Country visits: interviewing health information system stakeholders

2 EUROPEAN PROJECTS – 2 AIMS – 1 METHODOLOGY

PHIRI

TEHDAS

EUROPEAN PUBLIC HEALTH WEEK – MAY 20 2022

Agenda

- Introduction PHIRI & TEHDAS projects
- Methodology
- Preliminary results PHIRI
- Preliminary results TEHDAS
- General meeting: June 23
- Q&A

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INTRODUCTION PHIRI & TEHDAS

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Two European projects:

	PHIRI Population Health Information Research Infrastructure	TEHDAS Towards the European Health Data Space
Project coordinator:	Sciensano	The Finnish Innovation Fund Sitra
Project acronym:	PHIRI	TEHDAS
Start date:	1 November 2022	1 February 2021
Duration:	36 months	30 months
Participants:	30 European countries	25 European countries
(Co-)funding:	€5 M, DG RTD, 100%	€4.16 M, DG SANTE, 60%
Websites:	www.phiri.eu	www.tehdas.eu
Contact:	PHIRI.coordination@sciensano.be	TEHDAS.Sciensano@sciensano.be

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Two aims:

	PHIRI Population Health Information Research Infrastructure	TEHDAS Towards European Health Data Space Towards the European Health Data Space
Aim of the country visits:	Map the health information system that monitors the **effects of COVID-19 on population health.**	Map the state-of-play of the national health data management developments **in relation to a future European Health Data Space (EHDS)**
Start date:	December 2021	December 2021
Duration:	14 months	12 months

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One methodology:

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Population Health Information Research Infrastructure

TEHDAS Towards European Health Data Space

Towards the European Health Data Space

Methodology: Semi-structured interviews with key stakeholders in the national health information system

Tool: Adapted from WHO's support tool to strengthen health information systems

Covering:

Data sources, data quality and analysis, reporting, data governance and resources and training needs, dissemination and knowledge translation

Data sources, data quality, data infrastructure (storage, access and interoperability), data governance, resources and training needs, EHDS preparedness

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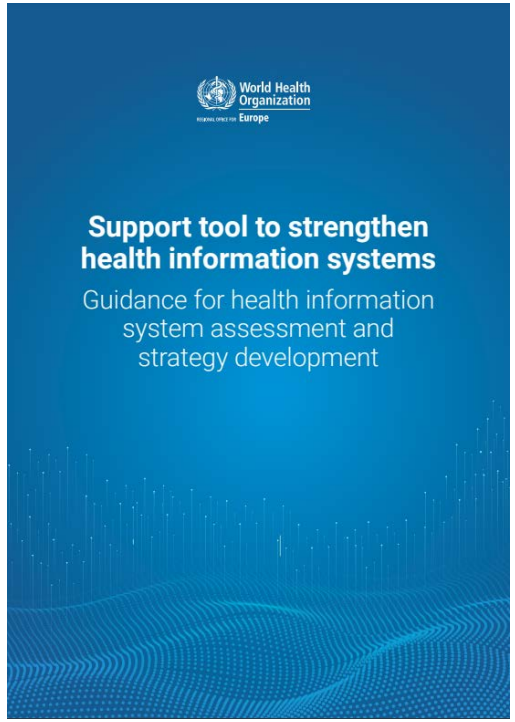
Tool and roles

Adaptation of the tool to accommodate the aim of the country visit

Defined Roles:

- **Assessor:** act as independent, professional assessors, create engagement and carry out the assessment (preparatory desk report, interviewing, summarising outcomes)
- **Contact person(s):** national liaison during the assessment, provide the assessors with relevant documentation, identify the stakeholders to be interviewed, planning the interviews
- **Observer (only in PHIRI):** provide support during the assessment based on previous experience with the assessment methodology and map potential overarching outcomes across the assessments



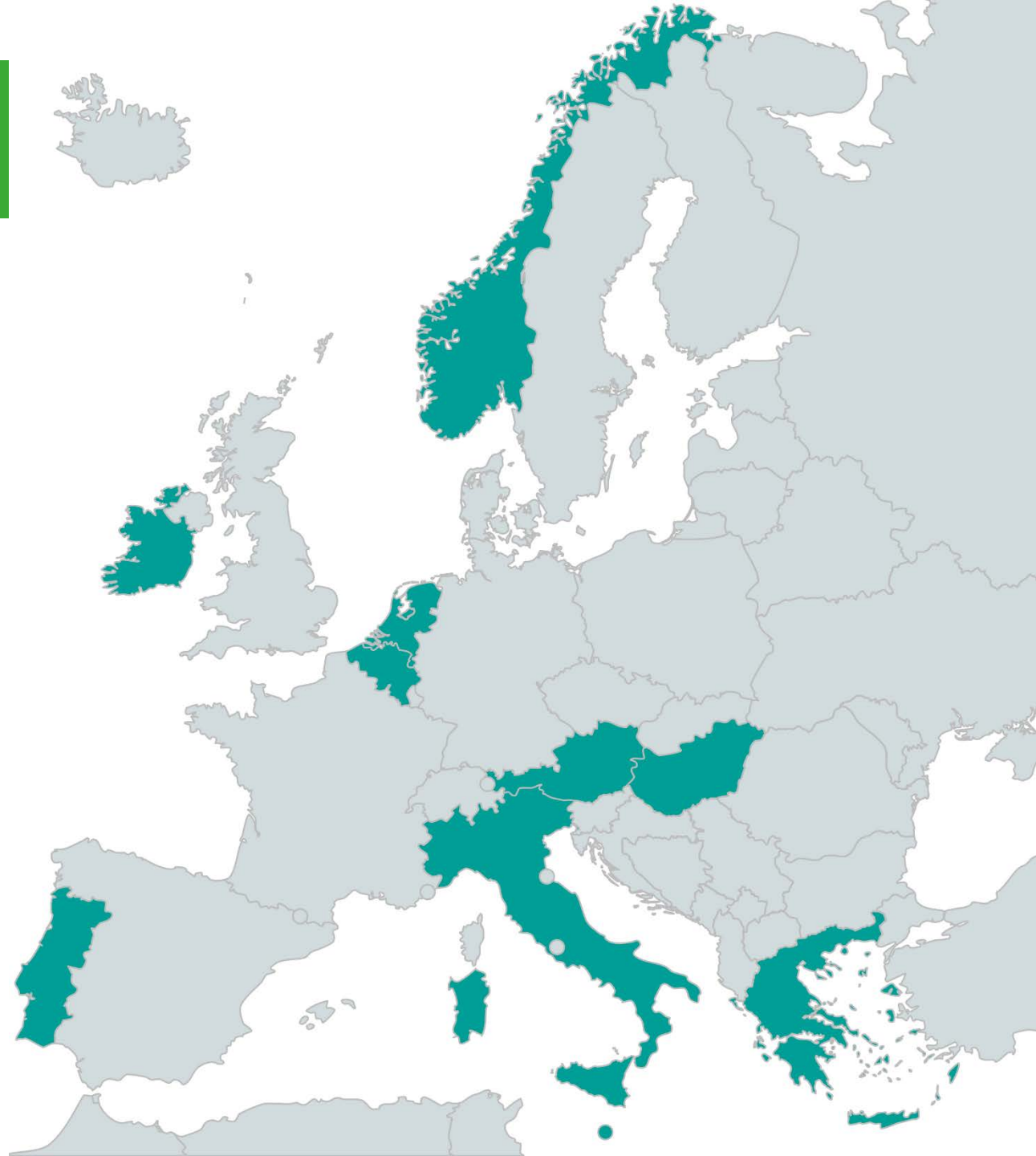
The PHIRI country visits

PHIRI

Population Health Information Research Infrastructure

10 Assessments scheduled

Q4 2021 – Q1 2023



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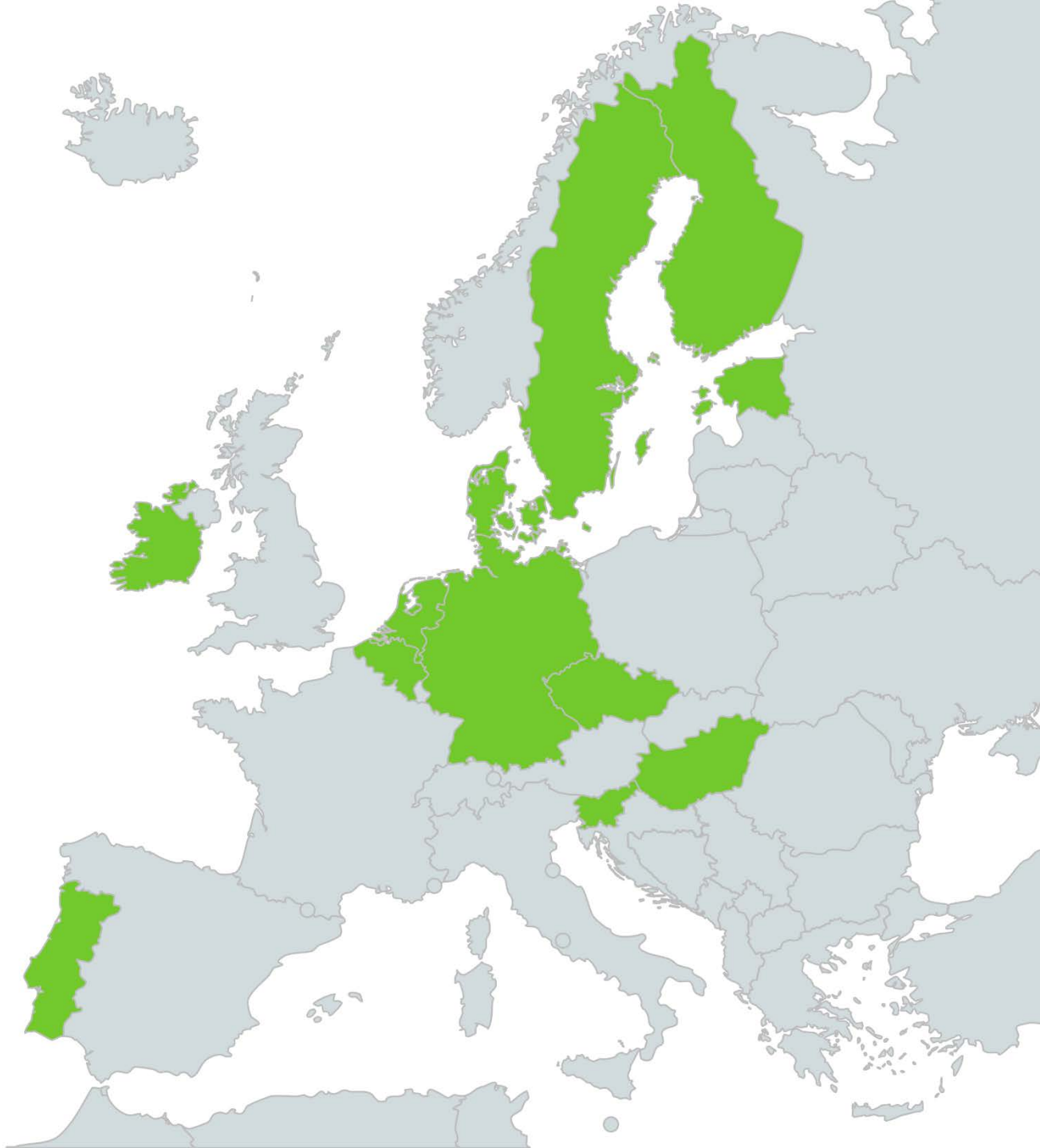
The TEHDAS country visits

Towards
European
Health
Data
Space

12 Assessments scheduled

Q4 2021 – Q4 2022



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METHODOLOGY

Methodology

1. Preparatory desk review

- Preparatory report
- Stakeholders selection

2. Country visit

- Semi structured-interviews using the adapted assessment tool

3. Debriefing meetings

- Multi-stakeholder meeting
- General meeting

4. Reporting

- One-pager
- Report

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Methodology

1. Preparatory desk review

- To gain initial insight into the country's health information system (HIS) and data management processes

- To identify initial knowledge gaps in the country

  → **PHIRI:** focus on COVID-19 data flows and changes during the pandemic
  → **TEHDAS:** focus on the sharing of data for secondary use & preparedness for the EHDS

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Methodology

1. Preparatory desk review

- To identify the main stakeholders with country contact person
  - National Public Health Institute
  - Ministry of Health and/or Research
  - Statistical Office
  - Health insurance company
  - IT or eHealth infrastructures
  - Data permit authority or similar
  - Universities
  - Hospital groups

Methodology

2. Country visit

- Semi-structured interviews with key stakeholders
  - Virtual or face-to-face
  - Guided by assessment tool
  - Complement with debriefing sessions among assessors

Methodology

3. Debriefing meetings

- A stakeholders meeting is organised shortly after
  - → Bring national stakeholders together and conclude the country visit
  - → Deliver initial findings of the county visit
  - → Discuss potential feedback and comments

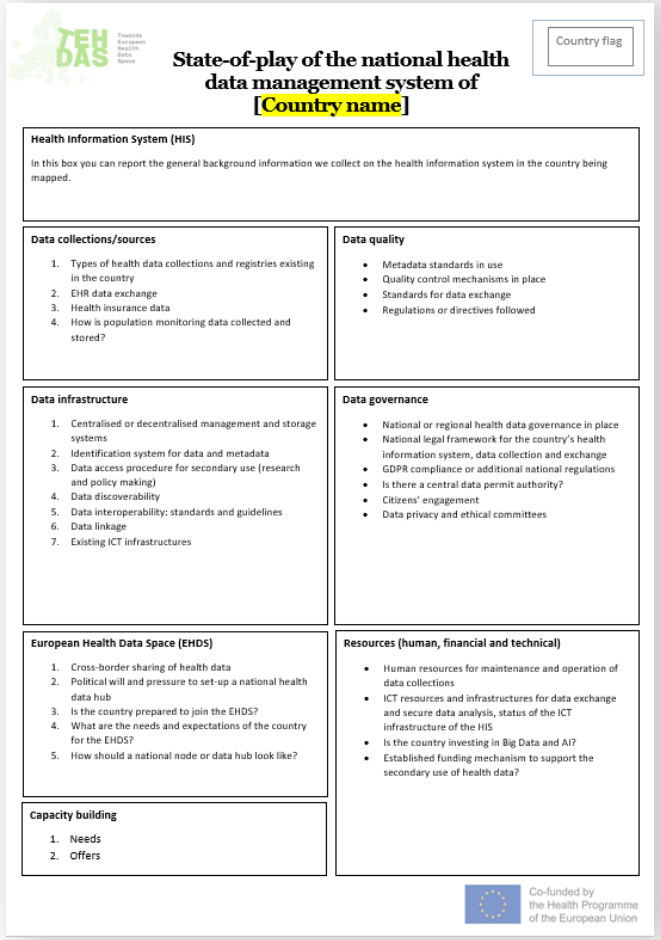
- A general mid-term meeting is organised to publicly present the main findings of the first countries assessed

Methodology

4. Reporting

- The results are summarised into a detailed ***report*** and a ***one pager*** per country

- The reports are sent to the participating stakeholders for feedback and comments



State-of-play of the national health data management system of [Country name]

Country flag

Health Information System (HIS)

In this box you can report the general background information we collect on the health information system in the country being mapped.

Data collections/sources

1. Types of health data collections and registries existing in the country
2. EHR data exchange
3. Health insurance data
4. How is population monitoring data collected and stored?

Data quality

- Metadata standards in use
- Quality control mechanisms in place
- Standards for data exchange
- Regulations or directives followed

Data infrastructure

1. Centralised or decentralised management and storage systems
2. Identification system for data and metadata
3. Data access procedure for secondary use (research and policy making)
4. Data discoverability
5. Data interoperability: standards and guidelines
6. Data linkage
7. Existing ICT infrastructures

Data governance

- National or regional health data governance in place
- National legal framework for the country's health information system, data collection and exchange
- GDPR compliance or additional national regulations
- Is there a central data permit authority?
- Citizens' engagement
- Data privacy and ethical committees

European Health Data Space (EHDS)

1. Cross-border sharing of health data
2. Political will and pressure to set-up a national health data hub
3. Is the country prepared to join the EHDS?
4. What are the needs and expectations of the country for the EHDS?
5. How should a national node or data hub look like?

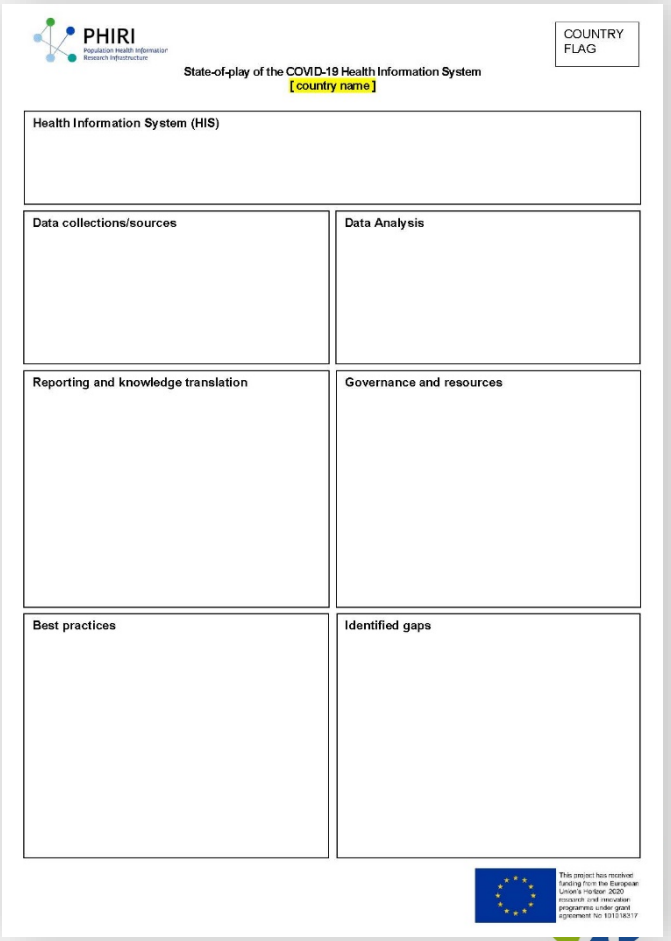
Resources (human, financial and technical)

- Human resources for maintenance and operation of data collections
- ICT resources and infrastructures for data exchange and secure data analysis, status of the ICT infrastructure of the HIS
- Is the country investing in Big Data and AI?
- Established funding mechanism to support the secondary use of health data?

Capacity building

1. Needs
2. Offers

Co-funded by the Health Programme of the European Union



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State-of-play of the COVID-19 Health Information System [country name]

COUNTRY FLAG

Health Information System (HIS)

Data collections/sources

Data Analysis

Reporting and knowledge translation

Governance and resources

Best practices

Identified gaps

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

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Methodology

Added value for the assessed country

- An opportunity to bring together stakeholders
- An overview of the main stakeholders of national HIS, their roles, and data management processes
- Pinpoint capacity building and training needs, and raise expertise by participating in the assessment of a different country as an assessor

- PHIRI: Identify strengths and weaknesses of the different data flows monitoring the wider effects of COVID-19, and draft recommendations
- TEHDAS: Provide an insight into the current state of the national HIS to potentially join the EHDS, and the awareness thereof among stakeholder

PRELIMINARY RESULTS PHIRI

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Preliminary results PHIRI

Best practices

- Strong vaccination information system implemented before the COVID-19 crisis hit
- Strong and rapid technological surveillance system set-up
- Pivotal role of telemedicine during COVID-19
- Data dashboards and regular reports (publicly) available
- Ad hoc health surveying during COVID-19 or add-on modules specific to COVID
- Strong formal and informal communication between different stakeholders; building a trust relationship with the public
- Development of Robotic Process Automation to align COVID-19 data across information systems and process laboratory records, notifications and contact-tracing data
- Creation of COVID-19 databases for secondary use of data

Preliminary results PHIRI

Concerns

- Elements of the COVID-19 surveillance system operating based on national state-of-emergency or other emergency decrees
- Slow integration of newly developed systems for surveillance of COVID-19 in the existing surveillance system
- Challenges with human resources
- Lack of single unique person identifier in the health system
- Lack of data from the private healthcare sector
- Weak data collection at the community level (heterogeneous systems)

Preliminary results PHIRI

Lessons learnt

- Difficulty of linking data when a unique person identifier is not collected
- Relevance of preparing for appropriate legislation for collection, processing, sharing and reuse of health data
- Significance of having infodemic management in an overarching strategy for health information system
- Need of including health information system elements in the pandemic preparedness strategy
- Need for more harmonised data systems across the different hospitals and community to exchange data
- Relevance of paying attention to security threats

PRELIMINARY RESULTS TEHDAS

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Preliminary results TEHDAS

Best practices

- Citizen empowerment and control over their data
- National level data guardian to act as a representative of the citizens (ombudsman)
- Strong investment in infrastructure for primary use, which can be used for secondary use
- Dedicated support services for researchers and data users (e.g., data access, analysis, data support centres)
- Initiatives allowing interaction and collaboration between legal officers
- Allowing access to health data for secondary use on the basis of public interest
- Involvement of healthcare professionals to improve data quality and interoperability (e.g., in deploying standards)
- Improving data literacy (e.g., training to healthcare providers on using IT technology)
- Involvement in international co-operations (e.g. B1MG, TEHDAS, BBMRI, ELIXIR)

Preliminary results TEHDAS

Concerns & needs

Concerns

- Dependence on paper-based records
- Inconsistent use of single unique personal identifier for linking data
- Data gaps from the private healthcare sector
- Practices limiting foreign users access to data
- Inconsistent use of international standards and high amount of unstructured data
- Unclear/inconsistent interpretation of GDPR

Needs

- Legal, organisational and semantic interoperability across Europe
- Financial resources, trainings and sharing of best practices at EU level
- EU and local level incentives to enable digitalisation
- Consideration of diversity and local sensitivities
- Skilled human resources (e.g., data stewards, data analysts, cyber-security experts, legal officers)

Preliminary results TEHDAS

Expectations of the European Health Data Space (EHDS)

- Ensure and communicate equal benefit for all countries
- Focus on cybersecurity, trust and citizens' empowerment
- Enable cross-border research and international comparisons on certain parameters
- Establish a European Health Data Academy
- Improve transparency in access processes and decisions
- Establish a European level platform for legal officers to share best practices (e.g., through workshops)
- Develop a manual providing overview of national health data management systems in EU countries
- EHDS must be relevant for citizens and health service providers, demonstrating clear and tangible benefits

Preliminary results TEHDAS

Preparedness for the EHDS

- Political will to join the EHDS (6 / 6 countries visited)
- National contact point established (1 / 6)
- Digitalisation (5 / 6)
- Common metadata catalogue (3 ongoing / 6)
- Usage of a unique personal identifier for health (5 / 6)
- Remote secure processing environments (3 / 6)
- Semantic interoperability (1 / 6)
- Give equal access for national and foreign researchers (5 / 6)

GENERAL MEETING: JUNE 23 (10:00-12:00 CET)

“Mapping Health Information Systems for COVID-19 and a future EHDS”

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