



# PHIRI

Population Health Information  
Research Infrastructure



# Member States' Health Information Systems: State-of-play and best practices

European Public Health Conference 2023



# Moderators



**Nienke Schutte,**  
Head of EU Health Information  
System Unit  
Sciensano, Belgium



**Neville Calleja,**  
Head Of Department - Public  
Health  
Ministry For Health, Malta

# Background

- Health Information Systems (HIS) are at the basis of the generation of knowledge for improving the health and well-being of the population
- Assessments of health information systems allows identification of strengths and weaknesses
- To assess HISs in Europe in different contexts, mapping exercises are conducted across three different European projects:
  - the Population Health Information Research Infrastructure (PHIRI),
  - the Joint Action Towards the European Health Data Space (TEHDAS), and
  - the European Interoperability with the HERA IT Platform (EU-HIP) project.

# Speakers



## **WHO Support tool to strengthen health information systems**

*Stefania Davia – World Health Organisation (WHO)*



## **State-of-play of the COVID-19 health information system in 8 European countries**

*Miriam Saso – Population Health Information Research Infrastructure (PHIRI)*



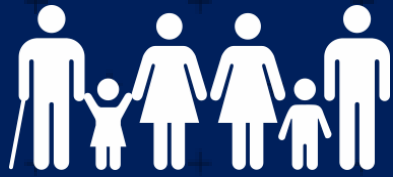
## **State-of-play of the national health data management systems in relation to the European Health Data Space**

*Linda Abboud – Towards the European Health Data Space (TEHDAS)*



## **Mapping of surveillance systems for health crisis preparedness and response in Member States**

*Shona Cosgrove – EU interoperability with HERA's IT Platform (EU-HIP)*



# Support tool to strengthen health information systems

EUPHA

9 November 2023

Stefania Davia

Data and Digital Health Unit

*Division of Country Health Policies and Systems  
World Health Organization, Regional Office for Europe*



European Region

# In this presentation

01

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HIS assessment  
methodology

02

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Core and add  
on modules

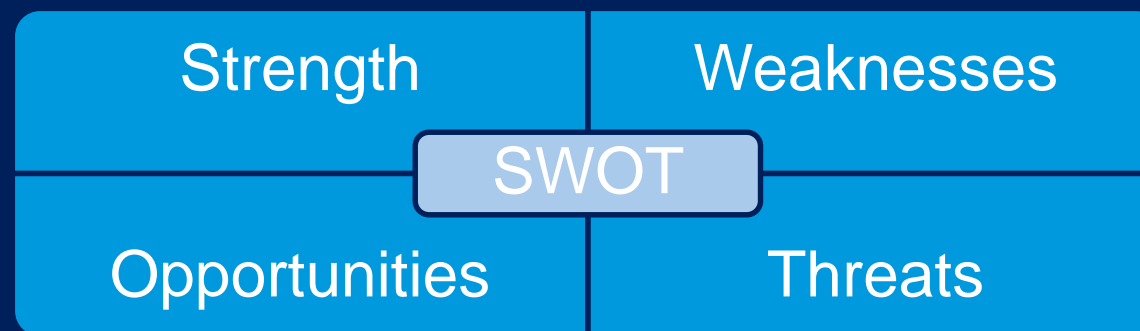
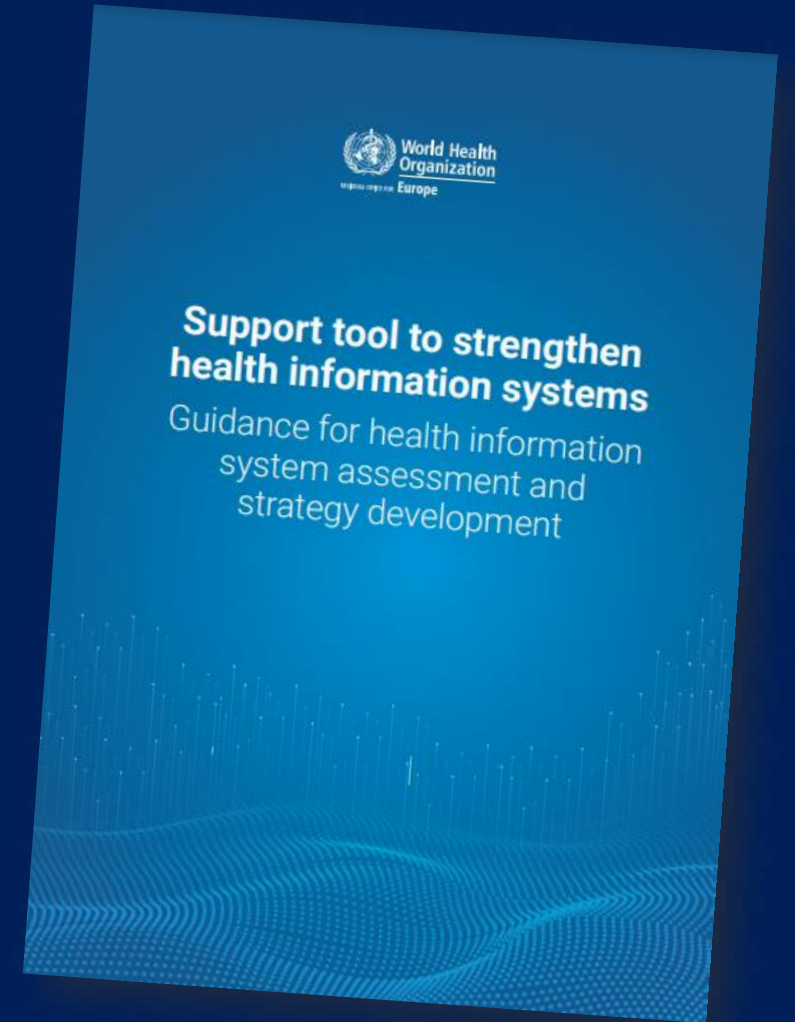
03

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How it works in  
practice

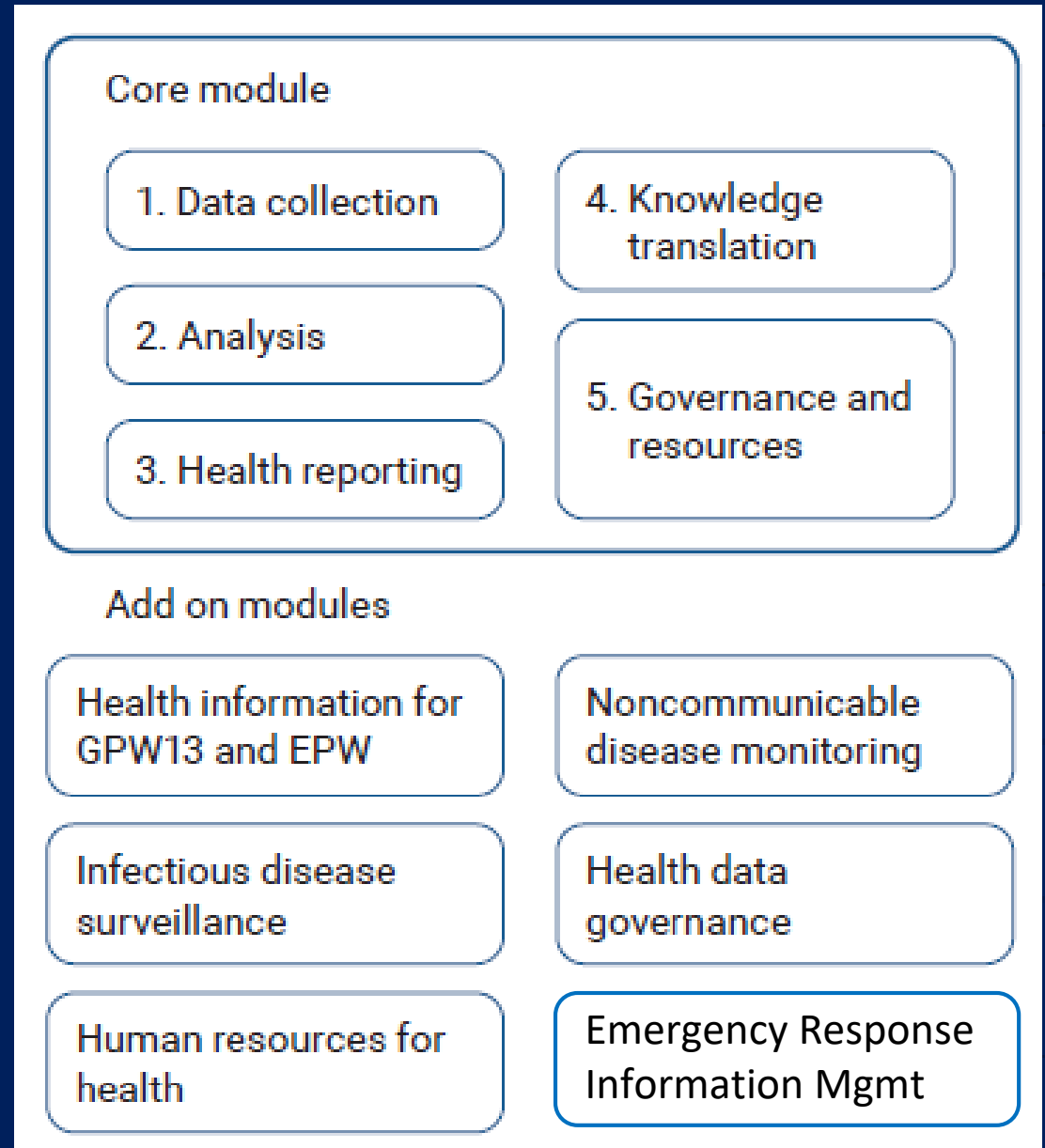
# HIS Assessment: methodology

- Developed in 2015; revised in 2021 to reflect the current HIS context in the WHO EURO
- Two parts:
  1. Performing an assessment
  2. Development of an HIS strategy



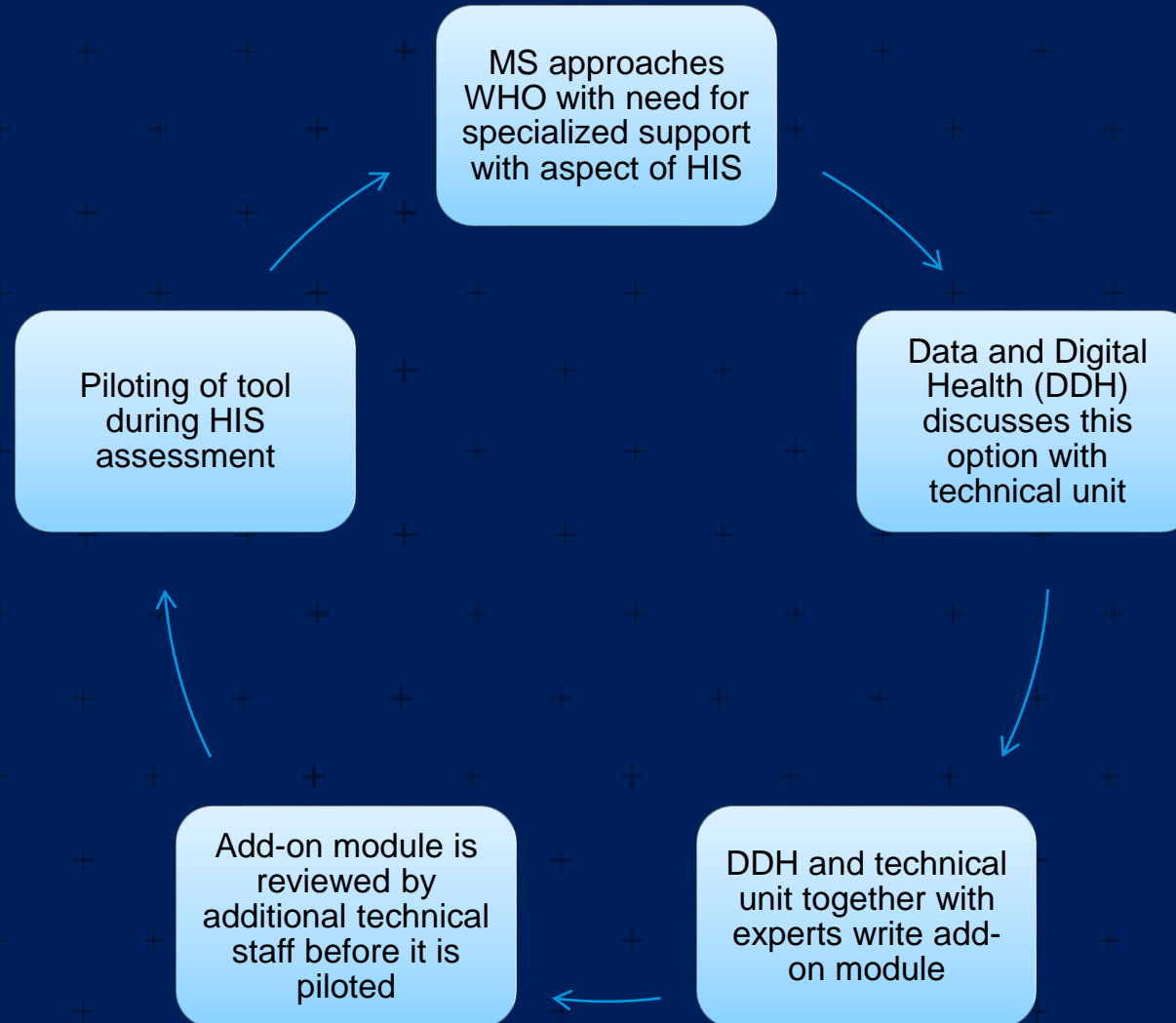
## Core module and add on modules

- The aim of the core module is to obtain a generic overview of the functioning of the entire national HIS.
- The aim of the add-on modules is to look in more detail at specific parts or functions of the national HIS.
- The core module is the basis, and the add-on modules build on that.





# A living document – always reevaluating!



# Domains of the modules (core and add-on)



**Data collection:** Available data collections, efficiency of data flows, and the quality and usability of existing data collections. Including the availability, usability, and interoperability of digital data collection systems.



**Analysis:** Availability, comprehensiveness and use of indicator sets.



**Health reporting:** Availability, comprehensiveness and use of health reports for policy-making and planning.



**Knowledge translation:** assesses the extent to which stakeholders are familiar with available health information and knowledge products, and which knowledge translation tools and mechanisms are being used.



**Governance & resources:** covers HIS governance mechanisms and general HIS resources, which include the legal framework, ICT infrastructure, and financial resources. (Note: human resources are addressed as part of the other four dimensions.)



## How is the item sheet built up?

Expectations = what the situation would be like in a fully matured HIS

Item ID	Main question	Probing questions	Expectations
Analysis_1	Is a core set of health indicators defined in the country?	1) Is the core set linked to a specific health policy (process) and/or to specific health goals or targets?	(1) The core set is linked to a specific health policy (process) and/or to specific health goals or targets
		2) How were core indicators selected?	(2) National minimum core indicators have been transparently identified for national and subnational levels. The selection of indicators is also informed by international indicator sets
		3) Which categories does the indicator set cover?	(3) Indicators cover all categories of health indicators (e.g. determinants of health; health system inputs, outputs and outcomes (health systems performance assessment); health status; health inequalities) (Examples: Joint Monitoring Framework, SDG, NCD). If possible it includes also relevant indicators from other policy sectors (e.g. social affairs, education)
		4) How is the indicator defined and calculated?	(4) An indicator definition exists and the method for its calculation is documented. If applicable: the numerator and denominator of the indicator are clearly defined

# Excel scoring sheet with room for detailed comments



## CORE Data collection

Item ID	Question	Probing question	Expectations	Assessor's comments
<b>Data sources</b>				
Data sources_1	Are regular censuses performed in the country?	(1) What is the frequency at which censuses are performed?	(1) Censuses are planned and conducted at fixed, regular intervals, at least once every 10 years, in line with the United Nations recommendation on the frequency of population censuses.	
		(2) Is the census based on surveys and/or administrative data sources?	(2) In line with Eurostat requirements for the 2021 census, the census is primarily based on administrative data sources.	
		(3) Are time series revised backwards? If so, for how many years?	(3) If time series are revised backwards, a communication strategy is in place on how to communicate to the ministry of health and other health information users about the reasons for the retroactive amendment of indicators and the impact of the revision on the	
		(4) Are different indicator values used in parallel, based on different population figures/different denominators?	(4) If different indicator values are used in parallel, a communication strategy is in place on how to communicate to the ministry of health and other health information users why different versions of the same indicator are being calculated and reported, and how these should be	
		(5) (Only necessary if civil registration covers less than 95% of deaths) Are questions on mortality included in the census?	(5) If questions on mortality are included, results are used to estimate child mortality and household deaths in the past 12/24 months, including sex of deceased and age at death.	
Data sources_2	What is the status of registration of vital statistics?	(1) Are any births unregistered and, if so, what share of births – and which subgroups of the population – does this concern?	(1) The coverage of registered births is (close to) 100%.	
		(2) What kind of medical information is regularly collected on births?	(2) Information on birth weight, gestation period/prematurity, birth order (for multiple births), method of delivery, complications during delivery, stillbirth and date of the mother's most recent delivery is part	

- 1
- 2
- 3 Introduction
- 4 **CORE Data collection**
- 5 CORE Analysis
- 6 CORE Health reporting
- 7 CORE Knowledge translation
- 8 CORE Governance and resources
- 9 CORE Summary and scoring sheet
- 10 Add-on GPW13-EPW
- 11 Add-on Infectious disease surveillance
- 12 Add-on Human resources for health
- Add-on NCD monitoring
- Add-on Health data governance

# Thank you

For more information, please contact:

**Data and Digital Health Unit**

*Division of Country Health Policies and Systems*

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 [euhiudata@who.int](mailto:euhiudata@who.int)





# PHIRI

Population Health Information  
Research Infrastructure



## State-of-play of the COVID-19 health information system in 8 European countries

Miriam Saso, Sciensano (Belgium)



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



# What is PHIRI?

The Population Health Information Research Infrastructure:

- a **European mechanism**, that aims to
- facilitate and support **data-driven population health research**
- and **exchange of best practices**
- to support **decision making**

**41**  
partners

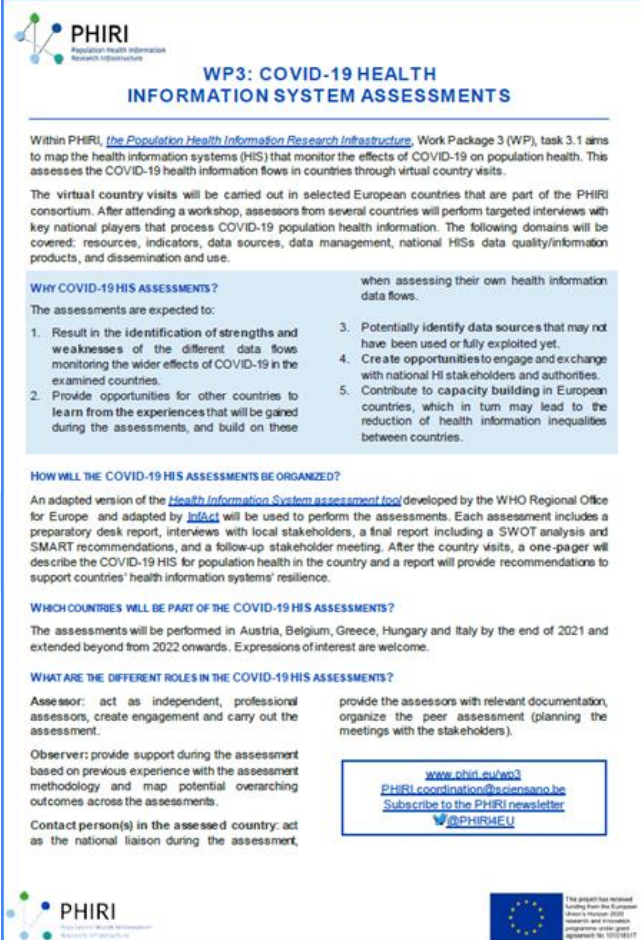
**30**  
countries



Map of PHIRI Partners

# COVID-19 Health Information System assessments

- Aim
  - ✓ **Map the COVID-19 health information system (HIS) that monitors the effects of COVID-19 on population health: identifying strengths and weaknesses**
- Objectives
  - ✓ Learn from best practices
  - ✓ Capacity building: reducing health information inequalities
  - ✓ Recommendations for resilient HIS
- Assessors trained to use adapted [WHO tool](#)
- Covering: data collection, analysis, reporting, knowledge translation, governance & resources



**PHIRI**  
Population Health Information  
Research Infrastructure

## WP3: COVID-19 HEALTH INFORMATION SYSTEM ASSESSMENTS

Within PHIRI, *the Population Health Information Research Infrastructure*, Work Package 3 (WP), task 3.1 aims to map the health information systems (HIS) that monitor the effects of COVID-19 on population health. This assesses the COVID-19 health information flows in countries through virtual country visits.

The virtual country visits will be carried out in selected European countries that are part of the PHIRI consortium. After attending a workshop, assessors from several countries will perform targeted interviews with key national players that process COVID-19 population health information. The following domains will be covered: resources, indicators, data sources, data management, national HISs data quality/information products, and dissemination and use.

**WHY COVID-19 HIS ASSESSMENTS?**  
The assessments are expected to:

1. Result in the identification of strengths and weaknesses of the different data flows monitoring the wider effects of COVID-19 in the examined countries.
2. Provide opportunities for other countries to learn from the experiences that will be gained during the assessments, and build on these
3. Potentially identify data sources that may not have been used or fully exploited yet.
4. Create opportunities to engage and exchange with national HI stakeholders and authorities.
5. Contribute to capacity building in European countries, which in turn may lead to the reduction of health information inequalities between countries.

**WHEN ASSESSING THEIR OWN HEALTH INFORMATION DATA FLOWS:**


**HOW WILL THE COVID-19 HIS ASSESSMENTS BE ORGANIZED?**  
An adapted version of the *Health Information System assessment tool* (developed by the WHO Regional Office for Europe and adapted by [InfAct](#)) will be used to perform the assessments. Each assessment includes a preparatory desk report, interviews with local stakeholders, a final report including a SWOT analysis and SMART recommendations, and a follow-up stakeholder meeting. After the country visits, a one-pager will describe the COVID-19 HIS for population health in the country and a report will provide recommendations to support countries' health information systems' resilience.

**WHICH COUNTRIES WILL BE PART OF THE COVID-19 HIS ASSESSMENTS?**  
The assessments will be performed in Austria, Belgium, Greece, Hungary and Italy by the end of 2021 and extended beyond from 2022 onwards. Expressions of interest are welcome.

**WHAT ARE THE DIFFERENT ROLES IN THE COVID-19 HIS ASSESSMENTS?**  
**Assessor:** act as independent, professional assessors, create engagement and carry out the assessment.  
**Observer:** provide support during the assessment based on previous experience with the assessment methodology and map potential overarching outcomes across the assessments.  
**Contact person(s) in the assessed country:** act as the national liaison during the assessment, provide the assessors with relevant documentation, organize the peer assessment (planning the meetings with the stakeholders).

[www.phiri.eu/wp3](http://www.phiri.eu/wp3)  
[PHIRI.coordination@sciensano.be](mailto:PHIRI.coordination@sciensano.be)  
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The project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101018317



# Methodology

## 1. Preparatory desk review

- Preparatory report
- Stakeholder selection



## 2. Country visit

- Semi structured-interviews with adapted WHO item list



## 3. Debriefing meeting

- Multi-stakeholder meeting



## 4. Reporting

- One-pagers
- Report



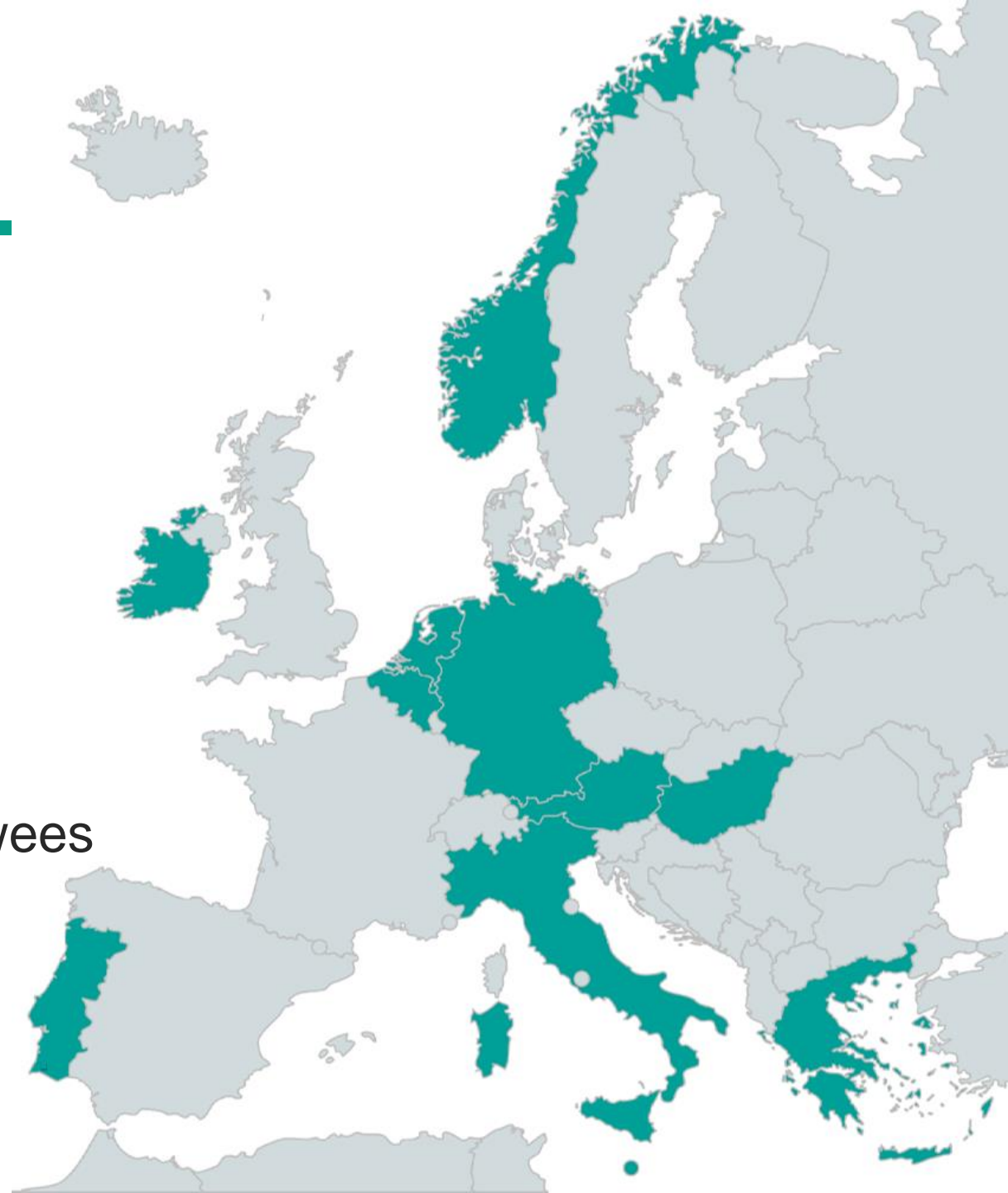


# Countries assessed

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## Assessments performed

-  Italy (Jan 2022) – 13 interviewees
-  Portugal (Mar 2022) – 4 interviewees
-  Ireland (Apr 2022) – 17 interviewees
-  Malta (May 2022) – 20 interviewees
-  Norway (Jun 2022) – 9 interviewees
-  Hungary (Oct 2022) – 4 interviewees
-  Netherlands (Nov 2022) – 14 interviewees
-  Belgium (April 2023) – 9 interviewees



# Best practices

- **Preparedness:** Strong vaccination system implemented before the COVID-19 crisis
- **Resilience:** Rapid technological surveillance system set-up
- **Responsiveness:** Pivotal role of telemedicine during COVID-19
- **Transparency:** Data dashboards and regular reports (publicly) available
- **Multidisciplinary collaboration:** Involvement of private companies outside health to learn from e.g. their supply chain expertise
- **Knowledge Translation:** Experts involved in an interdisciplinary manner to improve communication and dissemination activities
- **Trustworthiness:** Trust in relation to health information identified as a key priority in peacetime and was built over time
- **Interoperability:** Linkage of databases to ensure e.g. coverage of vulnerable groups
- **Innovation:** Increased use of water sewage surveillance

# Identified gaps & recommendations

Organisational

Technical

Legal

Resources

# Identified gaps & recommendations

## Organisational

- No unique personal ID consistently used
- Communication gaps to the public
- Network to exchange
- Use of paper-based records

- Increase potential of the unique identifier for automated linkage of different databases
- Include infodemic management in an overarching strategy for health information system
- Continue promoting collaboration across national and regional stakeholders
- Modernise systems and digitalise paper-based processes for integration with more robust digital systems

# Identified gaps & recommendations

## Technical

- Lack of systems interoperability
- Data gaps
- Inconsistent use of definitions and international standards

- Minimize the administrative workload on healthcare providers by establishing interoperable systems that prevent redundant reporting
- Set up the legal and technical framework to systematically share data with academia and other health stakeholders
- Encourage the promotion of the FAIR Data Principles to support the findability, accessibility, interoperability and reusability of health data and related (meta)data international standards
- Develop indicators with defined thresholds with key stakeholders

# Identified gaps & recommendations

## Legal

- Lack of preparedness plans
- Need for long term monitoring and surveillance strategies
- Interpretation of the GDPR

- Strengthen the health information system elements in the pandemic preparedness plan
- Continue working on post-pandemic situation: options for an alternative sustainable COVID-19 surveillance system
- Develop clear guidelines for safe sharing and secondary use of data

# Identified gaps & recommendations

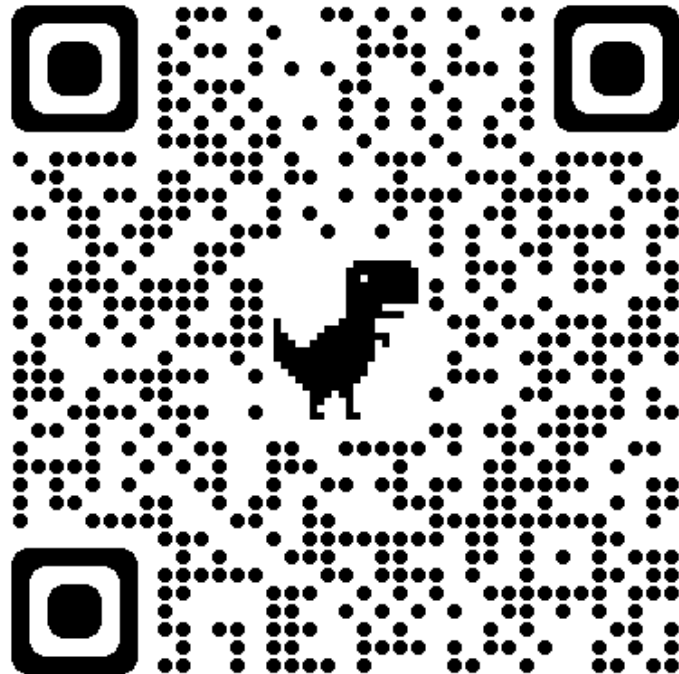
## Resources

- Systematic lack of human resources, especially with technical skills, at all levels
- Need for long term monitoring and surveillance strategies

- Increase early training in data management tools starting from the undergraduate level training
- Align employment and training possibilities to address the shortage of health professionals



# Additional Material



Scan the code to  
read all our  
***additional  
material!***



# PHIRI

Population Health Information  
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## Thank you for your attention!

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



# **State-of-play of the national health data management systems in relation to the European Health Data Space**

Linda Abboud (Sciensano, Belgium)

The Joint Action TEHDAS was set up to help Members States and the Commission in **developing and promoting concepts for sharing health-related data for secondary use purposes** such as health research, innovation and policy making in Europe



# TEHDAS Country visits

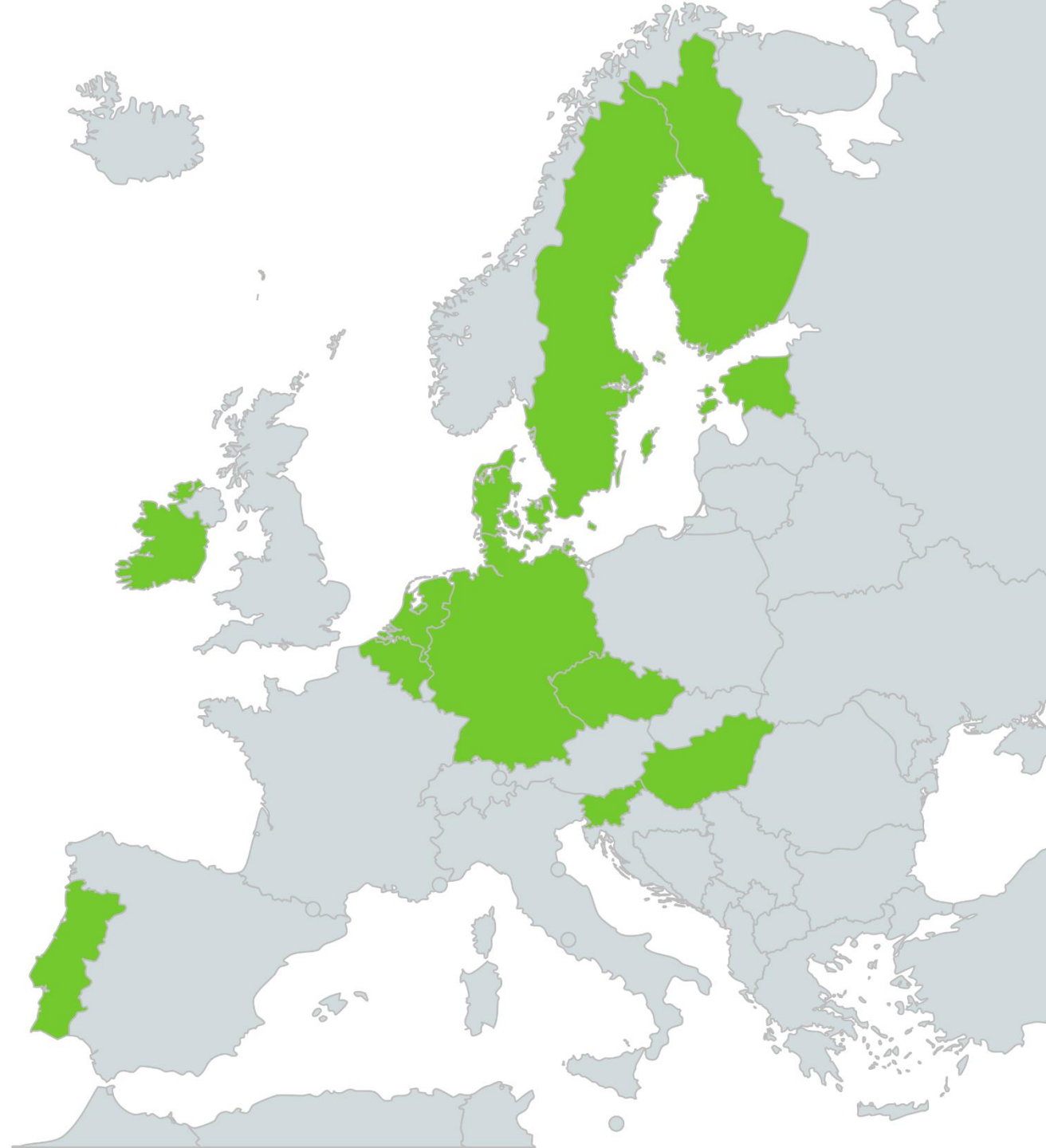
## Aim

To engage with national stakeholders and map the state-of-play of the national health data management systems and their preparedness to join a future European Health Data Space for secondary use (EHDS2)

## 12

### Timeline:

December 2021 – December 2022  
12 member states, 178 interviews



# 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



## 4. Reporting

- Report
- [One-pager](#)



## Challenges & Needs

Organisational

Technical

Legal

**RESOURCES, RESOURCES, RESOURCES !**

## Organisational



Paper-based records



No unique personal ID



Data gaps

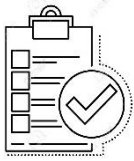


Interpretations of the GDPR

- Incentives to achieve full digitalisation
- Unique personal identifier implemented across the health sector
- Manual providing overview of national data management systems
- Transparency in access processes and decisions



## Technical



Inconsistent use of internationally recognised standards



Unstructured data



Lack of interoperability



Inconsistent use of SPEs

- Guidance on standards for collecting, storing and structuring data
- Training on data interoperability and harmonisation
- Requirements for SPEs

## Legal



Limited foreign users access



Unclear definition of anonymisation or pseudonymisation



Lack of legal framework for secondary use

- Adequate privacy protection practices
- Clear legislative framework for secondary use and linking data
- Harmonised rules on how to pseudonymise and anonymise
- Guidelines for GDPR interpretation

# Preparedness for the EHDS

- Digitalised health data (9 / 12)
- Common metadata catalogue in place or work ongoing (5 / 12)
- Universal usage of a unique personal identifier for health (10 / 12)
- Use remote secure processing environments for data analysis (8 / 12)
- Wide use of internationally recognised standards for data management (4 / 12)
- Use of semantic interoperability standards, health data structure (9 / 12)
- Similar access rights for national and foreign researchers (11 / 12)
- Political will to join the EHDS (12 / 12)
- Potential national contact point for the EHDS2 already existing (3 / 12)

# Conclusion

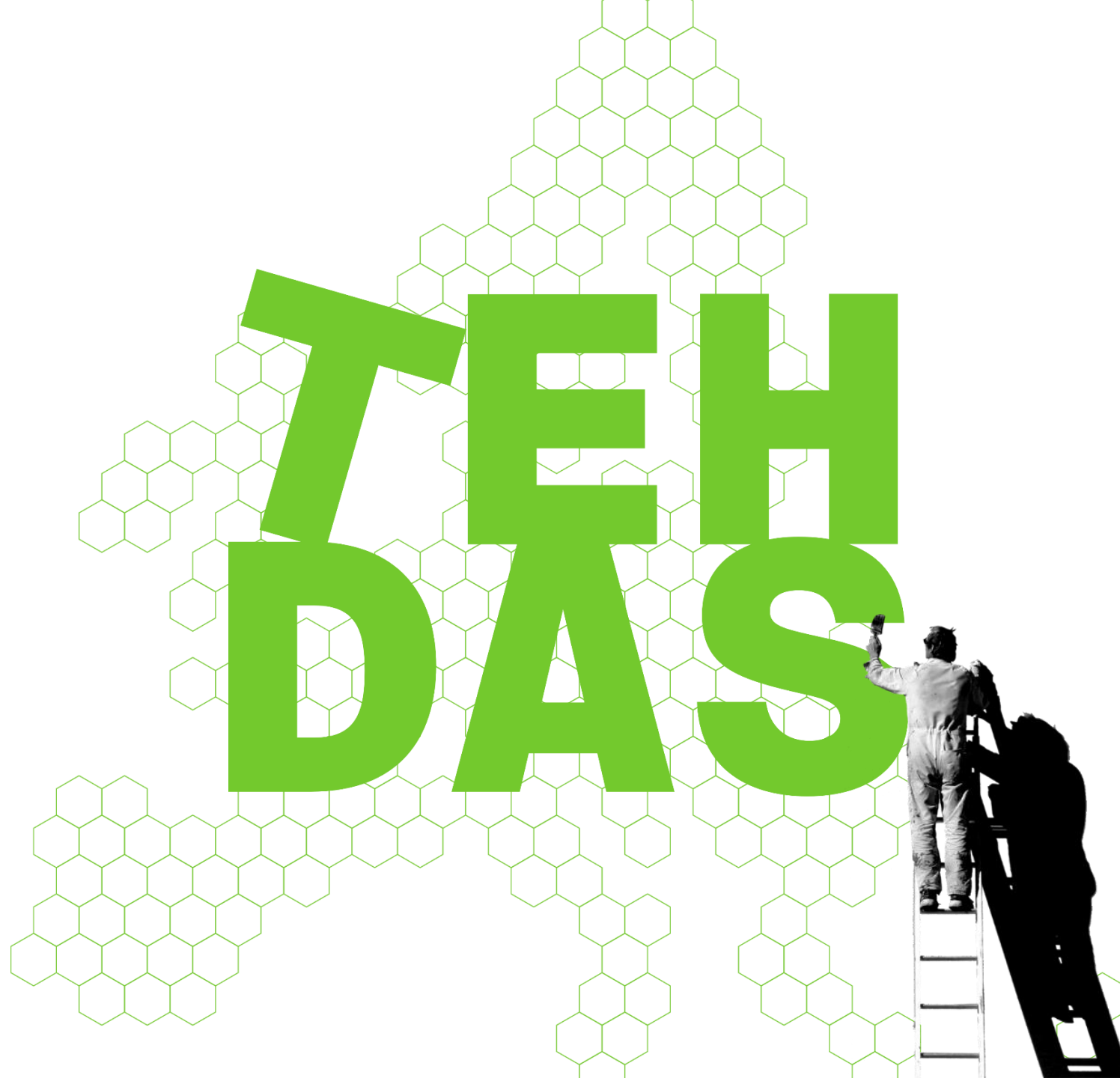
In general, positive views on the impact and added value of the EHDS for secondary use, and willingness to join. Concerns and needs remain:

- ✓ Consider **diversity** and local sensitivities
- ✓ Ensure **equal benefit** for all countries and stakeholders
- ✓ Need for **more time** for implementation and to update national legislative frameworks
- ✓ Need for more **resources**: human, technical and financial
- ✓ Ensuring **data security**, maintaining **citizens' trust**, and demonstrating **equal benefits** for all
- ✓ Improve **transparency** in access processes and decisions
- ✓ Communicate with **all stakeholders and citizens**
- ✓ Consider **capacity building** needs and training

# Explore the findings: [www.tehdas.eu/country-visits](http://www.tehdas.eu/country-visits)



1. Results: Country factsheets
2. Methodology on how to conduct country visits



# Mapping of surveillance systems for health crisis preparedness and response in Member States

Shona Cosgrove  
EPH Conference Dublin  
11 November 2023



# EU-HIP

EU INTEROPERABILITY WITH HERA'S IT PLATFORM



EU-HIP is co-funded by the  
European Union under Grant  
Agreement No 101102774



# Health Emergency Preparedness and Response Authority (HERA)

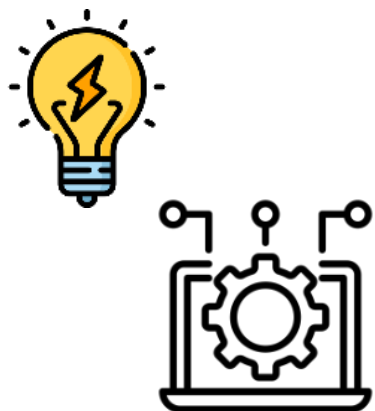
**Prevent, detect,** and **rapidly respond to** serious cross-border health emergencies

Intelligence gathering and threat assessment:

- Health threats requiring **medical countermeasures (MCM)**
- Tracking MCM supply chains, shortages, vulnerabilities and strategic dependencies



Assess the health threats to identify response options for decision/policy-making concerning MCM



## Advanced Technology for Health INtelligence and Action IT system

- Information systems linking, threat assessment, simulation and analytics, and emergency response
- Public health (PH) and medical countermeasures (MCM)

# EU-HIP Landscape assessment

Digital ecosystem for health crisis preparedness and response

## What?

Mapping of:

1. Digital infrastructures and systems (including data and standards)
2. Key actor and stakeholder networks
3. Relevant legislation



## Why?

- ✓ Analysis and comparison → baseline state of affairs
- ✓ Best practices and lessons learned
- ✓ Inform implementation of changes and improvements → harmonisation
- ✓ Input for development of HERA's IT Platform – ATHINA

# EU-HIP Landscape assessment

Collaborative work between several countries



**Belgium**

Sciensano (Public Health  
Institute)



**Finland**

Finnish Institute for  
Health and Welfare (THL)



*Ministero della Salute*

**Italy**

Ministry of Health

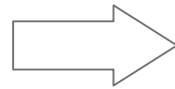


# How? Methods



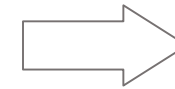
## 1. Tool development

- Based on WHO, TEHDAS, PHIRI, Joint External Evaluations
- Adapted to HERA's topic
- Collaboration between EU-HIP and HERA



## 2. Data collection

- National-level data collection
- Desk review
- Validation by relevant experts



## 3. In-depth country visits

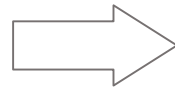
- On-site country visits in a sample of countries
- Interviews

# How? Methods



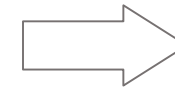
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## 3. In-depth country visits

- On-site country visits in a sample of countries
- Interviews

# How? Methods



1. Tool development

- Basic
- TEH
- Join
- Eval
- Ada
- topic
- Colla
- betw
- HER

Question	Comment / explanation	Topics	Answer	Additional information	Source
<b>Data sources</b> In terms of Public Intelligence gathering in your country, which of the following health threats are monitored? 1) Antimicrobial resistance (AMR), 2) Chemical, Biological, Radiological and Nuclear threats (CBRN), 3) Pathogens with high pandemic potential (WHO list)	Fill out the rest of the tool for each relevant topic.				
Do you apply a standardised approach to public health intelligence gathering, or does it depend on the pathogen (e.g. among pathogens with high pandemic potential, is the system similar or different for COVID-19, influenza, etc.?)		AMR CBRN COVID-19 Influenza viruses Crimean-Congo haemorrhagic fever Ebola virus disease and Marburg virus disease Lassa fever Middle East respiratory syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS) Rift Valley fever Zika Chikungunya Yellow fever Dengue			
What sources of data are used for intelligence gathering purposes related to these health threats?	<i>Please answer yes/no for each surveillance system</i>  - Laboratory data - Hospital data - Primary care data - Vaccine registry - Wastewater monitoring - Nursing home monitoring - Mortality monitoring - Internet-based media - Infectious disease registry - Other, namely ...	AMR CBRN COVID-19 Influenza viruses Crimean-Congo haemorrhagic fever Ebola virus disease and Marburg virus disease Lassa fever Middle East respiratory syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS) Rift Valley fever Zika Chikungunya Yellow fever Dengue			

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country visits  
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# How? Methods

## Topics

1. Antimicrobial resistance (AMR)
2. Pathogens with high pandemic potential
3. Chemical, biological, radiological and nuclear (CBRN)
4. Medical countermeasures (MCMs)
5. OneHealth



# Where? Countries

**Landscape  
assessment**  
17 countries



**In-depth  
country visit**  
~ 3 countries



# Learnings so far

- Importance of collaboration and regular communication
- Involvement of local experts: wide expertise required, obtain a realistic picture
- Allocation of sufficient time (e.g., for feedback from local experts)

# Contact



<https://www.linkedin.com/company/eu-hip/>



[https://twitter.com/EU\\_HIP\\_](https://twitter.com/EU_HIP_)



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<http://eepurl.com/iBywpw>

# Panel discussion



## WHO Support tool to strengthen health information systems

*Stefania Davia – WHO*



## State-of-play of the COVID-19 health information system in 8 European countries

*Miriam Saso – Population Health Information Research Infrastructure (PHIRI)*



## State-of-play of the national health data management systems in relation to the European Health Data Space

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## Mapping of surveillance systems for health crisis preparedness and response in Member States

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