchange and supports hubs

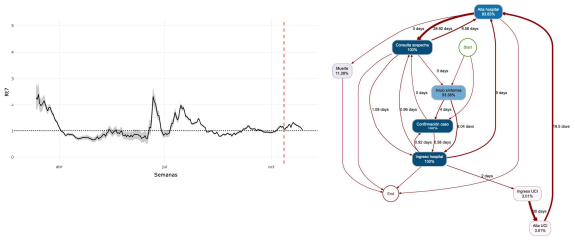
Routine linkable data
Individual level (anonymised or pseudonymised)

Qs



*Available @ http://doi.org/10.5281/zenodo.3952495 / https://hub.docker.com/repository/docker/iacsbiocomputing/ictusnet_analysis

Demonstration pilot on rapid cycle analysis



Linkage and exchange

- TEDHAS JA
  - Development of the European Health Data Space
- HEALTHY CLOUD
  - Strategic Agenda for the development of the Health Research and Innovation ecosystem in Europe.
- ECDC
  - Assessment and/or reuse and/or adaptation of ECDC data models and analytical pipelines
- JRC
  - Taking advantage of JRC developments on distributed analysis
- EOSC – upgrading the FRI services

Kick-off meeting
Dec 16th, 12 to 2 pm

WP7 Building a federated research infrastructure for a rapid policy response

Kick-off meeting, November 19th, 2020

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101015917

PHIRI - WP8 Rapid Exchange Forum
(PHIRI-REF)
Intro at the Kick-off Meeting 19/11/2020

Claudia Habl, Isabella Röhrling (GÖG,
PHIRI.Austria@goeg.at)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

Objectives

Establish a sustainable infrastructure to **support and facilitate rapid exchange** between
- competent authorities for pandemic response and their advisors,
- researchers in the field and
- stakeholders (EU networks, ECDC, JRC, WHO)

in our joint efforts to handle the COVID-19 pandemic.

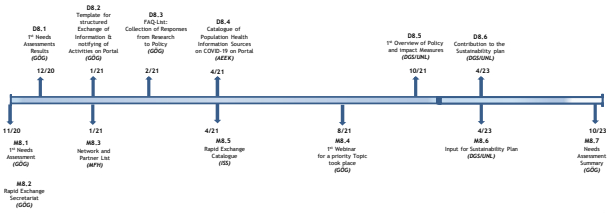
We offer
1. rapid responses to research and policy questions that are raised in countries
2. to promptly disseminate internationally agreed guidelines, standards and reports
3. to exchange (best) practices among countries regarding COVID-19
4. to provide expertise to policy considering the shifting landscape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

Tasks and Partners

WP Lead: GÖG (AT), Co-Lead: MFH (MT)

Task	Topic	Months	Lead + Partners
8.1	Needs Assessment of COVID-19 topics to be covered in first instance	1-36	**GÖG**, DGS/UNL, AEEK, MZ
8.2	Build up a one-stop shop for and between countries seeking for urgent answers	1-36	**GÖG**, MFH, Sciensano, DGS/UNL, NCZI, AEEK, ISS, ISCIII, NCZI, MZ, EOPYY/UOC, + all other partners
8.3	Establish a reliable network of experts and expertise for short-term inquiries involving existing and future Networks	1-36	**MFH**, GÖG, DGS/UNL, NCZI, Sciensano, ISS, MZ, NCZI, MZ, EOPYY/UOC;
8.4.	COVID-19 related international guidelines, initiatives, projects and information sources	1-36	**AEEK, ISS,** DGS/UNL, MFH;
8.5	Monitor COVID-19 Policy and Impact Measures	1-36	**DGS/UNL**, ISCIII, GÖG

Timeline



Our Activities / Outputs

- **Bi-weekly Rapid Exchange Forum every 2nd Monday from 10.00-11.00 am** → first one took place on 16/11/2020 with 29 attendees
- **Needs Assessment Survey to collect priorities** in pandemic response from a public health perspective → Snowballing planned through national partners → Priority List will be regularly up-dated
- Address book with **"National Focal Points for Corona Response in charge of Public Health Topics"** i.e. collection of list of official advisors to MoH, Agencies → we will need your help
- Based on Needs Assessment expressed by participants in the REF, a **catalogue of topic experts** will be compiled and such experts would be asked for briefings in future REFs → input in REF

Our Activities / Outputs

- We will provide relevant population health guidelines, standards, and reports and create a **catalogue of existing international initiatives and projects on COVID-19 related treatments, interventions and measures** in Europe → AEEK/ISS working on inclusion criteria for "relevant" guidelines, initiatives, projects for priority topics identified in the Needs Assessment Process (T8.1)
- Mapping, regular monitoring and assessing of **policy and impact measures** (non-pharmaceutical interventions) to control the pandemic → links (e.g. Oxford Governance Response Index) to be provided in the planned "Catalogue" on the **Health Information Portal**

Success Stories from JA InfAct

- In the first exchanges the "counting of Covid-19 deaths" was heavily debated, finally leading also due to WHO Guidance on a coordinated approach in Europe
- Data on ICU resp. intermediary care use and capacity were exchanged
- Austria abolished the very popular face shields / visors as the unclear evidence for their uselessness was backed up with expertise from other countries, where it had not worked

→ EXPERTISE GOT a FACE which will be continued in PHIRI Rapid Exchange Forum

INVOLVEMENT OF OTHER WPs/PROJECT PARTNERS

- WP 1: Close cooperation of Sciensano and GÖG in the role as "Secretariat"
- WP 3: Cooperation in the Exchange with Stakeholders and Input to Sustainability Plan (T3.3)
- WP 4: Web-based search of T 8.4. will be performed in cooperation with Task 4.3 collecting relevant scientific population health publications. FAQ-Section for portal.
- WP 6: Use cases will be presented in T 8.2. bi-weekly webinars
- WP 7: Will use T8.4. and T8.5. findings as well as FAQ derived from T8.2. as data driven source of evidence → our catalogue is a "living source" of the mentioned Health Information Portal.
- WP All PHIRI project partners will be asked to share relevant guidelines, reports and policy measures resp. their impact with T8.4 resp. T8.5.

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

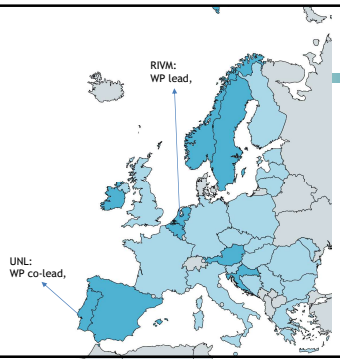
General Assembly, 19th November 2020

WP9 Foresight
Modelling and Scenarios

Henk Hilderink, Linda Berger, Daniela Moye Holz, Mariken Tijhuis (RIVM, NL); Luis Lapão (UNL, PT)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101016577

WP9 Partners



Nine countries

Capacity building in all countries

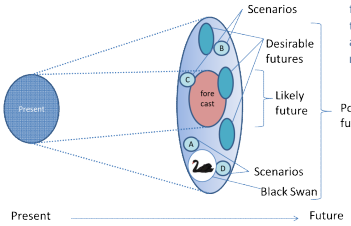
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101016577

WP9 overall aim and objectives

To gain insight in possible future health impacts of the SARS-CoV-2 outbreak by developing scenarios for countries' national situation, and from this collectively also draw lessons for the EU

1. overview of European public health foresight experience
2. level and strengthen European public health foresight capacity
3. support evidence-informed policy decisions
   1. direct and indirect effects
   2. on short and long-term
   3. broad conceptual model of health and care

Foresight: from present to future



Foresight is a systematic, participatory, future-intelligence-gathering and medium-to-long term vision-building process aimed at enabling present-day decisions and mobilizing joint actions.

Scenario is a coherent, internally consistent, systematic and plausible description of a possible future state of the world.

WE DON'T PREDICT THE FUTURE

WP9 stepwise approach = tasks

1. Inventory of current foresight activities and initiatives in EU & beyond (scenario studies, modelling, preparedness, other e.g. dashboards)
2. Building foresight capacity (leveling knowledge and networking)
3. Using this capacity to develop scenarios providing insight in potential future challenges (national and pan-European) for public health and care
   - direct and indirect
   - short term (0-5 years) and longer term (5-20 years)
   - route 'in-depth' or route 'general picture'
4. Guiding development of promising policy strategies to anticipate the identified possible future trends or to achieve a more desirable future (translating the knowledge, identify gaps and needs to face preparedness)

WP9 outcomes & timeline

Tasks	Outcomes	Date
9.1	Survey 'foresight-related activities'	M03
	Overview of foresight-related activities	M06
9.2	Capacity building workshops with all interested countries	M12
9.3	Collective template 'foresight scenarios'	M12
	Countries present key uncertainties and challenges, partners collectively draw lessons for EU (synthesis report)	M20
9.4	Policy workshop	M27
	Fact sheets with main recommendations for policy making	M33

Nov 1st 2020

Jan 2021
Apr 2021
Oct 2021
Oct 2021
Jun 2022
Jan 2023
Jun 2023

WP 9 Foresight	M1-3	M4-6	M7-9	M10-12	M13-15	M16-18	M19-21	M22-24	M25-27	M28-30	M31-33	M34-36
9.1 Inventory foresight	M9.1	D9.1										
9.2 Capacity building				D9.2								
9.3 Scenario development				M9.2					D9.3			
9.4 Knowledge translation							M9.3				D9.4	

WP9 First steps

- Kick-off 13th November 2020
- Organise Task 9.1 meeting (UNL/PT) and start the work
- Organise WP9 general meeting to exchange experience and practically prepare the foresight capacity building and scenario building (RIVM/NL)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

Collaboration and exchange with EU stakeholders

(among others…:)

- ECDC
- EUPHA:
  - Section 'Foresight'
- EuroHealthNet
- European Burden of Disease networks (EU, WHO-EU)
- JRC
  - EC Competence Centre on Foresight
- OECD

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In summary

- A better understanding of possible future developments is essential for policy makers to anticipate and possibly influence these trends.
- Public health foresight studies (PHFS) are tools to support this kind of understanding and to support its translation into policies.
- WP9 will help countries/organisations prepare for the future
  - Deliver foresight information to the Health Information Portal
  - Develop and provide foresight capacity building and training
  - Develop and provide tools and methodology for coronavirus-inclusive foresight studies
  - Assist the health research and policy community in knowledge translation

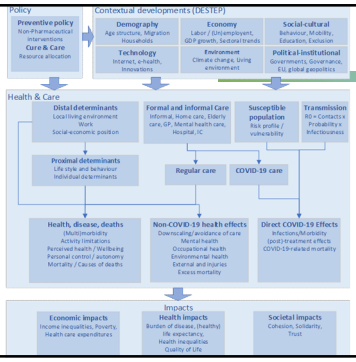
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

Thank you!

UNIVERSIDADE NOVA DE LISBOA

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317

National Institute for Public Health and the Environment
Ministry of Health, Welfare and Sport

Additional slide

Conceptual model