PHIRI
Population Health Information Research Infrastructure

Scientific Stakeholder Meeting Minutes

14th of January, 09:00-12:30 via Webex (online)

Phiri.coordination@sciensano.be

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

Attendees - 143

Aleksandar Medarevic (IPHS), Adelina Comas-Herrera, Agnes Toll (AEEK), Akofa Bart- Plange, Alberto Cusinato (EC), Alex Patak (EC), Alexis Sentís, Amalia Munoz Pineiro (EC), Andreas Holtel (EC), Anne-Catherine Vanhove (Cochrane), Arshiya Merchant (Elixir), Ausra Zelviene, Bangin Brim (EC), Barthélémy Moreau de Lizoreux (PHIRI), Brecht Devleesschauwer, Brigid Unim (ISS), Cahill Alan (Ireland department of health), Carlos Telleria (ARAGON), Carmen Rodriguez-Blazquez (ISCIII), Catarina Luis (EVI), Cátia Sousa Pinto (SPMS), Claudia Dima (INSP), Claudia Habl (GÖG), Claudius Griesinger (EC-JRC), Clemens Wittwehr (EC-JRC), Cornel Riscanu (EC-RTD), Daniela Moye (RIVM), Danny Van Roijen (COCIR), Dimitra Lingri (EOPYY), Brigitte Sambain (EC), Elena Petelos EOPYY), Eline Verhoeven (NIVEL), Elke Hanssens (EC), Emmanuelle Huck (EC), Enrique Bernal Delgado (IACS), Evelyn Depoortere (EC), Fabienne Lefebvre (EC- SANTE), Franca Moretti (ISS), Francisco Estupiñán (IACS), Francois Domergue (EMA), Gaetan Lafortune (OECD), Gergely Sipos (EGI), Graziano Onder (ISS), Hanna Tolonen (THL), Henk Hilderink (RIVM), Herman Van Oyen (Sciensano), Howard Needham (ECDC), Ilze Burkevica (EC-Eurostat), Inga Selecka (SPKC), Irisa.Zile (SPKC), Isabelle Chatelier (EC-SANTE), Istvan Csizmadia (OKFO), Ivana Ilijasic Versic (CESSDA), Ivo Rakova (WHO), Jan Cap (NHIC SVK), Jana Makedonska (EC-RTD), Jane Idavain (TAI), Janis Misins (SPKC), Jan-Willem Boiten, Jaroslaw Waligora (EC-SANTE), Jelena Dimnjakovic (HZJZ), Jinane Ghattas, John Middleton (ASPHER), Jose Penalvo (UnCover), Juan Gonzalez-Garcia (IACS), Julia Knoblechner, Julia Levy, Karen Andersen-Ranberg, Karen Facey, Karin Nygard (FHI), Katharina Lauer, Katja Kivinen, Lacramioara Brinduse (INSP), Lander Willem (EpiPose), Laure Carcaillon-Bantata (Sante publique France), Leonor Nicolau, Licinio Kustra Mano (EC-SANTE), Linda Abboud (InfAct), Lore Merdrignac (EpiConcept), Lucia Gonzalez (HOPE), Luciana Neamtiu (EC), Luigi Palmieri (ISS), Luigi Bertinato (ISS), Luís Lapão (UNL), Luisa Minghetti (ISS), Lydia Fenz (GÖG), Sabine Lyson (EC), João Forjaz (ISCIII), Maddalena Querci (EC), Maire Connolly, Maria Panagiotopoulou (ECRIN), Marie Delnord (Sciensano), Marie Guichardon (EUPHA), Mariken Tijhuis (RIVM), Marina Karanikolos, Marta Marin (ISCIII), Marta Valenciano (EpiConcept), Martin Thißen (RKI), Merike Rätsep (TAI), Metka Zaletel (NIJS), Miguel Penalver (EC), Mika Gissler (THL), Minna Hendolin (SITRA), Miriam Saso (PHIRI), Mirza Balaj (CHAIN), Monika Ślęzak (EUVaccine), Neville Calleja (Government of Malta), Nigel Hughes (EHDEN), Nienke Schutte (PHIRI), Pascal Garel (HOPE), Paul Timmers, Pauline White, Peter Bezzegh (AEEK), Petr Holub (BBMRI), Philibert Marianne (INSERM), Patrick Mahy, Robert Lang (AEEK), Ronan Lyons (SU), Rosalyn Keys (EC), Rosita Claesson Wigand, Saara Malkamäki (SITRA), Sabrina Montante (ISS), Sarah Vercruysse (EpiPose), Dimitrios Sarikizoglou (EC), Sarka Dankova (UZIS), Sergei Gorianin (ECRIN), Sharon Kappala (HRB), Sharon Sorohan, Sherry Merkur, Simon Thompson, Stefan Mathis-Edenhofer (GÖG), Stefanai Davia (WHO), Stefanie Seeling (RKI), Stephan Schug (IQMED), Szabo Mihaly (EC), Tapani Piha (SITRA), Tatjana Makovski (Sante publique France), Teresa López-Cuadrado (ISCIII), Tina Purnat (WHO), Toni Andreu (EATRIS), Veronika Máté, Zuzana Nordeng (FHI).

Aim of the meeting

We believe that exchanging expertise, methods, and tools and identify synergies with other organizations, projects and initiatives working in the same field is essential to build on what exists, to learn from each other and to avoid duplication. Therefore, this Stakeholder Meeting aims to:

- Present PHIRI´s activities that are relevant for researchers across Europe in four themes: Health Information Portal, federated research infrastructure and research use cases, methodologies to assess the impact of COVID-19 and foresight (modelling and scenarios).
- Host pitches from relevant stakeholders who are working in similar fields to identify synergies and areas of collaboration across international projects.
- Connect European researchers and projects leaders with relevant PHIRI partners and vice versa.

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I. Welcome session – Herman van Oyen, Sciensano

a) Introduction
b) Permission to record

II. PHIRI overview – Nienke Schutte, Sciensano

a) Aim of the meeting
b) Structure of the meeting

The meeting is divided in 4 main topics:

1. Health Information Portal for COVID-19
2. Federated research infrastructure & research use cases
3. Methodologies to assess the impact of COVID-19
4. Foresight: modelling and scenarios

Within each topic, a partner of PHIRI presents the work done within the PHIRI project. Then, relevant stakeholders are invited to present their work (3 minutes pitch). Finally, a short discussion between the PHIRI speaker and the invited stakeholders is promoted.

c) PHIRI overview

PHIRI stands for Population Health Information Research Infrastructure. It is a project financed under the Horizon 2020 from the Directorate-General Research and Innovation. It is divided in 9 work packages and it is driven by the work of 41 partners (27 National Institute of Public Health or Research or Disease Control, 7 Universities, 7 Ministries of Health) in 30 countries.

The project builds on two consecutive initiatives in health information: BRIDGE Health and the Joint Action on Health Information (InfAct). The project started in the beginning of November 2020 and it will last for 3 years. PHIRI will function as a practical pilot for the building of DIPoH - a Distributed Infrastructure on Population Health. During BRIDGE Health and InfAct, it already emerged that there is a need to address the 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 immediate needs to overcome future crises and needs by identifying, accessing, assessing and reusing research population health and non-health data in Member States and across Member States that can underpin public health policy decisions relevant for COVID-19. The activities will be performed in close interaction with key stakeholders in the health information landscape, in particular with ECDC, EUROSTAT, JRC, OECD, and WHO.

This project has been developed during challenging times and with short deadlines, but a comprehensive and strong set of activities has been put together and is presented during the meeting. Colleagues in the health information field are experiencing on a day to day the struggles with health information and COVID-19. These experiences are reflected into the activities of PHIRI which aim to strengthen our approach to overcome the crisis whilst developing methodologies, expertise, infrastructure and a network for years to come.

d) Objectives of PHIRI

The objectives of PHIRI are:

1. To provide a Health Information Portal for COVID-19 with FAIR catalogues on health and healthcare 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.

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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.

e) Work performed by PHIRI

See presentation slides (Annex B)

III. Health Information Portal for COVID-19 – Hanna Tolonen, THL

See presentation slides (Annex B)

The Health Information Portal on health and health care data for COVID-19 will support structured information exchange between EU countries. It will cover not only data sources on patients but also data sources at the population level more broadly.

The Health Information Portal will be launched soon: healthinformationportal.eu

a) CESSDA ERICS – Ivana Ilijasic Versic: For what and for whom?

See presentation slides (Annex B)

- Cross-European resource discovery
- Improved quality of data and metadata
- A wider selection of comparable data
- Certification of data archiving organisations
- Professional training for data archivists and scientific community
- Improved mechanisms for data dissemination and analysis
- Strong involvement of organisations outside Europe

Connection with PHIRI

- Webpage on COVID-19 connected with the data catalogues. All data connected to COVID-19 is listed together with related topics. Started in the beginning of the pandemic
- Free trainings on COVID-19
- Open to collaborate

b) ECDC - Howard Needham: Possible areas of ECDC engagement

See presentation slides (Annex B)

- Collection of health information on infectious diseases
- ECDC produces several COVID-19 surveillance outputs
- Core datasets: TESSy with over 7 million COVID-19 cases included in database (Jan 2021)
- Epidemiological data: case numbers (COVID-19 cases, deaths), severity (Hospital and ICU admission) and genomic data: genetic variants
- Public health response: testing and country response measures

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Connection with PHIRI

- Share of data - TESSy
- Share of expertise (knowledge and understanding of the data but also strong links with COVID-19 networks and other agencies)
- Links to EU-level policy action: knowledge broker between research and policy at EU level
- Collaboration on understanding Member States research activities and data sets, and how that could support EU-wide public health goals
- Collaboration in guiding ECDC: as PHIRI is driven by Member States it offers unique "intelligence" on emerging concerns/uncertainty in Member States partner organisations

c) EUPHA - Marie Guichardon: EUPHA and PHIRI, what future?

See presentation slides (Annex B)

Connection with PHIRI

- EUPHA-Public Health Monitoring and Reporting (EUPHA-PHMR) section can ensure rapid transmission of the information between the two structures
- EUPHA can assist PHIRI in dissemination of the information and evidence – newsletter, column in European Public Health News of the EJPH (every two months), e-collection

d) ASPHER – John Middleton: Opportunities for joint work

See presentation slides (Annex B)

Connection with PHIRI

- PHIRI could support ASPHER in the review of the curriculum on health information
- Dissemination activities
- ASPHER 2021 member survey on topics connected with PHIRI
- Work on competencies e.g. disinformation

e) JRC – Clemens Wittwehr: Health Knowledge Factory

See presentation slides (Annex B)

- Produce knowledge from all the information sources that reach them: assembling health knowledge. Two approaches: top down and bottom up.

Connection with PHIRI

- Become familiar with selected research use cases in connection with the CIAO project (see presentation slides in annex B)
- Create policy based on scientific knowledge coming from e.g. PHIRI
- Help PHIRI in the development of soft skills: long experience of JRC in international collaborations

f) Questions

Gaetan Lafortune: Could someone say a few words about the "SANTE COVID registry". What might be the scope? How will it link with ECDC and Eurostat databases? Is it intended to become a public registry?

> **Nienke Schutte**: More information is needed on the COVID-19 registry to ensure there will be no duplication of work between DG SANTE, ECDC and Eurostat.

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Evelyn Depoortere: How will you get the information on all the research networks and how do you define them? Do they include EU research projects as well?

> **Hanna Tolonen**: Information on existing EU projects has been already collected. Initially the information is collected from the projects´ websites to avoid overburdening the research networks with extra work. It would be interesting to investigate further the process of web scraping of ECDC to obtain more information for the research networks. The collection of information is about to start so inputs on how to perform it best and keep the information up to date are welcome.
>
> **Herman Van Oyen**: PHIRI is the result of the collaboration of different research networks in InfAct, the joint action on health information on which PHIRI is built. Inclusion and exclusion criteria for adding the different research networks have been prepared and they are available on the InfAct website.

Claudia Habl and Karen Andersen-Ranberg: Could you (Gaetan Lafortune) explain the main activities performed by OECD on COVID-19?

> **Gaetan Lafortune**: OECD has started to and is continuing to collect and analyse data COVID-19.

- Analysis of data has been already released in the Health at the Glance in November (impact of COVID-19 on the EU countries - measures to contain the pandemic and the healthcare responses. Data from ECDC, Eurostat and own data collection.
- Production of policy briefs on multiple topics (health, education, poverty…).
- Update of the EU countries health profiles: COVID-19 will also be included especially in the resilience chapter.
- The crucial challenge is to get high quality data and real time data. Focus in the extra funding provided to the healthcare of countries. High use of ECDC data however, difficulties in splitting data on mortality by age.

Elena Petelos: The policy brief produced by OECD were really useful but they have not been updated since March. Are there plans to expand them?

> **Gaeten Lafortune**: Not in the pipeline at the moment. The focus will be more on vaccines and the role of primary healthcare and mental health issues.

Leonor Nicolau: How are you dealing with information in different languages for the Health Information Portal?

> **Hanna Tolonen**: The portal will be in English. Since we will be in contact with the national nodes, we can obtain information also in other languages. Yet, we have not decided how to present information in the portal which is not originally in English.

IV. Federated research infrastructure for rapid policy response – Enrique Bernal-Delgado, IACS

See presentation slides (Annex B)

The work and the results obtained by the PHIRI use cases presented in the next point of the meeting are the inputs and the information feeding the research infrastructure for rapid policy response. The objectives of the work package are to:

1. Build a federated demonstration pilot on rapid cycle analysis on COVID-19 with open source dashboard with trends and predictions on a number of measures

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2. Validate solutions for a federated research infrastructure on COVID-19 based on use cases of WP6 (next point of the meeting) which will feed the Health Information Portal on COVID-19
3. Establish a network of IT developers capable of sustaining and upgrading the federated research infrastructure

Building on the secondary use of routinely collected data.

a) ECRIN – Sergei Gorianin: Metadata Repository (MDR) for clinical research

See presentation slides (Annex B)

Metadata repository (MDR) for clinical research launched on 29 April 2020

- Single portal system linking clinical studies with related data objects (e.g., study protocol, datasets, statistical analysis plan, publications)
- Developed within the H2020-funded project XDC in cooperation by ECRIN, OneData and INFN (http://www.extreme-datacloud.eu/)
- Based upon the ECRIN metadata schema (https://zenodo.org/record/4133889#.X_RoY9hKjcs)
- Put in production for the ECRIN task force on COVID-19, linked as related resource to the European COVID-19 data portal and referenced in the RDA COVID-19 guidelines and recommendations
- Currently update and extension of the MDR in EOSC-hub (early adapter) and EOSCLife with expansion of data sources

b) BBMRI – Petr Holub: Potential PHIRI and BBMRI-ERIC collaboration

See presentation slides (Annex B)

Connection with PHIRI:

- Activities focusing on data on COVID-19
- Joint work on data standardization
- Development of production infrastructure to get reliable structured health data. Harmonization of the ecosystem to make the request for searching the data easier
- Standardization of provenance and its implementation – machine readable documentation of the history of data – Participation of PHIRI as a case test

c) EATRIS – Toni Andreu: EATRIS Health-data Actions and Activities

See presentation slides (Annex B)

Connection with PHIRI:

- Developing tools to ensure the highest quality and reproducibility of data generated during the research and innovation value chain
- Accelerating capacities of the use of health data for the clinical decision-making processes
- Cooperating with other health data-related initiatives to improve the efficiency of the value chain in the health care domain e.g. PHIRI
- EATRIS COVID-19 Research Forum: interactive platform for EATRIS COVID-19 researchers to interact, find collaborators, exchange protocols, samples, ideas…)
- Supporting European academy and industry for the fast progress of translational medicine

d) EGI-ACE – Sergely Sipos: Opportunities for PHIRI

See presentation slides (Annex B)

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Connection with PHIRI:

- PHIRI as an early adopter of the computer services offered by the project EGI-ACE
- EGI-ACE as a set of tools that can be deployed inside other projects e.g. PHIRI
- IT Service Management and trainings
- Tools to build the distributed data catalogues
- Technologies to facilitate the federation
- Use of data on the website without the need to download the data on the devices of the researchers

Interactions:

- Feb 5: EGI-ACE public launch event. Register at https://indico.egi.eu/event/5359/
- EGI-ACE Communities Workshop
    - Feb (Date TBD)
    - Resulting community-specific support plans and teams

e) Questions

Nigel Hughes: What common data model will PHIRI be adopting? Interested in discussing this topic further. PHIRI is using a bespoke Common Data Model, not a currently available one?

> **Enrique Bernal-Delgado**: Open to learn from others. Thinking to build on ad hoc data models.

Bangin Brim: What is the timeline regarding the Federated Research Infrastructure - and what was the rationale for these use cases (e.g. data availability, ...?)

> **Martin Thißen**: The criteria were: (1) public health importance (2) geographic coverage (3) feasibility of producing actionable results in 18 months and (4) relevance for the PHIRI infrastructure.
>
> Timeline: A demonstration pilot will be presented around month 12 of the project. In the third year, the focus will be on the upgrading of the services provided.

V. Research use cases on the impact of COVID-19 on population health – Martin Thissen, RKI

See presentation slide (Annex B)

The research use cases should 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

Real life use cases of immediate relevance

1. Direct and indirect determinants of COVID-19 infection and outcomes in vulnerable population groups with reference to inequalities
2. COVID-19 related delayed care in breast cancer patients
3. The impact of COVID-19 on perinatal health and perinatal health inequalities
4. COVID-19 related changes in population mental health

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f) Eurostat – Ilze Burkevica

See presentation slides (Annex B)

Connection with PHIRI:

- Recovery Dashboard
- COVID-19 statistics area on Eurostat website
- Methodological corner: support session for statisticians to help them in data collection

VI. Research methodologies to assess the impact of COVID-19 – Joao Forjaz, ISCIII

See presentation slides (Annex B)

Objectives:

- Study the indicators and methodologies used to assess COVID-19 impact
- To describe a roadmap on indicators, methodologies and data pathways used to assess the impact of Covid-19 across Europe
- To explore the determinants of the severity and long-term health outcomes of SARS-COV2 infection
- To identify digital tools for contact tracing of COVID-19 patients and summarizing the available evidence regarding the effectiveness and impact of these tools in the European context
- Capacity building exercise on COVID-19 impact assessment
- Workshop on disease burden

a) SHARE - Karen Andersen-Ranberg: research on health and well-being of populations

See presentation slides (Annex B)

Face-to-face interviews by trained interviewers

Broad range of questions, measurements and tests:

- Socio-economic status: labour force participation, retirement, income (amount and sources), wealth, housing, consumption, pension claims, expectations, well-being
- Health: subjective-objective (self-report, ADL/IADL, conditions, physical performance tests, biomarkers: HbA1c, CRP, Cholesterol), physical-mental (cognition, MMSE, CES-D, Euro-D), health behaviours, health utilization and insurance coverage
- Social participation: activities (volunteering), family and social networks (size and intensity), help (time, money)

b) CHAIN – Mirza Balaj: Social inequalities in COVID-19

See presentation slides (Annex B)

Collaboration with PHIRI

- Joint webinars: CHAIN collaborates with several international organisations to deliver their messages. Translate research in actionable outcomes
- Scientific writing and commentaries. Scandinavian Journal of Public health – Objective of the project or aim of the stakeholder meeting on how it could help to avoid duplication of work
- Join annual CHAIN meeting – invitation of collaborating centers and new stakeholders

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c) Questions

Joao Forjaz: What do you think are the main barriers and challenges for using the data in your organisations?

> **Mirza Balaj**: We try to collect our own data but we also collaborate with other organisations. Sometimes to save resources and to be more efficient, we make use of pre-existing questionnaires. However, we have experience in building surveys and we would be interested in collaborating on certain topics with PHIRI.

Gaetan Lafortune: When do you (SHARE COVID) expect to start releasing the results from your wave in June 2020?

> **Julia Knoblechner**: SHARE COVID Data is already available. We had an early release in December. http://www.share-project.org/home0/news/article/share-covid-19-data-available-now.html
>
> **Gaetan Lafortune**: This is very quick! Congratulations!
>
> **Karen Andersen-Ranberg**: COVID-19 wave 1 data is already on the SHARE server and can be downloaded if you have access to the SHARE data. The data is freely available for researchers, but you have to apply.

Gaetan Lafortune: Can you please confirm that your SHARE survey only covers people living at home, not those living in nursing homes?

> **Karen Andersen-Ranberg**: SHARE covers people in nursing homes too. We follow people, but in some countries it is difficult to trace people, when they move. So this particular group may be underrepresented.

Luís Lapão: Great presentation Mirza, are you addressing mental health?

> **Mirza Balaj**: Yes, mental health is a very important part of our portfolio. I am currently on maternity leave and will not be able to follow up on a lot of the work that is going on but I can get you in touch with our team working on mental health so you can discuss with them directly. My email is mirza.balaj@ntnu.no

Sarah Vercruysse: is the SHARE survey always focused on 50+ adults or is this COVID-19 specific?

> **Karen Andersen-Ranberg**: SHARE is about ageing, and how we age differently in Europe. That is why we interview 50+ year olds. We interview households, where at least one in a couple is 50+. That is the core SHARE survey. As people are getting old, we normally invite 50+51 year old refreshers in every wave. Only the SHARE population had/will have the COVID-19 questionnaire.

VII. Foresight: Modelling and Scenarios – Henk Hilderink, RIVM

See presentation slides (Annex B)

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

We seek to level and strengthen European public health foresight capacity and support evidence-informed policy decisions by

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- Mapping direct and indirect effects
- Using a broad conceptual model of health and care
- on short and long-term effects

a) EpiPose – Willem Lander: Epidemic intelligence to minimize COVID-19´s public health, societal and economic impact

See presentation slides (Annex B)

The EpiPose project:

- Focus on social contact patterns – no contagious with no contact
- Survey covering 20 categories
- Symptomatic surveillance network based on voluntary online participants
- Nowcasting, forecasting and scenarios analysis to get key epidemiological factors
- Health economics and public health

CoMix: comparing mixing patterns in the Belgian population during and after lockdown

A scenario analysis is not a prediction but more an exploration of the future

- Possible to predict what will happen to the disease if we know how people will behave but it is hard to predict how people will behave also in the near future

b) Questions

Henk Hilderink: How can we increase interoperability of infectious disease modelling and modeling of indirect health impacts (e.g. chronic diseases), to have valuable input for scenario development?

- common indicators for morbidity and mortality (e.g. Burden of disease)
- common conceptual framework (e.g. same DESTEP approach)

Sarah Vercruysse: in the EU funded EpiPose project, we are conducting the CoMix study in about 20 European countries. We track changes in contact behaviour over time (and in relation to the timing of different measures). We also collaborate with ECDC about this endeavour. Data collection in Greece should start next week. Don't hesitate to contact me if you would like more information (sarah.vercruysse@uhasselt.be) .

Leonor B Nicolau: Thank you Henk! How does your modelling/scenario modelling approach deals with uneven impacts over regions, populations... ?

> **Henk Hilderink**: Often what we report is about averages however, averages might not really reveal what is happening. Therefore, we are trying to make a distinction of different groups (e.g. age, social economic status, region) depending on the topic of interest.

Luís Lapão: Dear Lander. Thank you for your presentation. What sort of stakeholders do you engage while developing your models?

> **Willem Lander**: The team of EpiPose has people coming from different backgrounds. We use our complementary knowledge and scientific publications on transmission modelling to create our models.
>
> **Henk Hilderink**: the information we seek also depends on the topic we are focusing on. Contacting different stakeholders help us to integrate different perspectives in our model.

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VIII. Concluding remarks – Herman Van Oyen, Sciensano

Pleased to see how many European initiatives and organisations are active in the field of health information ranging from the provision of trainings to medical data collection to scenarios forecasting.

a) Next appointments

- This was the first PHIRI Stakeholder Meeting but more will follow (6 months)
- InfAct Joint Action final General Assembly: 21-22nd of January 2021

IX. Participants interested in being involved in PHIRI

Patrick Mahy: I would like to inform you on VAC4EU existence that respond to willingness to have a federated research infrastructure collecting secondary data from European States on vaccines including anti COVID-19 vaccines. VAC4EU members are public health institutes, universities, research institutes. In the IMI Advance project, several tools were developed and are accessible on Advance or IMI website. Amongst the tools, vocabularies, dictionary, mappings, CDM were developed

Adelina Comas-Herrera: It is great to learn more about PHIRI and all the projects. I represent the https://ltccovid.org/ initiative that has been documenting the impact of COVID-19 on people who use and provide long-term care since March.

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X. Annex A – Agenda of the meeting

Nr	14th January, 09:00-12:30 via Webex (online)	Speaker	Time
1	**Welcome** Aim of the meeting and overview of PHIRI	Nienke Schutte *Sciensano, Belgium*	09:00
2	**Health Information portal for COVID-19** Building a Health Information portal on health and health care data for COVID-19 to support structured information exchange between EU countries. The portal will offer a FAIR catalogue with overviews of COVID-19 population health data sources, studies and capacity building exercises in the framework of PHIRI and beyond. • CESSDA - Ivana Ilijasic Versic • ECDC - Howard Needham • EUPHA - Marie Guichardon • ASPHER - John Middleton • JRC - Clemens Wittwehr	Hanna Tolonen *THL, Finland*	09:15
3	**Building a federated research infrastructure for a rapid policy response** Creating and validating a federated research infrastructure that overcomes data reuse & data sharing hindrances for rapid policy relevant research response to the evolving pandemic. • ECRIN - Sergei Gorianin • BBMRI - Petr Holub • EATRIS - Toni Andreu • EGI ACE - Gergely Sipos **Research use cases measuring the impact of COVID-19 on population health** Conducting research through use cases of immediate relevance for public health policies and management of the COVID-19 pandemic. • EUROSTAT - Ilze Burkevica	Enrique Bernal Delgado *IACS, Spain* Martin Thißen *RKI, Germany*	10:15
BREAK			11:05
4	**Research methodologies to assess the impact of COVID-19** Supporting European countries to understand the impact of COVID-19 on population wellbeing and health, morbidity and mortality using a multidisciplinary approach. • CHAIN - Mirza Balaj • SHARE - Karen Andersen-Ranberg	João Forjaz *ISCIII, Spain*	11:20
5	**Foresight: Modelling and Scenarios** Gaining insights in possible future health impacts of the COVID-19 outbreak, by developing scenarios for MS and associated countries' national situation. EpiPose - Lander Willem	Henk Hilderink *RIVM, Netherlands*	12:00
6	**Concluding Remarks**	Herman Van Oyen *Sciensano, Belgium*	12:20
END			12:30

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XIAnnex B – Slides of the presentations

PHIRI
Population Health Information Research Infrastructure

Scientific Stakeholder Meeting I

14/01/2021

Aim of the meeting

- Learn from the expertise, methods or tools that already exist in your projects or organisations and build on it.
- Identify synergies and routes for exchange between your project/organisation.
  1. Would you like to be involved in PHIRI? (projects/organisations input to PHIRI)
  2. Which of your activities should we be involved in? (PHIRI input to projects/organisations)
- The aim is NOT to discuss technical details during this meeting but find areas we need to connect and which links need to be made with the relevant activities/WP lead.

Agenda

Nr	14th January, 09:00-12:30 via Webex (online)	Speaker	Time
1	Welcome Aim of the meeting and overview of PHIRI	Petronille Bogaert *Sciensano, Belgium*	09:00
2	Health Information portal for COVID-19 Building a Health Information portal on health and health care data for COVID-19 to support structured information exchange between EU countries. The portal will offer a FAIR catalogue with overviews of COVID-19 population health data sources, studies and capacity building exercises in the framework of PHIRI and beyond. • CESSDA - Ivana Ilijasic Versic • ECDC - Howard Needham • EUPHA - Marie Gulchardon • ASPHER - John Middleton • JRC - Clemens Wittwehr	Hanna Tolonen *THL, Finland*	09:15
3	Building a federated research infrastructure for a rapid policy response Creating and validating a federated research infrastructure that overcomes data reuse & data sharing hindrances for rapid policy relevant research response to the evolving pandemic. • ECRIN - Sergei Gorlanin • BBMRI - Petr Holub • EATRIS - Toni Andreu • EGI ACE - Gergely Sipos Research use cases measuring the impact of COVID-19 on population health Conducting research through use cases of immediate relevance for public health policies and management of the COVID-19 pandemic. • EUROSTAT - Ilze Burkevica	Enrique Bernal Delgado *IACS, Spain* Martin Thißen *RKI, Germany*	10:15
	BREAK		11:05

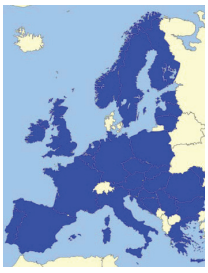
Agenda

4	Research methodologies to assess the impact of COVID-19 Supporting European countries to understand the impact of COVID-19 on population wellbeing and health, morbidity and mortality using a multidisciplinary approach. • CHAIN - Mirza Balaj • SHARE - Karen Andersen-Ranberg • EHTEL - Diane Whitehouse	João Forjaz *DGS/FUML, Portugal*	11:20
5	Foresight: Modelling and Scenarios Gaining insights in possible future health impacts of the COVID-19 outbreak, by developing scenarios for MS and associated countries' national situation. • EpiPose - Lander Willem	Henk Hilderink & Marlken Tijhuis *RIVM, Netherlands*	12:00
6	Concluding Remarks	Petronille Bogaert *Sciensano, Belgium*	12:20
	END		12:30

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

Overview

- Timeline: 1 November 2020 – 3 years
- Financing: European Commission Horizon 2020 – 5M€
- Coverage: 41 partners in 30 countries
  - 27 National Institute of Public Health or Research or Disease Control
  - 7 Universities
  - 7 Ministries of Health
- Structure: 9 workpackages and 3 transversal topics



Map of PHIRI Partners

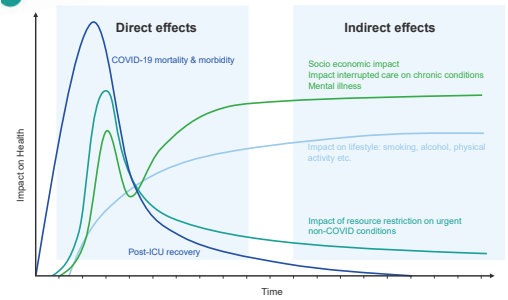
PHIRI for Covid-19

Population Health Information Research Infrastructure (PHIRI) aims to:

Identify, access, assess and reuse for research population health and non-health data in Member States and across Member States 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

(In)direct impact of COVID-19 on population health



PHIRI

Research use cases
Research methodologies

Health information Portal
Federated Research Infrastructure

Rapid Exchange Forum
Outreach & Engagement

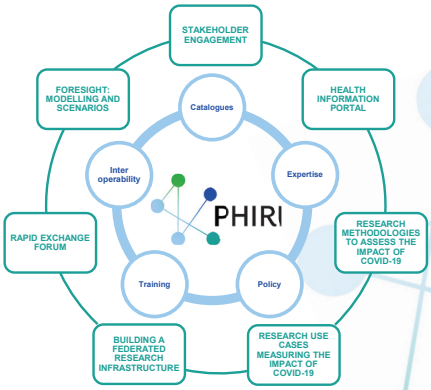
Foresight: Modeling & Scenarios

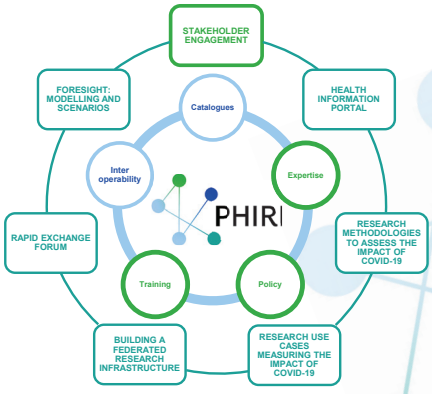
Stakeholder involvement
Capacity building
Policy linkage

PHIRI for COVID-19

Objectives:

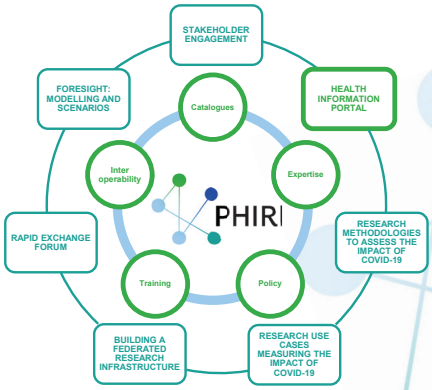
1. To provide a **Health Information portal** for COVID-19 with FAIR catalogues on health and healthcare data for structured information exchange across European countries. To link different data sources and to use Pan-European data in a GDPR compliant, federated way.
2. To provide structured exchange 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.





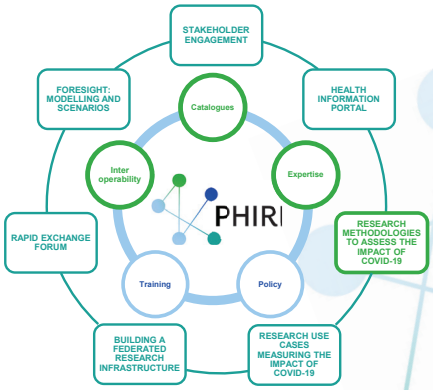
Engage and involve

- Addressing the COVID-19 infodemic (training, FAQ section, key messages)
- Country visits to map state of play on monitoring the wider effects of COVID-19
- Stakeholder meetings: 3 main meetings and short ones every two months
  - Overview of relevant COVID-19 activities



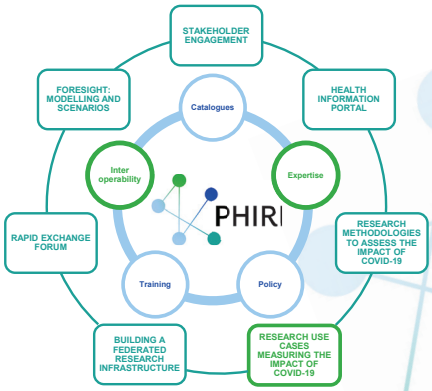
Health Information Portal

- Health information portal
  - Catalogue of population health data sources in countries
  - Catalogue of COVID-19 population health studies
  - Catalogue of COVID-19 international guidelines, initiatives and projects
  - Catalogue of COVID-19 training material and courses
  - Practices on COVID-19 ethical and legal aspects
- Strengthening National Nodes



Methodologies to asses impact of COVID-19

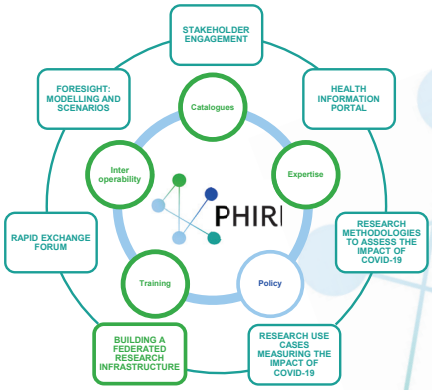
- Indicators and methodologies used to assess the wider impact of COVID-19
- Explore determinants of the severity of long-term health outcomes of SARS-CoV-2
- Efficacy of digital tools for contact tracing
- Innovative tools for COVID-19 health monitoring



Four use cases

The use cases will 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 to produce actionable insights.

1. Direct and indirect determinants of COVID-19 infection and outcomes in vulnerable population groups with reference to inequalities
2. COVID-19 related delayed care in breast cancer patients
3. the impact of COVID-19 on perinatal health and perinatal health inequalities
4. COVID-19 related changes in population mental health

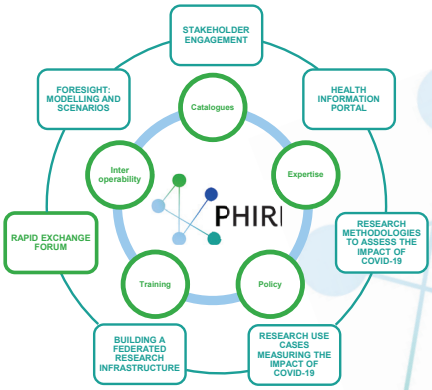


Federated research infrastructure

Showing the potential of the infrastructure for a rapid cycle analysis using a demonstration pilot case

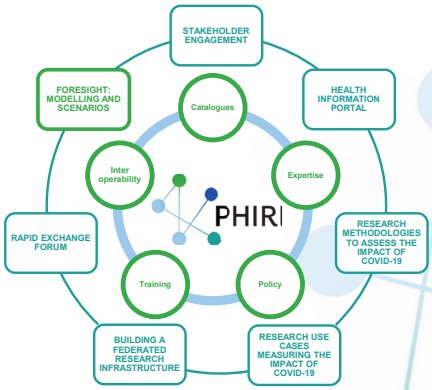
Pilot, developing an advanced version of the federated research infrastructure, including:

a) The development of a common data model for a COVID-19 rapid response
b) The design and deployment of the required data extraction, transformation and loading (ETL) processes and
c) The implementation of the distributed analytical solutions, in particular the FAIR implementation of intermediate processes and final research outputs. This advanced version will mainly build on WP6 use cases



Rapid exchange forum

1. To provide rapid response to research and policy questions that are raised in countries
2. To promptly disseminate internationally agreed guidelines, standards, reports and initiatives
3. To exchange (best) practices among countries regarding COVID-19
4. To provide a link with policy: the shifting landscape of evidence for policy

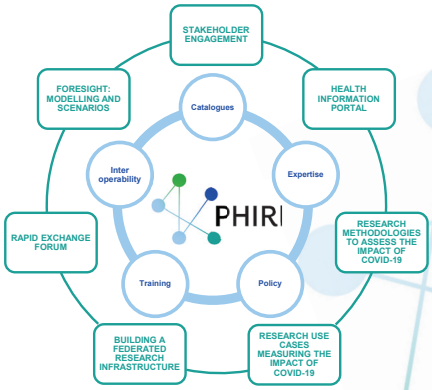


Foresight: Modelling and Scenario

The overall aim of this work package is to gain insights in possible future health impacts of the coronavirus outbreak, by developing scenarios for MS and associated countries' national situation and draw lessons for the EU.

The objectives are:

1. To get an overview of how European countries have been using foresight, modelling and preparedness regarding COVID-19 (mainly indirect effects)
2. To develop and provide foresight capacity (levelling the knowledge needed for performing foresight, reducing information inequalities, strengthening European data uniformity)
3. To support evidence-informed policy decisions, by exploring direct and indirect effects of COVID-19 on population health, on short and long-term, using scenarios and a broad conceptual model of health and care



PHIRI
Population Health Information Research Infrastructure

Thank you!

Name: Petronille Bogaert, Miriam Saso, Nienke Schutte, Linda Abboud, Barthélémy Moreau and Herman Van Oyen
E-mail: PHIRI.coordination@sciensano.be
Follow us on Twitter: @PHIRI4EU

PHIRI
Population Health Information Research Infrastructure

Scientific Stakeholder Meeting PHIRI
14th January 2021

Health Information portal for COVID-19

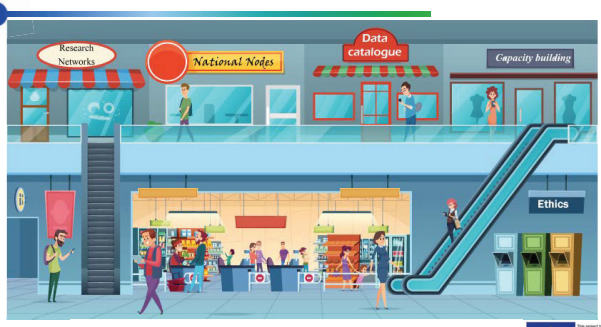
Hanna Tolonen

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 data sources on patients but more broadly on population level as well.

healthinformationportal.eu

One-stop-shop for health information



Portal will include

Catalogue of national nodes

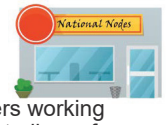
Catalogue of research networks

Catalogue of existing training materials and courses

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

Legal and ethical toolbox

National nodes



- National node = A network of national stakeholders working with the health information and being owners/controllers of health and health care data
- Portal will have a catalogue of national nodes describing
  - Included institutions and experts
  - Health information sources
  - Dissemination materials on health information
  - Involvement in different national projects
  - Involvement in different international projects and networks

Research networks

- Existing health domain specific research networks
- Provides information on
  - Included institutions and relevant international organizations
  - Experts
  - Tools and publications
    - Results of the project
    - Repository of documents
    - Tools, data and information
    - Legislation (if relevant)
    - Guidelines
    - Dissemination materials (presentations, videos, infographics etc.)
  - COVID-19 related activities
  - Events and news

Data catalogue

- In the first phase focused on Covid-19 related data sources but in a long-run covering population based health information in general
- Metadata catalogue of the existing population health data sources in EU countries
- Includes also population health studies e.g. health surveys, longitudinal studies and intervention studies but not clinical trials or surveillance systems

Capacity building

- A catalogue of existing COVID-19 related training activities, later on, other health information related training activities will be added
- Promotion of training activities such as webinars organized by PHIRI and other relevant institutions/networks
- Collection of available training materials and other supporting documents such as guidelines and online tools related to the collection and use of health information

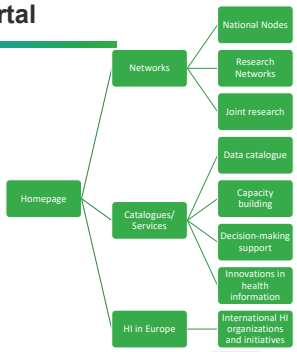
Legal and ethical issues

- A toolbox for legal and ethical guidelines
  - A review of the existing practices and guidelines on ethical and legal aspects of performing and exchanging health information on COVID-19
  - Guidelines for deployment, utilisation and governance of the health information portal on health and health care data information exchange

Other materials on the portal

- A special section for COVID-19
  - Includes for example Rapid Exchange Forum
- Search functions
- Special section for Media

Development of the portal is an iterative process where feedback from users is essential



Collaboration

Collaboration

PHIRI
Population Health Information Research Infrastructure

Thank you for your attention!

Name: Hanna Tolonen
E-mail: hanna.tolonen@thl.fi
Follow us on Twitter: @PHIRI4EU

cessda

CESSDA ERIC – for what and for whom?

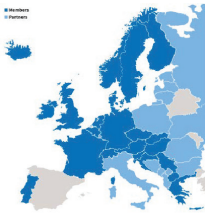
Ivana Ilijasic Versic, COO| CESSDA

14.01.2021 PHIRI stakeholder meeting

cessda.eu @CESSDA_Data

cessda

- Cross-European resource discovery
- Improved quality of data and metadata
- A wider selection of comparable data
- Certification of data archiving organisations
- Professional training for data archivists and scientific community
- Improved mechanisms for data dissemination and analysis
- Strong involvement of organisations outside Europe



Duration
Informal network: since 1976
Public company: 2013
ERIC status: since 2017

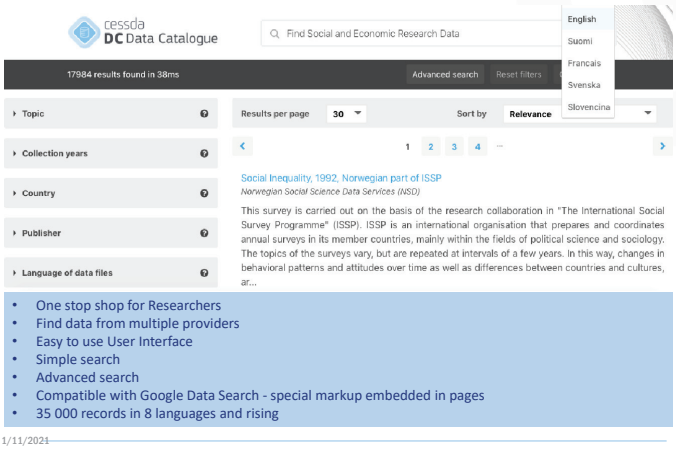
HQ
Bergen, Norway
Website: www.cessda.eu

Estimated cost
Capital value: 117M
Design: 4M
Implementation: 2.7M
Operation: 39M/year

ESFRI
Roadmap entry: 2006
Preparation phase: 2007-2010
Construction: 2011-2012
Implementation: 2015-2017

Membership
Members: 21
Observers: 1
Aspiring: 7

cessda



- One stop shop for Researchers
- Find data from multiple providers
- Easy to use User Interface
- Simple search
- Advanced search
- Compatible with Google Data Search - special markup embedded in pages
- 35 000 records in 8 languages and rising

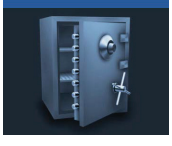
cessda

Training

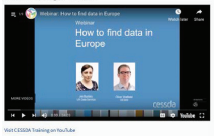
Discovering and using data
Social science data archives provide access to extensive collections of data that are useful for social and economic research.

Managing Research Data
Research data management is about looking after your data to ensure high quality as well as to facilitate potential reuse of data.

Preserving Data
In addition to simply providing storage, digital archives actively curate and preserve research data.



CESSDA Training on YouTube



Visit CESSDA Training on YouTube

Data Management Expert Guide
This guide is designed by European experts to help social science researchers make their research data Findable, Accessible, Interoperable and Reusable (FAIR).

You will be guided by different European experts who are - on a daily basis - busy ensuring long-term access to valuable social science datasets, available for discovery and reuse at one of the 18 CESSDA social science data archives.

Train-the-Trainers Package
The first Training Package forms an addition to the Data Management Expert Guide.

It consists of a set of materials that trainers can use for data management instruction for researchers.

TTT

Thank you!

Ivana Ilijasic Versic, COO

email: ivana.versic@cessda.eu
www.cessda.eu | @CESSDA_Data
www.sshopencloud.eu | @SSHOpenCloud

1/11/2021

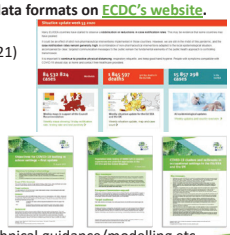
European Centre for Disease Prevention and Control

PHIRI Scientific Stakeholder meeting: Possible areas of ECDC engagement

Howard Needham, Expert-Scientific Liaison, 14 January 2021

1. What do you do with regards to structured exchange of health information on COVID-19 between countries that could be of interest?

- ECDC legally mandated to collect health information on infectious diseases collected by EU/EEA MSs (27MS +3EEA).
- ECDC produces several COVID-19 surveillance outputs (e.g. weekly COVID-19 surveillance report/ country overview). **Much of the data is downloadable in open data formats on ECDC's website.**
- Core datasets:
  - **TESSy:** Over 7M COVID-19 cases included in database (Jan 2021)
  - Supplemented by web scraping of public health websites etc.
- Epidemiological data include:
  - Case numbers (COVID-19 cases, deaths, setting of infection).
  - Severity (Hospital and ICU admission, risk factors etc.).
  - Genomic data (WGF): genetic variants.
- Public health response:
  - Testing.
  - Country response measures.
- Data used as a basis of many ECDC outputs: risk assessments/technical guidance/modelling etc.



2. What can we learn from your experience? What should we build on?

- Balance between depth/breadth for core data requirements; requires good understanding of what data is available, what can be collected and shared.
- Maintain awareness of EU level research-related activities to build synergy and avoid duplication….but……..
- ……no research should be off limits;
  - studies in similar domains but different approaches/methods etc. can enhance. knowledge
  - COVID research is vast, and fast moving; overlap may be inevitable.
- Data quality/consistency is key.
- ECDC has limited research capacity, so welcome research that builds PH knowledge base (eg using TESSy data).

3. How would you like to interact with PHIRI? Are there possibilities for interoperability?

- What can ECDC offer?
  - Data sets (Tessy) etc;
  - Expertise (knowledge and understanding of the data but also strong links with COVID network and other agencies)
  - Links to EU-level policy actions; knowledge broker between research and policy at EU level.
- What does ECDC hope to gain:
  - Understanding of MS-led research activities and data sets, and how that could support EU-wide public health goals.
  - Access to data and expertise outside established EU surveillance reporting structures; access 'new' data to support public health, and agility for rapid data-led knowledge gain around emerging issues.
  - PHIRI is MS–led; offers unique "intelligence" on emerging concerns/uncertainty in MSs partner organisations- guide ECDC actions.
  - Promote the use of ECDC data & tools.
  - Disseminate ECDC technical outputs and awareness of ECDC activities in MSs activities.

sciensano

PHIRI STAKEHOLDER MEETING 14/01/2021

EUROPEAN PUBLIC HEALTH ASSOCIATION

EUPHA
EUROPEAN PUBLIC HEALTH ASSOCIATION

AWARENESS ADVOCACY ACTION
VOICING KNOWLEDGE EUPHA BUILDING CAPACITY

WHAT IS EUPHA DOING ABOUT COVID-19 POPULATION HEALTH STUDIES?

- COVID-19 Updates webpage
- Rapid Response Team: we provide journalists with quality and up to date information within 48 hours
- COVID-19 articles are open access in our journal, the European Journal of Public Health (EJPH)
- Our communication manager has followed the training of the WHO on infodemic management

Upcoming

- COVID-19 supplement in the EJPH (end of 2021)
- Report on the COVID-19 track at the 16th World Congress on Public Health (February 2021)

OUR EXPERIENCE

- We need to be deliberately collaborative – the response cannot be the sole responsibility of public health professionals
- It is imperative to move out of silos, to build on existing partnerships but we have to be bold when creating new ones.
- We need to rethink how we present evidence – an infodemic crisis has emerged. We need to challenge our ways to communicate evidence.

> "Despite the naming of the pandemic, syndemic or infodemic, it is clear that what we need the most is solidarity."
>
> – EUPHA Executive Director in Open Access Government

EUPHA AND PHIRI – WHAT FUTURE

- EUPHA-Public Health Monitoring and Reporting (EUPHA-PHMR) section president, Petronille Bogaert, can ensure rapid transmission of the information between the two structures
- We can assist PHIRI in dissemination of the information and evidence – newsletter, column in European Public Health News of the EJPH, e-collection

For information or question, please contact us at office@eupha.org or our Policy Officer at m.guichardon@euphaoffice.org

EUPHA
EUROPEAN PUBLIC HEALTH ASSOCIATION

Click to find us on social media

ASPHER
The Association of Schools of Public Health in the European Region

THIS IS PUBLIC HEALTH
#thisispublichealth

PHIRI and ASPHER – opportunities for joint working

Professor John Middleton,
President, ASPHER

What does ASPHER do with regards to COVID-19 TRAINING: MATERIAL AND COURSES that could be of interest?

High level across all PH domains:
- **WHO-ASPHER competencies for the public health workforce**
- **Core-competencies for the public health professional**

Further work for ECDC infectious disease competencies

ASPHER COVID task force
- **Basic terms – health inequalities**
- **Basic terms – epidemiology 'How to count illness'**
- **Basic terms – contact tracing apps for COVID-19**
- **Range of statements, including masks, testing, inequalities, surveillance apps, planning for winter, Vitamin D, vaccination …**

Young professionals group (internships and course works)

What can we learn from your experience? What should we build on?

Check out ASPHER COVID-19 web platform

https://www.aspher.org/covid-19-task-force.html

Use our materials – you will be very welcome

Dissemination and use of materials important

Education for press and public needed in the era when everyone is an epidemiologist

How would you like to interact with PHIRI? Are there possibilities for interoperability?

ASPHER 2021 member survey: asking members about their involvement in:

- **Big data science**
- **Digital possibilities for preventing and managing disease and disability**
- **Digital governance and digital ethics**
- **Disinformation and downsides of digital**

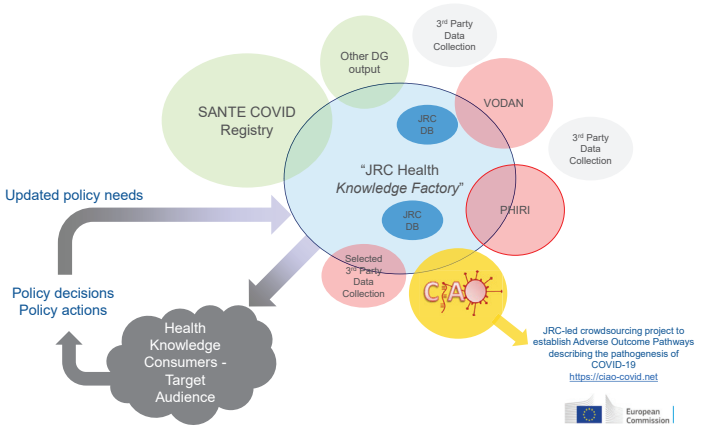
ASPHER work on competencies
EPH young researchers forums
ASPHER work on ethics and values

JRC Health Knowledge Factory

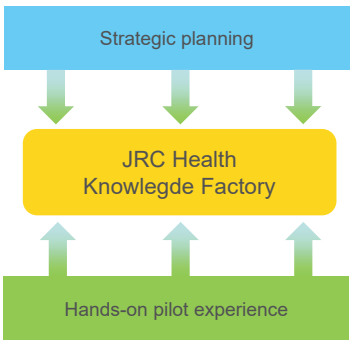
Possible collaboration with PHIRI

PHIRI Stakeholder Meeting

2021-01-14



Two pronged approach



Roadmap is currenty being drafted

PHIRI synergies

Possible collaboration JRC Health Knowledge Factory and PHIRI

- First step: Get familiar with selected use cases
- Then: Scientific knowledge creation using the PHIRI data
- Parallel:
  - Involve other JRC parties (currently ongoing)
  - involve their know-how
- Parallel – Contribute Soft skills
  - Stakeholder Buy-in
  - Promotion

PHIRI
Population Health Information Research Infrastructure

Building a federated research infrastructure for a rapid policy response

Stakeholders' meeting January 14th, 2021

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

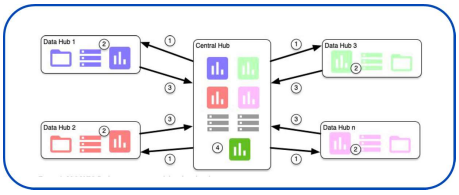
ROBERT KOCH INSTITUT · IACS Instituto Aragonés de Ciencias de la Salud

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 & 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

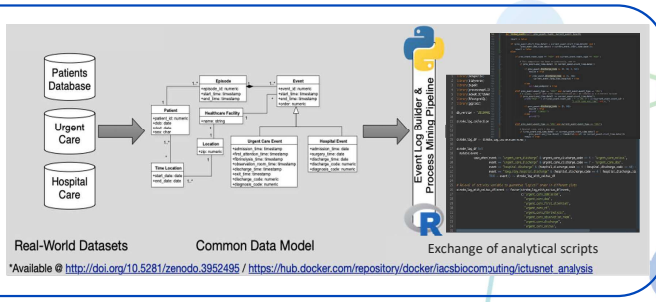
The architecture



- 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

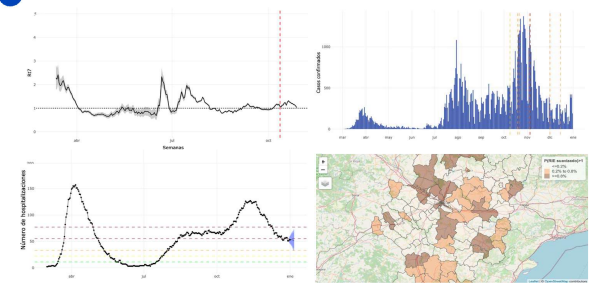
Routine linkable data
Individual level (anonymised or pseudonymised)

Qs



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

Demonstration pilot on rapid cycle analysis



WP6 use cases …

PHIRI
Population Health Information Research Infrastructure

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

Stakeholders' meeting January 14th, 2021

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

Topics

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

- Direct and indirect determinants of COVID-19 infection and outcomes in vulnerable population groups with reference to inequalities
- COVID-19 related delayed care in breast cancer patients
- The impact of COVID-19 on perinatal health and perinatal health inequalities
- COVID-19 related changes in population mental health

The outputs of the use cases will be processed by formalising data models, data management processes and analytical pipelines in an interoperable way to **feed into the federated research infrastructure**

(Preliminary) Research Questions

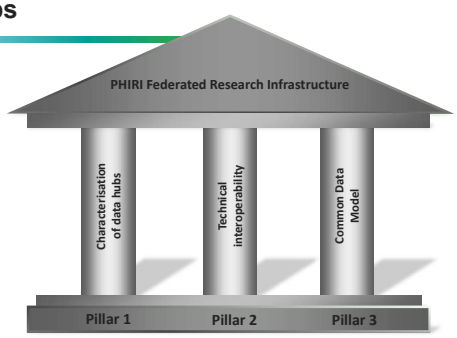
	1. Do area based deprivation measures, or individual measures of socioeconomic position, explain variations in SARS-COV2 infection rates, COVID19 health care **utilisation** and associated mortality between countries/settings? 2. Has the COVID19 pandemic changed existing socioeconomic patterns of non-COVID-19 health care **utilisation** and mortality within and between countries?
	1. Has **utilisation** (surgery rates, primary or specialist care visits) change before and after the crisis? 2. The **number of Lumpectomy vs. Mastectomy** has changed?
	1. Did access to and use of maternity and newborn **health services** decrease during the pandemic/lockdowns? 2. Were population indicators of maternal and newborn health affected by the pandemic/lockdown? 3. Did these effects differ across countries and by socioeconomic context?
	1. Has the prescription of psychotropic drugs (antipsychotics, antidepressants, anxiolytics, and hypnotics) changed during the COVID-19 pandemic? 2. Has the number of visits to **emergency services** due to psychotic and bipolar disorders changed during the COVID-19 pandemic? 3. Has the number of **psychiatry visits** changed during the COVID-19 pandemic? 4. Do these effects differ across countries and by socioeconomic context?

(Preliminary) Research Questions

	1. Do area based deprivation measures, or individual measures of socioeconomic position, explain variations in SARS-COV2 infection rates, COVID19 health care utilisation and associated mortality between countries/settings? 2. Has the COVID19 pandemic changed existing **socioeconomic patterns** of non-COVID-19 health care utilisation and mortality within and between countries?
	1. Has utilisation (surgery rates, primary or specialist care visits) change before and after the crisis? 2. The number of Lumpectomy vs. Mastectomy has changed?
	1. Did access to and use of maternity and newborn health services decrease during the pandemic/lockdowns? 2. Were population indicators of maternal and newborn health affected by the pandemic/lockdown? 3. Did these effects differ across countries and by **socioeconomic context**?
	1. Has the prescription of psychotropic drugs (antipsychotics, antidepressants, anxiolytics, and hypnotics) changed during the COVID-19 pandemic? 2. Has the number of visits to emergency services due to psychotic and bipolar disorders changed during the COVID-19 pandemic? 3. Has the number of psychiatry visits changed during the COVID-19 pandemic? 4. Do these effects differ across countries and by **socioeconomic context**?

Plans & Next Steps

- WP6 and WP7 are working together in the development of the PHIRI federated research infrastructure
- There are three different pillars to build:
  - The first two of them tell us about the actual capacities of each data hub in terms of access to data and technical expertise
  - The third one is meant to achieve semantic interoperability throughout harmonising data differences across data sources and data hubs



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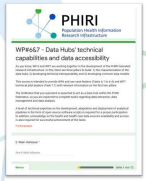
Plans & Next Steps

Two layer questionnaire:

1. Aims to get a better sense on the actual access to data and data hubs' capabilities
2. A second round survey, specific of each use case, to start off the process of harmonising data throughout a common data model



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PHIRI

Population Health Information Research Infrastructure

Name: Martin Thißen, Stefanie Seeling, Thomas Ziese
E-mail: PHIRI-Germany@rki.de
Follow us on Twitter: @PHIRI4EU

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Metadata repository (MDR) for clinical research

Scientific stakeholder meeting of PHIRI

ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK

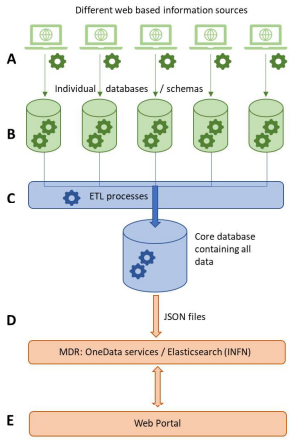
Sergei Gorianin – 14 January 2021

Metadata Repository in clinical research
Status information

- Single portal system linking clinical studies with related data objects (e.g., study protocol, datasets, statistical analysis plan, publications)
- Developed within the H2020-funded project XDC in cooperation by ECRIN, OneData and INFN (http://www.extreme-datacloud.eu/)
- Based upon the ECRIN metadata schema (version 5) (https://zenodo.org/record/4133889#.X_RoY9hKjcs)
- Officially launched on 29 April 2020
- Put in production for the ECRIN task force on COVID-19, linked as related resource to the European COVID-19 data portal and referenced in the RDA COVID-19 guidelines and recommendations
- Currently update and extension of the MDR in EOSC-hub (early adapter) and EOSC-Life (WP1 use case) with expansion of data sources

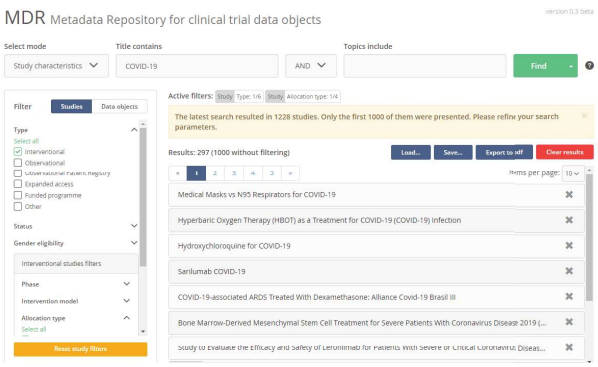
ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK

Metadata Repository in clinical research
Architecture



ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK

Metadata Repository in clinical research
*User Interface**



ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK

**old version, currently being replaced*

Metadata Repository in clinical research
*Data sources included**

- **Clinical studies**
  - 18 trial registries, 2 repositories included
  - 600.125 studies included
- **Data objects related to a study**
  - 18 registries, 2 repositories, Pubmed included
  - 31 data object types (e.g. study protocol, data, publication)
  - 913.832 data objects included

ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK

**CT.gov, Pubmed, YODA, BioLINCC, ISCTRN, EUCTR, WHO registries from ICTRP*

BBMRI-ERIC

MAKING NEW TREAT MENTS POSSIBLE

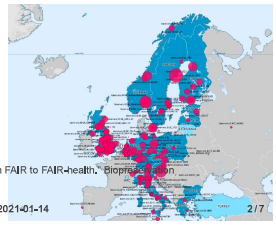
POTENTIAL PHIRI AND BBMRI-ERIC COLLABORATION

Assoc. Prof. RNDr. Petr Holub, Ph.D.
Senior IT/Data Protection Manager & CIO of Common Service IT

What is BBMRI-ERIC?

BBMRI-ERIC

- **One of largest European RIs for medical research**
  - spans **20 member states** + IARC
  - **federated** biobanks and other resources across members states
  - makes **biological samples & medical/health data more FAIR** (findable, accessible, interoperable, reusable) and complaint to **FAIR-HEALTH**[1]
  - aims at **improving efficiency & reproducibility** of medical research



[1] Holub, Petr, et al. "Enhancing reuse of data and biological material in medical research: from FAIR to FAIR-health." Biopreservation and biobanking 16.2 (2018): 97-105. doi.org/10.1089/bio.2017.0110

What is BBMRI-ERIC

BBMRI-ERIC

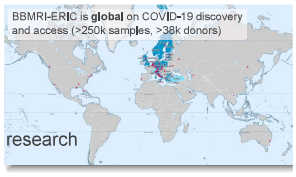
- A **federated/hierarchical infrastructure** that provides/facilitates secure and privacy-protecting access to key resources in order to support biomedical research and to support healthcare advancement:
  - bio**samples** from biobanks,
  - related **data**: clinical, omics, phenotypes, etc.,
  - **expertise** and other **services** (e.g., sample & data hosting),
  - selected **central data resources** on ERIC level
  - **clinical biobanks** and **population biobanks**


```
biobanks := samples + data + expertise + services;
```


BBMRI-ERIC and COVID-19

BBMRI-ERIC

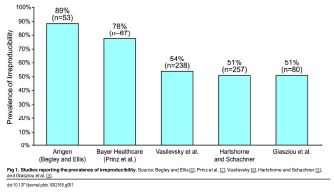
- BBMRI-ERIC is **global** on COVID-19 discovery and access
  - 55 biobanks with COVID-19 samples and data globally
  - >250k samples, >38k donors
    - big competition for getting the samples
  - clinical data, imaging data, etc.
  - on-demand collecting capability
- Services done by BBMRI-ERIC for COVID-19 research described in EJHG paper.[2]



[2] Holub, Petr, et al. "BBMRI-ERIC's contributions to research and knowledge exchange on COVID-19." European Journal of Human Genetics (2020): 1-4.

Challenges in Health Data Sharing

- **Interoperability** of health data in heterogeneous European space
- Availability of **reliable structured data** from health care
  - costs and expertise to obtain those
- **Privacy protection –** finding **balance between privacy and utility**
- **Reproducibility and fitness-for-purpose** (= quality)
- **Distributed responsibility** for data in health care



Potential Collaboration Areas

- Joint work on **data standardization**
  - consensus building on models, vocabularies, mappings, etc. for different domains
- Development of **production infrastructure to get reliable structured health data**
  - across various domains from primary sources in health care
  - while making it manageable and beneficial for the sources (incentive models)
- **Standardization of provenance and its implementation**
  - BBMRI-ERIC leads work in ISO TC276 on 23494 standard

MAKING NEW TREAT MENTS POSSIBLE

THANK YOU!

contact@bbmri-eric.eu
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BBMRI-ERIC

eatris
European infrastructure for translational medicine

Supporting European academy and industry for the fast progress of translational medicine

Facilities, resources and services to support cutting edge research

EATRIS countries
Bulgaria, Czech Republic, Finland, France, Italy, Latvia, Luxembourg, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden

110
Research Institutes

5 Scientific Platforms
ATMPs, Biomarker, Imaging & Tracing, Small Molecules, Vaccines

Legal status
Non-profit, ERIC legal status

Examples of key actions

eatris
European infrastructure for translational medicine

EATRIS supporting the European Health Data Space

- Developing tools to ensure the highest quality and reproducibility of data generated during the research and innovation value chain
- Accelerating capacities of the use of health data for the clinical decision-making processes
- Cooperating with other health data-related initiatives to improve the efficiency of the value chain in the health care domain

eatris
European infrastructure for translational medicine

EATRIS Health-data Actions and Activities

EOSC-life
Together with other Ris reuse of health data

EATRIS-Plus
Certificate of Quality for omic-data in diagnostic processes

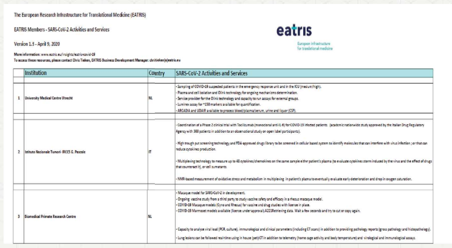
MULTIOMIC data integration
For Metabolic disorders (within EATRIS-Plus)

EU-PEARL
building master protocols for efficient generation of data from platform clinical trials

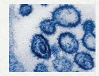
HEALTHY-CLOUD
Working with ECRIN and BBMRI for the establishment of the pan-European Health data portal

EATRIS Scientific support

- **Finding partners** for COVID19 Research Requests: 40 institutions within the COVID19 Resources and Activities Database
- **EATRIS COVID-19 Research Forum** An interactive platform for EATRIS COVID-19 researchers to interact, find collaborators, exchange protocols, samples, ideas…)
- **EATRIS Task force** to evaluate proposal ideas



EATRIS COVID-19 Resources and Activities Database available online e.g Challenge models e.g hamster, NHPs, access to SARS-COV-2 Virus, Patient samples….



COVID-19 Partnering Requests

Project Type	Project Description	Account Name	Account Type	Country	Status
Research service	BSL-3 Facilities for SARS-COV-2 Virus Candidate Testing	Latvian Biomedical Research and Study Center	Research Institute	Latvia	Matching
Consortium building	Erasmus Plus Call- Coronavirus Digital Education	University of Foggia	University	Italy	4 Institutions Matched
Research service	Rapid COVID-19 Test Validation	Perron institute	Research Institute	Australia	1 Institution Matched
Research service	Covid-19 Samples	Max Planck Institute of Experimental Medicine	Research Institute	Germany	1 Institution Matched
Consortium building	Infrared heating systems to reduce COVID-19 infections	University of Istanbul	Research Institute	Turkey	Ongoing
Research service	Manufacturing for Large scale production of viral proteins	BioMaric	Pharmaceutical company	Belgium	1 Institution Matched
Research service	COVID-19 Subject Trial	LIITA CARE	SME/Biotech	Denmark	1 Institution Matched
Expert advice	BSL3 Laboratory Certification	Latvian Biomedical Research and Study Centre	Research Institute	Latvia	Completed
Research service	Availability of SARS-COV-2 Virus	Materia Medica	SME/Biotech	Russia	3 Institutions Matched
Research service	Petrovax_SAR-COV-2 Animal Models	Petrovax	Pharmaceutical company	Russia	3 Institutions Matched
Consortium building	Exogenous Therapeutics_Lung Models	Exogenous Therapeutics	SME/Biotech	Portugal	3 Institutions Matched
Expert advice	SARS-COV-2 Virus Production	Vall d'Hebron Research Institute (VHIR)	EATRIS institution	Spain	Completed
Consortium building	EUREKANETWORK_COVID-19	Kuste Biopharma	SME/Biotech	France	1 institution Matched
Consortium building	Animal Models for Antiviral studies for SARS-COV-2 Vaccine candidate	Hercules Pharmaceutical	SME/Biotech	Netherlands	1 institution Matched
Consortium building	TRANSVAC-Immunogenecity Studies	Vall d'Hebron Research Institute (VHIR)	EATRIS institution	Spain	Ongoing
Consortium building	TRANSVAC- NHPs	University of Santiago de Compostela (USC)	University	Spain	Received Funding
Consortium building	TRANSVAC- Animal Models/Regulaory Support for funded EC Project	Københavns Universitet	University	Denmark	Received Funding
Consortium building	COVID-19 Lung Cells and Models	University of Helsinki	EATRIS institution	Finland	3 Institutions Matched
Consortium building	COVID-19 Cell Based Antiviral Assays	University of Zagreb	University	Croatia	3 Institutions Matched

19 Projects matched through the COVID-19 Response Group at various stages of development

Joining forces with BBMRI and ECRIN

BBMRI-ERIC® Biobanking and BioMolecular resources Research Infrastructure
ECRIN EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK
eatris European infrastructure for translational medicine

- **Fast response service to COVID-19 now available!**
  - ✓ List of complementary services/resources identified by each RI
  - ✓ One single contact point
  - ✓ Response within 72 hours
- Joint statement: 5 recommendations to accelerate COVID-19 Research
- Scientific publication: Biomarker Research and Development for COVID-19: European medical research infrastructures call for global coordination (*accepted, Clinical Infectious Diseases*)

Clinical Infectious Diseases

VIEWPOINTS

IDSA Infectious Diseases Society of America | hivma hiv medicine association | OXFORD

Biomarker Research and Development for Coronavirus Disease 2019 (COVID-19): European Medical Research Infrastructures Call for Global Coordination

Emanuela Oldoni,[1] Alain van Gool,[2] Laura García Bermejo,[3] Andreas Scherer,[4] Michaela Th. Mayrhofer,[5] Francesco Florindi,[5] Jacques Demotes,[6] Christine Kubiak,[6] Anne-Charlotte Fauvel,[1] Florence Bietrix,[1] Anton Ussi,[1] and Antonio L. Andreu[1]

[1]European Infrastructure for Translational Medicine (EATRIS), Amsterdam, The Netherlands, [2]Department of Laboratory Medicine, Radboud University Medical Center, Nijmegen, The Netherlands, [3]Department of Pathology, Instituto Ramón y Cajal de Investigación Sanitaria (IRYCIS), Madrid, Spain, [4]Institute for Molecular Medicine Finland (FIMM), Helsinki, Finland, [5]Biobanking and BioMolecular Resources Research Infrastructure-European Research Infrastructure Consortium (BBMRI-ERIC), Graz, Austria, and [6]European Clinical Research Infrastructures Network (ECRIN), Paris, France

Scientific Publication: October 2020

EGI-ACE: Advanced Computing for EOSC

www.egi.eu
@EGI_eInfra

Opportunities for PHIRI

Gergely Sipos
Head of Services, Solutions, Support (EGI Foundation)
EGI-ACE Technical Coordinator

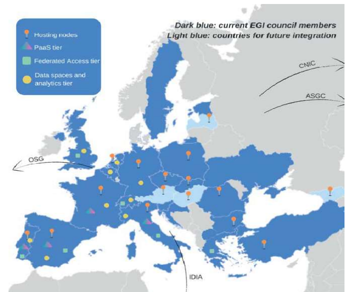
14 January 2021
PHIRI Stakeholder Meeting

The work of the EGI Foundation *is partly funded by the European Commission under H2020 Framework Programme*

EGI & EGI-ACE overview

Built on the sustainable EGI e-infrastructure

EGI-ACE implements the **Compute** **of the European Open Science C** contributes to the **EOSC Data Co**

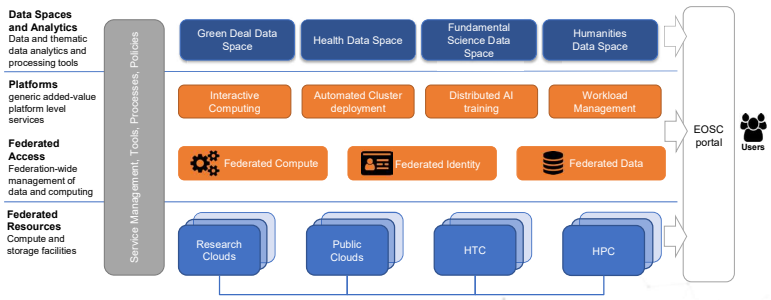


- Consortium:
  - Coordinator: EGI Foundation
  - 33 participating partners + 23 third-p
    - **Sciensano represents PHIRI in the 'Earl**
- **Focus on service delivery**
  - 16 partners to deliver **cloud, HTC and HPC**
  - 12 partners: **access and platform solutions**
  - 12 providers: **federation services**
  - 21 providers: **data spaces**

***Duration**: 30 months*
***Start date:** 1 January 2021*
***End date**: 30 June 2023*
***Budget**: 12,380,165 EURO*

www.egi.eu | @EGI_eInfra

EGI-ACE tier service architecture



Opportunities

- Relevant experiences
  - Operating a network of data & compute centres (IT Service Management, Governance, financial planning)
  - Building distributed data catalogues (e.g. ECRIN Metadata Repository - Slides)
  - Federated authentication-authorization in international context (e.g. ELIXIR AAI)
  - Data exploitation – Staging and processing data in national compute centres (Stories)
- Interaction
  - Feb 5: EGI-ACE public launch event. **Register at https://indico.egi.eu/event/5359/**
  - EGI-ACE Communities Workshop
    - Feb (Date TBD)
    - **Resulting community-specific support plans and teams**

Thank you!

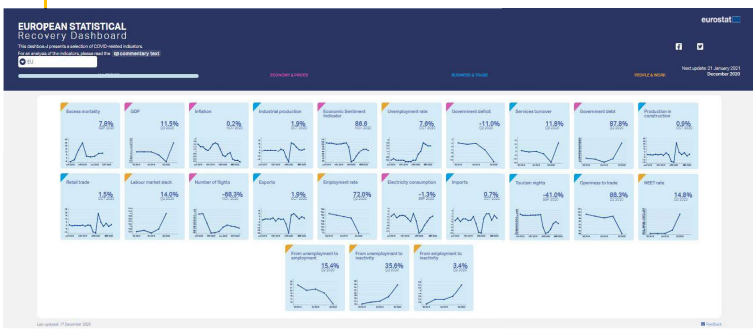
Questions: gergely.sipos@egi.eu

Stakeholder Meeting of PHIRI: Eurostat

Ilze Burkevica, Eurostat, Unit F.5

- **Eurostat** is the statistical office of the European Union
- **Mission**: to provide high quality statistics and data on Euro
- Eurostat produces European statistics in **partnership** with N Institutes and other national authorities in the EU Member S partnership is known as the European Statistical System (E
- Available official statistics cover wide variety of aspects, fro finance, industry, trade and services, international trade, ag fisheries, transport, environment and energy, science, techn society to population and social conditions, including **health**
- https://ec.europa.eu/eurostat/web/main/data/database

- On 17 December 2020 Eurostat launched the European Sta Dashboard.
- The Dashboard contains **monthly and quarterly indicator** of statistical areas, which are relevant for tracking the econ recovery from the COVID-19 pandemic.
- The Dashboard was developed in cooperation with the stati in the Member States.
- https://ec.europa.eu/eurostat/cache/recovery-dashboard/



European Commission

COVID-19 relevant datasets and methodological support for statisticians

- **COVID-19: Statistics serving Europe section**: https://ec.europa.eu/eurostat/web/covid-19/overview
- This section shows a **wide range of statistics** and data published by Eurostat related to COVID-19. This can give a baseline against which the impact of the crisis can be measured and to provide a wider background.
- The information covers a range of topics related to the economy, society and work, population and health as well as agriculture, energy, transport and tourism.
- **Methodological support** for statisticians on a wide range of data domains: https://ec.europa.eu/eurostat/data/metadata/covid-19-support-for-statisticians

European Commission

Thank you!

European Commission

PHIRI
Population Health Information Research Infrastructure

Research methodologies to assess the impact of COVID-19

M. João Forjaz

Objective 1

AIM:

- Study the indicators and methodologies used to assess covid-19 impact
- To describe a roadmap on indicators, methodologies and data pathways used to assess the impact of Covid-19 across Europe.

METHODS:

Literature review on main:

- Methodologies pathways
- Data pathways
- Indicators

Objective 2

AIM: To explore the determinants of the severity AND long-term health outcomes of SARS-COV2 infection

- **Main goal:** To assess the impact of morbidities and frailty as well as the role of socio-economical determinants on the severity and long-term health outcomes of SARS-COV2 infection

METHODS: to rely on systematic litterature reviews and meta-analyses when possible

- **Part I: Biomedical determinants (morbidities and frailty)**
- **Part II: Socio-economical determinants**
  - **of short term severity (Mortality/Hospitalization/ Intensive care)**
  - **and long-term health outcomes of SARS-COV2: Survival / Functioning (social, physical, psycho)/ Perceived health-Quality of life**

- Studies and sources:
  - *RCT*
  - *Prospective cohort studies*
  - *Retrospective cohort studies*
  - *Case-control studies*
  - *Cross-sectional studies*

Objetive 3

- **AIM:** to identify digital tools for contact tracing of COVID-19 patients and summarizing the available evidence regarding the effectiveness and impact of these tools in the European context

- **METHODS:**

a) A survey to collect information on innovative methods, state-of-the-art algorithms and contact tracing tools used to monitor health issues related to COVID-19 in Europe, as well as who is using them.

b) Literature review to summarized the effectiveness and impact of tracking COVID-19 patients and its pros and cons.

Objective 4

- Capacity building exercise on covid-19 impact assessment
- Workshop on disease burden

Stakeholder Meeting PHIRI
Online January 14, 2021

SHARE ERIC
SURVEY OF HEALTH, AGEING AND RETIREMENT IN EUROPE

RESEARCH ON HEALTH AND WELL-BEING OF POPULATIONS

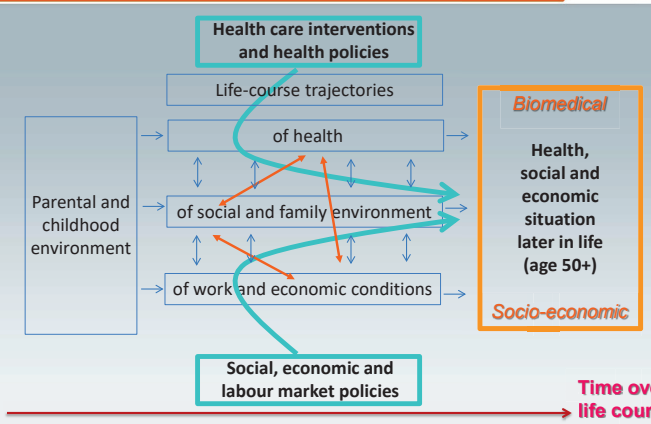
WWW.SHARE-PROJECT.ORG

Prof. Karen Andersen-Ranberg, MD, Ph.D.

SHARE Health Area Coordinator
University of Southern Denmark

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 676536
Federal Ministry of Education and Research
NIH National Institute on Aging
SDU
SHARE ERIC

Basic paradigm: Interactions over time



CROSS-NATIONAL ERIC and EU-COM | MULTIDISCIPLINARY Consortium | LONGITUDINAL: PANEL Long-term Stability

Multidisciplinarity

- **Face-to-face interviews** by trained interviewers
- Broad range of **questions, measurements and tests**:
  - **Socio-economic status**: labor force participation, retirement, income (amount and sources), wealth, housing, consumption, pension claims, expectations, well-being
  - **Health:** subjective-objective (self-report, ADL/IADL, conditions, physical performance tests, biomarkers: HbA1c, CRP, Cholesterol), physical-mental (cognition, MMSE, CES-D, Euro-D), health behaviors, health utilization and insurance coverage
  - **Social participation:** activities (volunteering), family and social networks (size and intensity), help (time, money)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 676536
Federal Ministry of Education and Research
National Institute on Aging

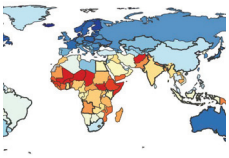
SHARE: now and in the future

- **Methods**
  Stable core every two years,
  - Short topical modules at much shorter intervals,
  - Special methods at longer intervals
- **Public health: Prevention vs. curation**
  health maintenance, e-health, healthcare access, Alzheimer's disease and related dementias
- **Flexible and tailored long-term care**
  institutionalization, formal/informal home care, e-care
- **Inequality**
  link between income, wealth, health, mortality
- **COVID-19 surveys: 1. wave (June 2020) and 2. wave (April 2021)**
- **WWW.SHARE-PROJECT.ORG**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 676536
Federal Ministry of Education and Research
National Institute on Aging

CHAIN

NTNU



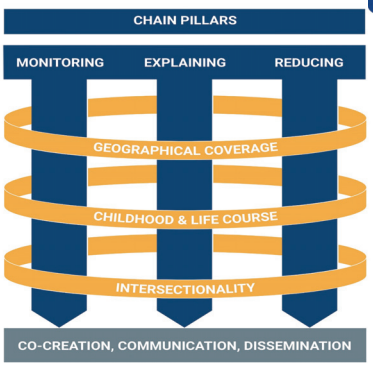
Social inequalities in Covid-19

CHAIN

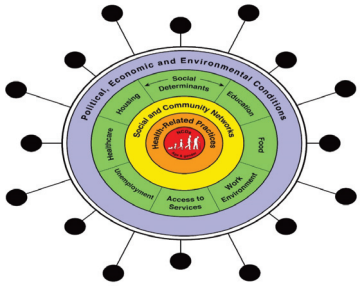
From research → to policy → to fieldwork

CHAIN

NTNU



CHAIN Syndemic Approach



The Syndemic of Covid-19, Non-Communicable Diseases (NCDs) and the Social Determinants of Health

Assessing impact of Covid-19 in population health

- Data sources
  - European social survey – Round 10/11
  - DEMETRIQ – European mortality data collection 2021/2026
  - Microdata- Statistics Norway
- Projects
  - Effectiveness of Welfare States in Mediating COVID-19 Related Exacerbations in Health Inequality
  - CHAIN Center of Excellence application

Collaboration with PHIRI

- Joint webinars
- Scientific writing and commentaries
- Join annual CHAIN meeting

PHIRI
Population Health Information Research Infrastructure

PHIRI stakeholder meeting

WP9 Foresight: scenarios and modeling

Henk Hilderink & Mariken Tijhuis,
on behalf of WP9

National Institute for Public Health and the Environment, Ministry of Health, Welfare and Sport
UNIVERSIDADE NOVA DE LISBOA

www.phiri.eu

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

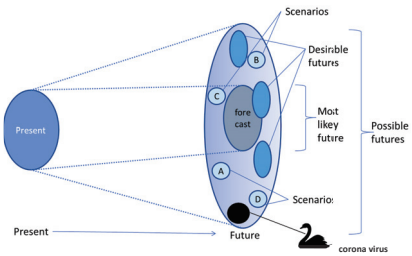
What is PHIRI WP9 about?

We aim to gain insight in possible future health impacts of the SARS-CoV-2 outbreak by supporting the development of **scenarios** for countries' national situation, and from this collectively also draw lessons for the EU

We seek to level and strengthen European public health foresight capacity and support evidence-informed policy decisions by

1. mapping **direct and indirect effects**
2. using a **broad conceptual model of health and care**
3. on **short and long-term**

Foresight: from present to future



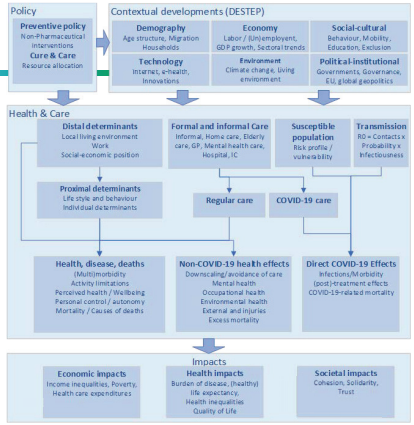
Foresight is a systematic, participatory, future-intelligence-gathering and medium-to-long term vision-building process aimed at enabling present-day decisions and mobilizing joint actions.

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

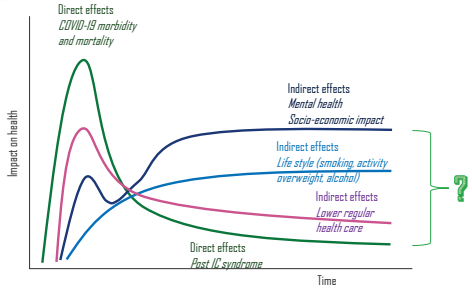
WE DON'T PREDICT THE FUTURE

Broad scope

- DESTEP trends (broad) driving forces for health
- Concept of Health beyond disease and mortality (QoL)
- Short and long term effects
- Direct and indirect effects



Direct and indirect impact on health

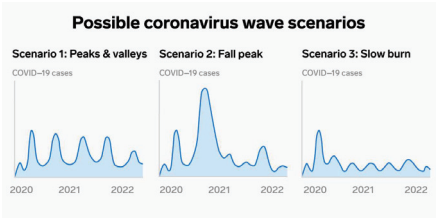


What are we facing: most important trends

Key uncertainties
- COVID-19
- Economic growth

And also:
- Technology
- Behaviour
- Poverty/unemployment

And still:
- Geopolitical, climate change, ageing, migration, food production



For discussion

How can we increase interoperability of infectious disease modelling and modeling of indirect health impacts (e.g. chronic diseases), to have valuable input for scenario development?

Think of:
- common indicators for morbidity and mortality (e.g. Burden of disease)
- common conceptual framework (e.g. same DESTEP apprach)

PHIRI
Population Health Information Research Infrastructure

Thank you for your attention!

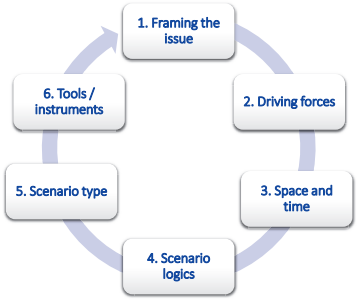
PHIRI.NL@rivm.nl

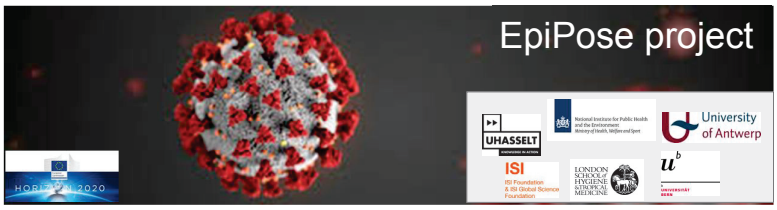
Additional slides

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)

Scenario building steps





Epidemic intelligence to minimize COVID-19's public health, societal and economical impact

Coordinated by Hasselt University
niel.hens@uhasselt.be

Presenter
lander.willem@uantwerp.be

EpiPose project (non-exhaustive overview)

Data collection

Social contact patterns (in 20 European countries), health conditions, awareness, perceptions

Symptomatic surveillance (through InfluenzaNet), weekly reporting on symptoms and tests

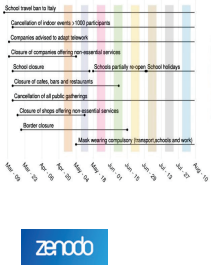
Epidemiological modelling

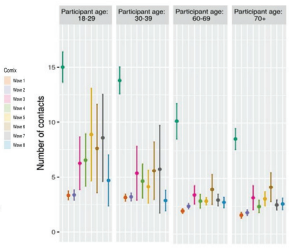
Epidemic nowcasting and forecasting to assess **key epidemiological parameters** in various countries and their change due to **intervention measures**

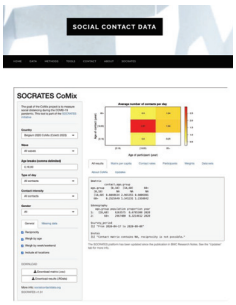
Health-economics and public health

COVID-19 **disease burden** and health **costs**, **healthcare-pressure**, impact on financial markets and of cost-effectiveness of treatments when they become available.

CoMix: comparing mixing patterns in the Belgian population during and after lockdown



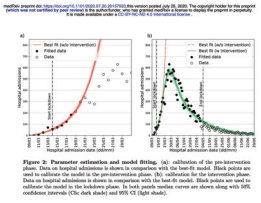




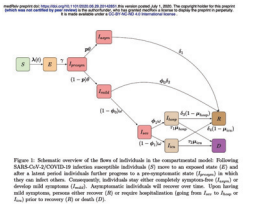
zenodo

www.socialcontactdata.org

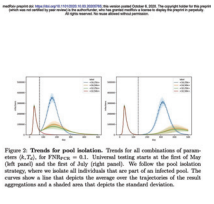
Transmission dynamics of SARS-COV-2 (Belgium)



Meta-population model
⇒ social contacts, mobility, ...



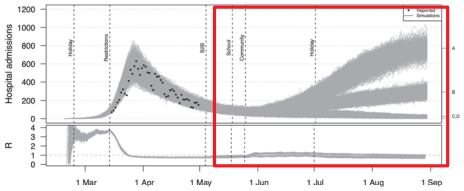
Stochastic compartmental model
⇒ Serology, mortality, social contacts, (a)symptomatic, ICU, …



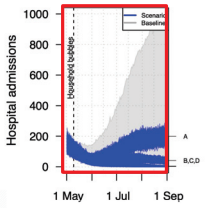
Individual-based model
⇒ universal testing, contact tracing, household bubbles, superspreading

Take home messages (non-exhaustive)

1. Model comparison and validation
2. Scenario analysis vs. prediction (w.r.t. transmission vs behaviour)
3. Network structure:



Deconfinement strategies with **open** contact networks



closed contact networks (household bubbles)

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- ...

More info: EpiPose page at UHasselt website

www.simid.be www.socialcontactdata.org www.covid-hcpressure.org