



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

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# InfAct and the Distributed Infrastructure on Population Health (DIPoH)

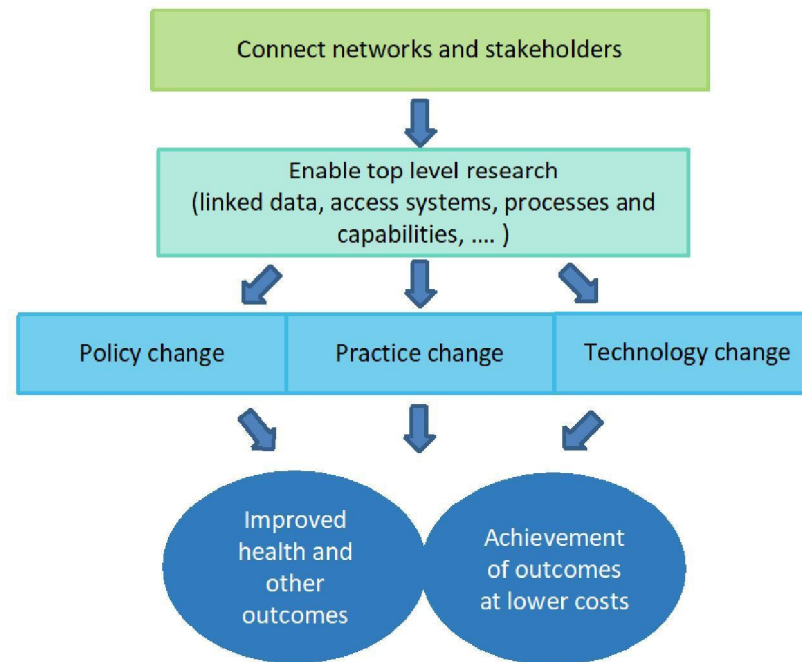
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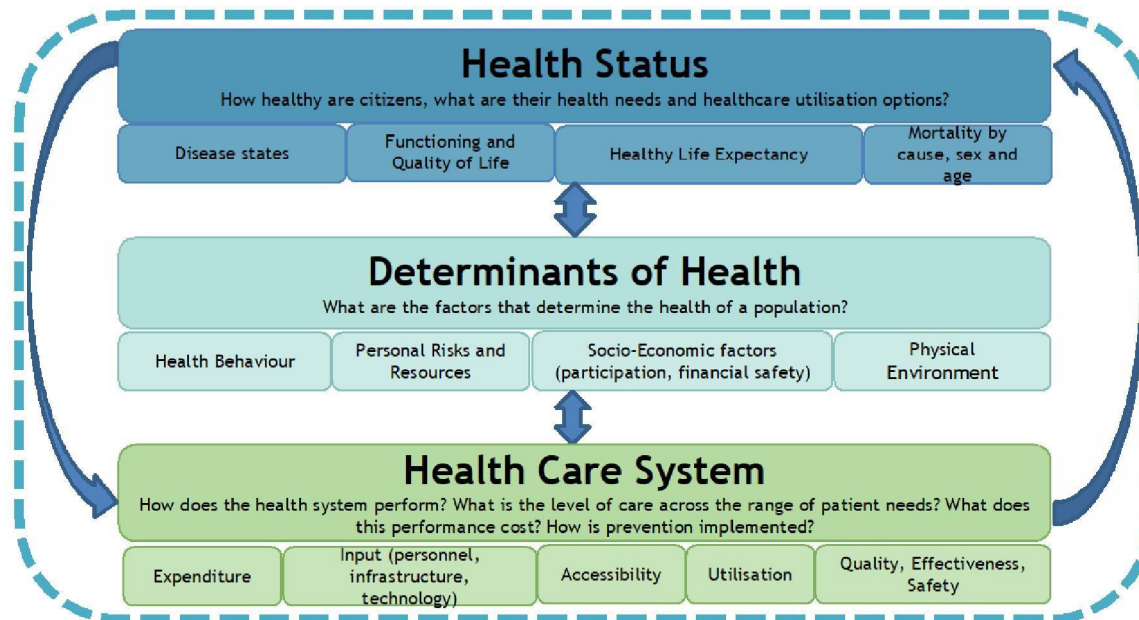
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## The concept of DIPoH

Aim: facilitate the identification, access, assessment, and reuse of population health information and data across Europe



## Framework of Population Health Information



## Uniqueness

- Covers the population as a whole (healthy and non healthy)
- Focus on non communicable chronic diseases
- Comprehensive view on health data: population health (administrative data, vital statistics, health surveys, longitudinal studies) and health care (e-health records, hospitalisations)
- Facilitate secondary use of routine data sources
- Include individual and aggregated level data
- Does not include experimental research
- Boost national population health research



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## Services



# InfAct and COVID-19

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## InfAct and COVID-19

- Partners at the core of the Covid-19 response teams have indicated a strong need to structurally exchange between countries.
- InfAct facilitates exchanges between partners and with international organizations
- How?
  - Rapid exchange with InfAct connecting experts and expertise
  - Two weekly meetings with specific questions
  - Storage of relevant information



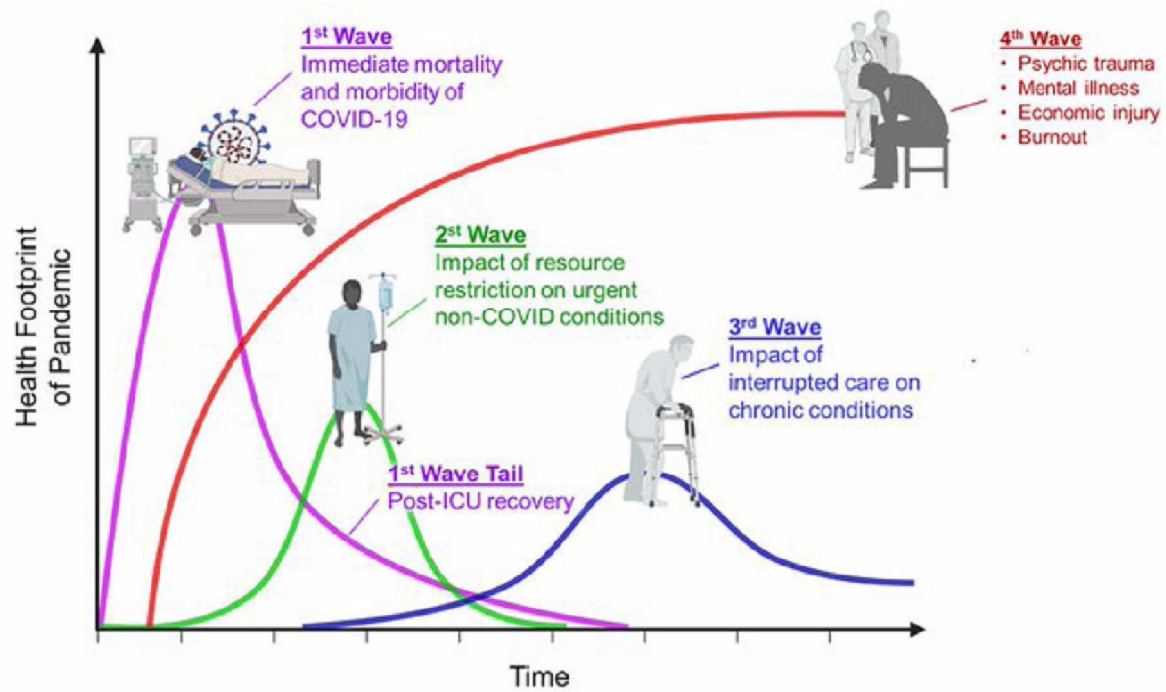
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## InfAct and COVID-19

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- What?
  - Exchange and provide overview of ongoing or planned Covid-19 studies
    - What data should be collected to analysis impact COVID-19 on with NCDs?
  - Exchange relevant regional, national and international data sources
    - Which data sources are available at sub-regional level?
  - Discuss and exchange on latest developments, recently validated tools, approaches, standard operating procedures, protocols and guidelines
    - How are you counting COVID-19 deaths in your country and who is being tested?
    - How are you carrying out contact tracing in your country?
  - Exchange policy and impact measures
    - Measure/guidelines about re-opening of schools and data indicating the consequences of the re-opening?
    - How are hospital visits and visits to LTCF organized in your country?
    - Impact on mental health through health surveys.



Source: Twitter post 7:04 PM · Mar 30, 2020 Victor Tseng

# Population Health Information Research Infrastructure for COVID-19

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## PHIRI for COVID-19: call

- Amendment published 17/06 in RI Work Programme 2020 for a [Population Health Information Research Infrastructure \(PHIRI\)](#)
  - Concerns the setting-up of a Population Health Information Research Infrastructure, to collect and make available population health and relevant non-health data in MS and at EU level that can support research and policy decisions regarding the COVID-19 public health crisis.
  - Budget 5 million.



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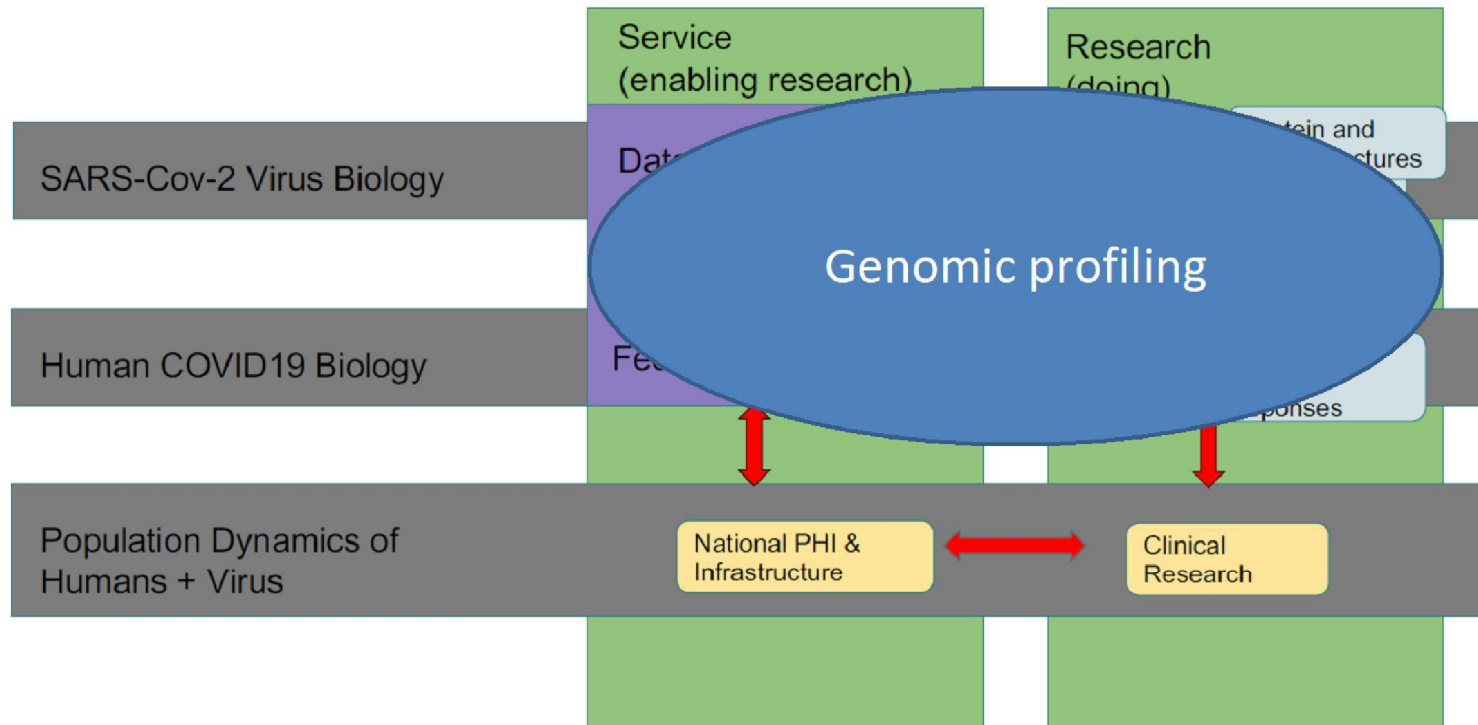
## PHIRI for COVID-19: call

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This new infrastructure should:

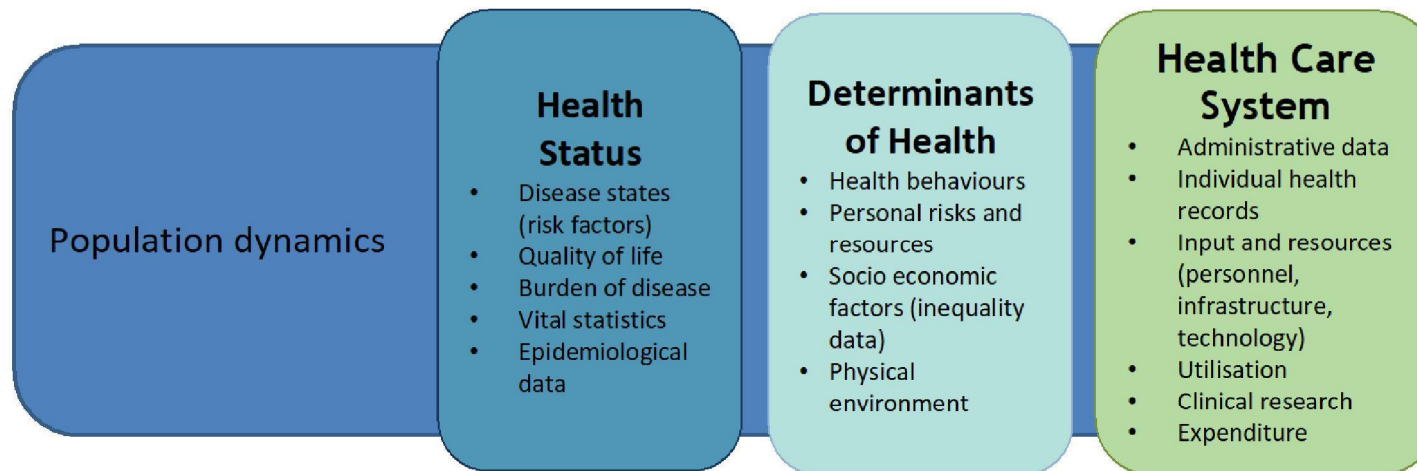
- Ensure interoperability with other relevant administrative data infrastructures, for analytical purposes and to support policy-making, including in the areas of employment and social policy, with respect of the GDPR.
- Form a cornerstone of the emerging *European Health Data Space*, and properly connect with the [EU COVID19 Data Platform](#).

## COVID-19 data platform



## Added value PHIRI

→ Population dynamics of human and virus: public health and societal impact



## PHIRI for COVID-19: call

- Provide a comprehensive view on
  1. health data (including from in-depth analyses of patients' biospecimen),
  2. data on social and physical environment (including behavioural data) and
  3. health care services (promotion-prevention-cure and care), thus informing on the dynamics of human health, diseases and mortality.
- Build on InfAct



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## PHIRI for COVID-19: call

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In synergy with different types of actors and initiatives such as:

- European research networks in the domain of population health;
- relevant national population data owners/curators (e.g. MS Health Data Space);
- national population health co-ordination entities;
- and EU and international data collectors and registries relevant for COVID-19 and future epidemics, notably ECDC, WHO, OECD, EEA, ESAF, JRC, EOSC, and European research infrastructures.
- Participation of experts in ethics and law as well as patient representatives is strongly encouraged.

The proposal should already present a number of research **use cases** that are of immediate relevance for public health policies or aspects of clinical management of the COVID-19 epidemic and disease, respectively.

## PHIRI for COVID-19: Expected Impact

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- Provision of high quality and standardised COVID-19 relevant population health and care institutions data across EU Member States to inform policy-making and feed into pertinent health data registries, collections and statistics at EU and international levels.
- Identification of best practices for handling the COVID-19 epidemic at public health and clinical management level.
- Enable advanced research to address and find solutions to COVID-19 and other health crises, in connection to the EOSC and the related *EU COVID19 Data Platform*.
- Contribute to the formation of a true European Health Data Space thus responding to the EU's Digital Health agenda.

## PHIRI for Covid-19: our proposal

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Population Health Information Research Infrastructure to facilitate:

- the identification, access, assessment and reuse for research,
  - population health and non-health data in and across MSs
  - that can underpin public health policy decisions relevant to Covid-19.
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- What?
    1. Create a one-stop shop platform with FAIR catalogues
    2. Provide tools for population health research for Covid-19
    3. Provide overview of capacity building and training
    4. Assist the health research community in knowledge translation

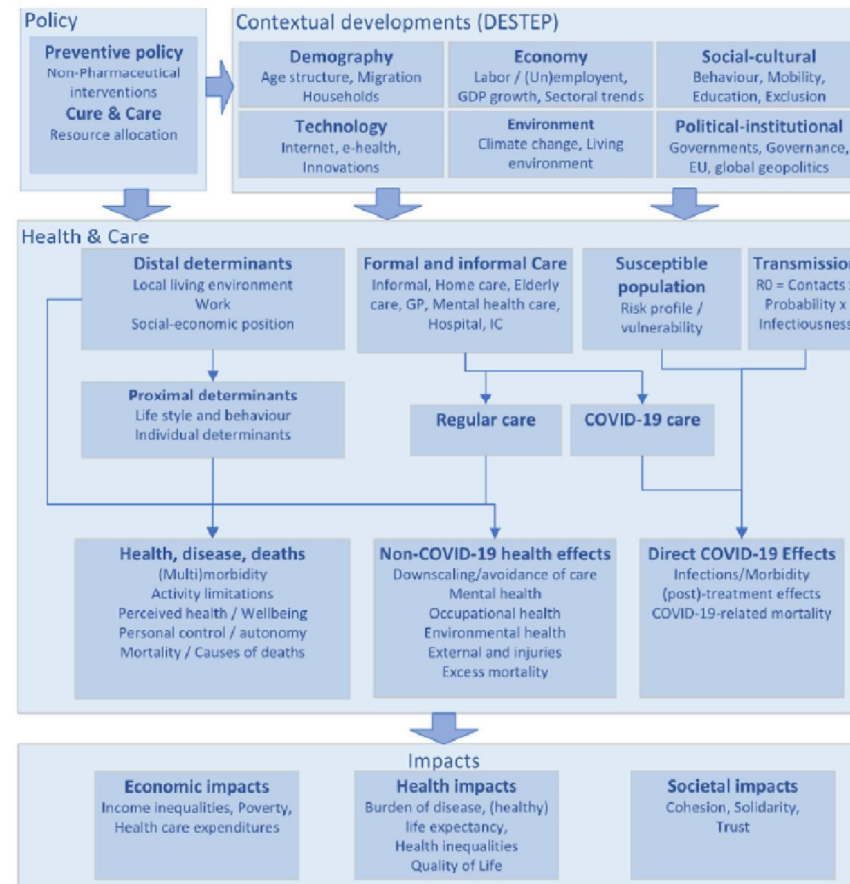
## PHIRI for Covid-19: our proposal

- PHIRI should not do everything itself, but should work closely with existing initiatives and integrate data and results
- PHIRI should facilitate users to get access to data

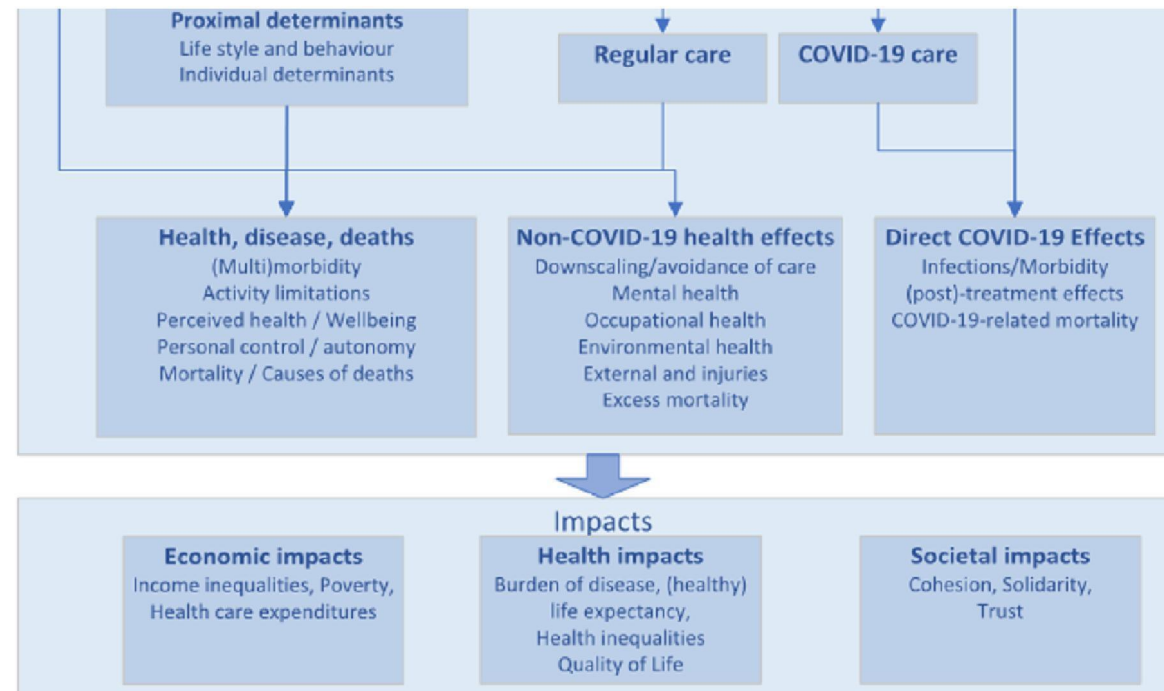


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# Potential conceptual model



## Potential conceptual model



## PHIRI for Covid-19: Work packages

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1. Coordination and management

2. Communication

3. Engagement, outreach and sustainability

4. Platform with FAIR catalogues

5. Monitoring long term effects of COVID-19

6. Immediate relevant use cases

7. Building federated infrastructure

8. Rapid exchange

9. Foresight, modelling and mitigation

## PHIRI for Covid-19: Work packages



1. Coordination and management

2. Communication

3. Engagement, outreach and sustainability

Collaborate with existing initiatives and project + connect in FAIR catalogue:

- COVID-19 H2020 calls
- EU COVID-19 data platform
- Relevant research infrastructures
- European Open Science Cloud (EOSC)
- European Research and Innovation Cloud: HealthyCloud
- European Health Data Space and the Joint Action TEHDAS
- European and international organisations as mentioned in the call



## PHIRI for Covid-19: Work packages

### 4. Platform with FAIR catalogues

1. Build FAIR catalogue with metadata repository on relevant COVID-19 population health information (including information on accessibility)  
→ Through close collaboration with National Nodes and Research Networks to feed the information
2. Provide overview of national and European upcoming or ongoing COVID-19 population health studies (including protocols, outputs and reports)
3. Provide overview of COVID-19 training material and courses in population health
4. Provide overview of COVID-19 policy and impact measures (through existing initiatives)
5. Provide overview of relevant COVID-19 international initiatives and projects
6. Ethical and legal aspects: produce code of conduct, support with GDPR: strengthen reuse and linkage of data (bring together and not repeat)
7. Allow tools for analysis and queries searches
8. Identify data gaps for better response to future crises

## InfAct and COVID-19

- What COVID-19 question would you like to see answered?
  - Multimorbidity, prolongation of waiting lists, consequences of stopping prevention programs (e.g. cancer screening, vaccination,...). (Si)
  - What happened to patients with chronic diseases during the pandemic? (Si - PT - FR -LT)
  - Unmet needs in the crisis and preparation for future waves (LT)
  - Data linkage:
    - We have data about everything but we cannot link it- I think there is a lack of European crisis strategy approach- guidelines on how to and when to link data. (PT)
    - Data linkage and anonymously linking individual data in households, schools, healthcare workers to understand how the infection is spreading and the impact on the measures. (Wales)
    - Link data with SES (LT)
  - Interested in preparedness and training and how to use decision making systems. Interested in EU approach on decision making. (PT)
  - 5 domains (FR):
    - Consequence of COVID-19 on care with NCD
    - Impact in disadvantaged and vulnerable populations homeless, prisoners, etc (LT)
    - Premature death due to COVID-19
    - impact on health inequalities, taking into consideration SES.
    - Risk factors with direct or indirect impact.

## InfAct and COVID-19

- Data gaps:
  - What we would like to have more is data from hospitals, experts, specialists. For example data on obesity and SES are difficult to obtain (AT)
- Risk factors and associated disease (ES)
  - Information about the risk factors and chronic diseases associated to infection by COVID-19 and seriousness of the disease.
- Seroconversion of infected cases and the long term effect (ES)
- Different domains (FI):
  - Mental health.
  - Chronic conditions-we have seen that people skipped cancer screening, less coronary events diagnosed, children aren't being vaccinated- we want to look at long term impact for chronic and health in general.
  - Risk factors and health status of COVID-19 patients.
  - Monitoring drug and alcohol use.
  - What happens to elder with lockdown and restrictions
  - Health inequalities due to loss of jobs.



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## PHIRI for Covid-19: Work packages

5. Monitoring long term effects of COVID-19 (effects of COVID-19 on secondary morbidity)

Consequences of COVID-19 on non-communicable diseases through holistic approach:

Promotion	Prevention	Cure
Campaign	Vaccination	Unmet need
Violence	Screening	Premature death

1. Develop indicators
2. Link with digital health tools, big data, artificial intelligence and devices

Make available to WP4. Platform with FAIR catalogues

## PHIRI for Covid-19: Work packages

6. Immediate relevant use cases of COVID-19

Doing research with immediate short term outcome

Potential use cases:

1. Impact on health inequalities, taking into consideration SES.
2. Well-being and mental health (based on health surveys) → link with JA mental health
3. Risk factors with direct or indirect impact
4. Delayed medical care due to COVID-19: use case on cancer → link iPAAC
5. Impact in disadvantaged and vulnerable populations (chronic patients, homeless, prisoners)

Other options: Burden of disease, follow-up of COVID-19 recovered persons, link health data and administrative data and SES, analysis at low granularity level (regional, subregional, departments etc.)

Make available to WP4. Platform with FAIR catalogues

## PHIRI for Covid-19: Work packages

### 7. Building federated infrastructure

- Facilitate real-time data exchange and data requests: securely make available federated data sets and variables in countries to monitor population health with controlled access policies through data access-granting organisation (DAO)
- Work on common data models and OMOP
- Allow tools for analysis and queries searches
- Investigate data capture possibilities
- Collaboration with relevant computational organisations e.g. EGI, the Hyve



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## PHIRI for Covid-19: Work packages

### 8. Rapid exchange

- Provide rapid response to questions that are raised in countries
- Rapidly spread internationally agreed standards, reports and initiatives possibly using data mining techniques
- Exchange (best) practices
- Provide a link with policy: the shifting landscape of evidence for policy

Make available to WP4. Platform with FAIR catalogues

## PHIRI for Covid-19: Work packages

9. Foresight, modelling and mitigation

Based on the experience from Covid-19 identify what were the needs?

- What was the information that countries needed from other countries?
- Which guidelines from international organisations were needed?
- Can we anticipate responses and support needed in the future at European level?
- Decision making models

Make available to WP4. Platform with FAIR catalogues



## Next steps

- Circulation of survey:
  1. Comments on WPs?
  2. Interest in WPs?Deadline: 01/07
- Next meeting: 03/07, 10/07 from



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