



PHIRI

Population Health Information
Research Infrastructure

A sustainability roadmap for the European Health Information Portal

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Table of Contents

Executive summary.....	2
Key points.....	2
I. Vision and goals of the Health Information Portal.....	3
II. Expected impact of the Portal	4
1. Stronger Health Information Systems.....	4
2. More effective population health research and policy actions through enhanced secondary use health information	5
3. Better capacities of public health workforce	5
4. More coherent ELSI principles across the Member States	5
5. GDPR compliant multi-country data analysis	6
III. Sustainability Assessment.....	7
A. SWOT analysis for sustainability of the Portal	7
B. Current efforts to ensure sustainability of the Portal.....	7
IV. Sustainability strategy.....	8
A. Key elements of the sustainability.....	8
B. Sustainability strategy for difference existing sections	9
1. National Nodes	9
2. Data sources.....	9
3. Capacity building	10
4. Ethical, legal, and societal issues (ELSI).....	10
5. Publications	10
6. COVID-19 section or section for other health crises.....	10
7. National and international projects.....	11
8. Required annual personnel resources.....	11
V. Roadmap for sustainability of the Portal.....	12
A. Sustainability of the networks	12
B. Services supporting research	13
C. Activities supporting policy making.....	14
References	15
Disclaimer	16

Executive summary

The Health Information Portal (referred to as “the Portal”) was established as a ‘one-stop-shop’ for population health information, aiming to support research and policy development at regional, national, and international level. The Portal’s overarching mission is to facilitate the enhancement of the Health Information System, foster more effective population health research and policy initiatives, enhance the capacities of public health workforce, promote consistent application of Ethical, Legal, and Social Implications (ELSI) principles across Member States, and support compliance with the General Data Protection Regulation (GDPR) for multi-country data analysis.

To ensure sustainability of the Portal beyond the conclusion of the PHIRI funding period, scheduled to terminate at the end of October 2023, the primary focus lies in securing future funding for sustained operations. In addition to securing financial support, it is imperative to maintain the accuracy and relevance of the existing information contained within the Portal. Furthermore, when necessary, the Portal must be updated by appending current information to its existing modules and sections, or through the creation of new modules and sections.

Simultaneously, the continual advancement of the Portal's technical infrastructure is essential to ensure seamless interoperability of the information with other relevant portals and websites, thereby enhancing its utility in conjunction with other associated projects and initiatives. Furthermore, it is crucial to maintain an ongoing strategy for the dissemination of information pertaining to the Portal and its contents.

Key points

- Primary objective of the Portal is to serve as a comprehensive resource for population health information.
- To ensure the long-term sustainability of the Portal, key components are secure future funding, accuracy and relevance of information, technical development of the Portal and sustainable dissemination strategy.

A sustainability roadmap for the European Health Information Portal

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I. Vision and goals of the Health Information Portal

The Health Information Portal (referred to as “the Portal”, <https://www.healthinformationportal.eu/>, <https://doi.org/10.25504/FAIRsharing.8690f1>) was established with the primary purpose of serving as a centralized, comprehensive resource. It functions as a one-stop-shop, catering to the needs of researchers and policymakers, providing them with a wealth of population health information and facilitating the secondary utilization of health information.

The primary audience targeted by the Portal comprises researchers specializing in public health, population sciences, epidemiologists, statisticians, pharmacists, healthcare professionals, data scientists, ethicists, sociologists, among others. Additionally, the Portal's valuable resources are pertinent to data custodians, domain-specific developers, policy and decision-makers in national and international organizations, and various stakeholders involved in the field of public health. Non-governmental organizations, civil societies operating within the public health and healthcare domain, media professionals, journalists, patient organizations, students, educational institutions focused on population health and health services, the general population, and representatives from the industry and private sector also stand to benefit from the material available on the Portal.

The Portal is constructed using modular sections, which can be seamlessly incorporated as the need arises. These modules encompass a series of catalogues meticulously designed to adhere to the FAIR (Findable, Accessible, Interoperable, and Reusable) principles, as well as existing metadata standards such as Schema.org, DDI LifeCycle, DCAT-AP, and DCAT-AP-Health. As of September 2023, the Portal hosts the following catalogues, as depicted in Figure 1: national nodes within the PHIRI network, data sources, health information projects and initiatives, capacity-building activities, COVID-19 related resources, publications, materials pertaining to Ethical, Legal, and Societal Issues (ELSI), and European research networks, initiatives, and infrastructures. Furthermore, the Portal offers comprehensive information and tools for the PHIRI federated demonstrators and assessments of health information systems.

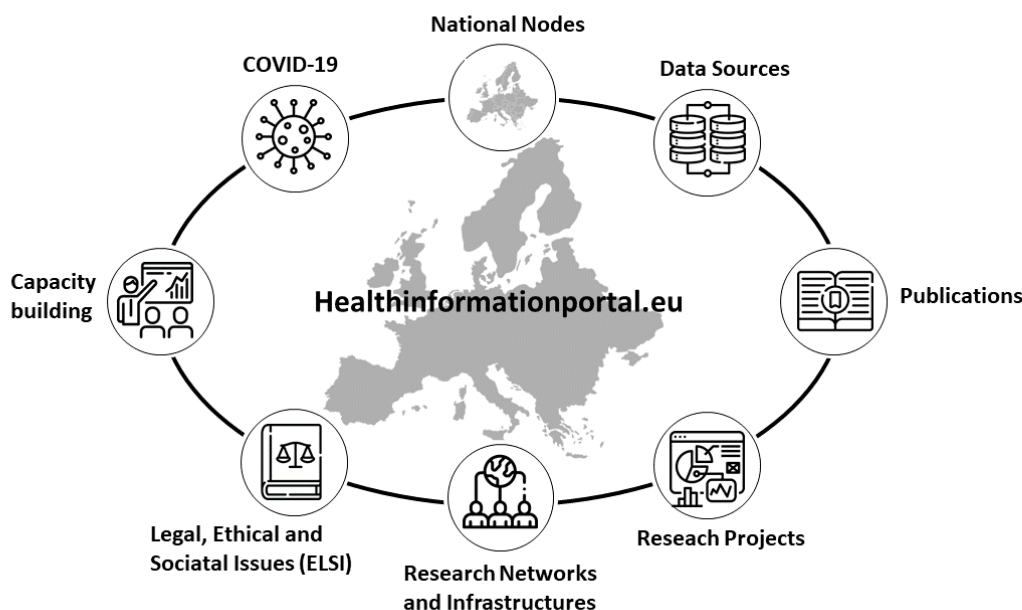


Figure 1. Sections of the Portals

II. Expected impact of the Portal

1. Stronger Health Information Systems

The Portal assumes a pivotal role in fortifying the health information systems across European nations, contributing to their robustness and efficacy through the following means:

- **Fostering national collaboration:** The Portal brings together different national actors in the field of population health through the PHIRI national nodes. This collaborative approach encourages the exchange of knowledge, sharing of experiences, and dissemination of best practices among diverse array of stakeholders. By promoting active dialogue and cooperation, European countries can harness one another's strengths, collectively reinforcing their individual health information systems.
- **Showcasing best practices:** The Portal offers a comprehensive compendium of findings derived from health information system assessments conducted within the framework of PHIRI, along with those emanating from other European initiatives, such as the Joint Action on Health Information – InfAct [1] and the Towards the European Health Data Space Joint Action – TEHDAS [2]. These assessments adhere to a similar methodology. The dissemination of best practices and insights garnered from these assessments equips European nations with the tools to enhance the resilience of their health information systems.
- **Capacity building initiatives:** Additionally, the Portal serves as a repository for a catalog of capacity-building activities in the realm of population health information. These activities encompass training programs, workshops, seminars, and educational resources thoughtfully designed to cultivate a sustainable and proficient workforce. This workforce is strategically equipped to confront the evolving challenges presented

by population health information, thus ensuring the continuous adaptability and resilience of health information systems.

2. More effective population health research and policy actions through enhanced secondary use health information

The Portal serves as an invaluable resource for the research community seeking information across more than 45 European countries regarding population health data sources and their accessibility. This functionality carries several profound implications:

- **The valorisation of existing health data:** The Portal effectively elevates the value of pre-existing health data by promoting their secondary utilization. This approach not only enhances cost-efficiency but also contributes to environmental sustainability. By negating the necessity for redundant data collection in the initiation of new research endeavors, researchers can concentrate their efforts on the judicious reuse of readily available data resources.
- **Streamlining the research process:** The Portal, by furnishing comprehensive information on data access protocols, optimizes the research workflow. This streamlined approach obviates the need for protracted and costly data collection phases. Consequently, researchers can respond with agility to emerging public health inquiries or crises, thereby expediting the generation of evidence-based outcomes.
- **Promoting research collaborations across Europe:** The Portal facilitates the identification of datasets possessing congruent characteristics, thereby enabling the consolidation of data resources to augment statistical robustness. This incentive further encourages research communities to pool their collective resources and foster enduring collaborative partnerships.
- **Adherence with upcoming regulation:** The Portal aligns seamlessly with forthcoming regulations pertaining to the European Health Data Space. This regulation stipulate that each Member State must expose its available health data within a metadata catalog. Adhering to the 'only-once' principle, the Portal functions as a metadata-as-a-service provider, delivering fully compliant metadata records conforming to proposed European standards. These records can be effortlessly transferred or harvested, ensuring adherence to upcoming regulatory directives.

3. Better capacities of public health workforce

The Portal provides an extensive directory of available capacity-building activities within the realm of population health information. In conjunction with the European School on Health Information, this resource plays a pivotal role in fortifying the capacity of the public health workforce. It facilitates the advancement of equity in training opportunities and capacities across various countries.

4. More coherent ELSI principles across the Member States

Although all EU Member States are bound to adhere to the same European Union-level regulation on data protection, the General Data Protection Regulation (GDPR), variations persist in the interpretation and implementation of these regulations at the national level. These disparities present challenges in the realm of data exchange and the harmonization of data practices across countries.

To address these challenges, the Portal offers the Ethical, Legal, and Social Implications (ELSI) tool. This tool delivers a repository of best practices from different countries, serving as a benchmarking resource. It is designed to inspire countries to seek common ground in the utilization and sharing of health data. The content provided within this tool equips stakeholders with the means to evaluate their existing data practices and sharing mechanisms in comparison to those of other Member States, thus identifying potential areas for enhancement. This fosters the alignment of data practices and encourages collaborative progress in the ethical and legal aspects of health data utilization.

5. GDPR compliant multi-country data analysis

PHIRI is dedicated to the development, execution, and establishment of a federated research infrastructure (RI) meticulously designed to harness the potential of real-world data for the resolution of pertinent research inquiries pertaining to the direct and indirect consequences of the COVID-19 pandemic on the European populace.

The PHIRI federated RI employs a methodical, stepwise approach aimed at achieving full interoperability at each stage, as depicted in Figure 2. The process commences with the formalization of the research query into a unified data model shared among all participating nodes. Subsequently, an on-premise analytical pipeline is deployed to execute the analyses. The culmination of this effort involves the collection of research outcomes and their subsequent publication, ultimately contributing to the growing body of knowledge addressing the impact of the COVID-19 pandemic on the European population.

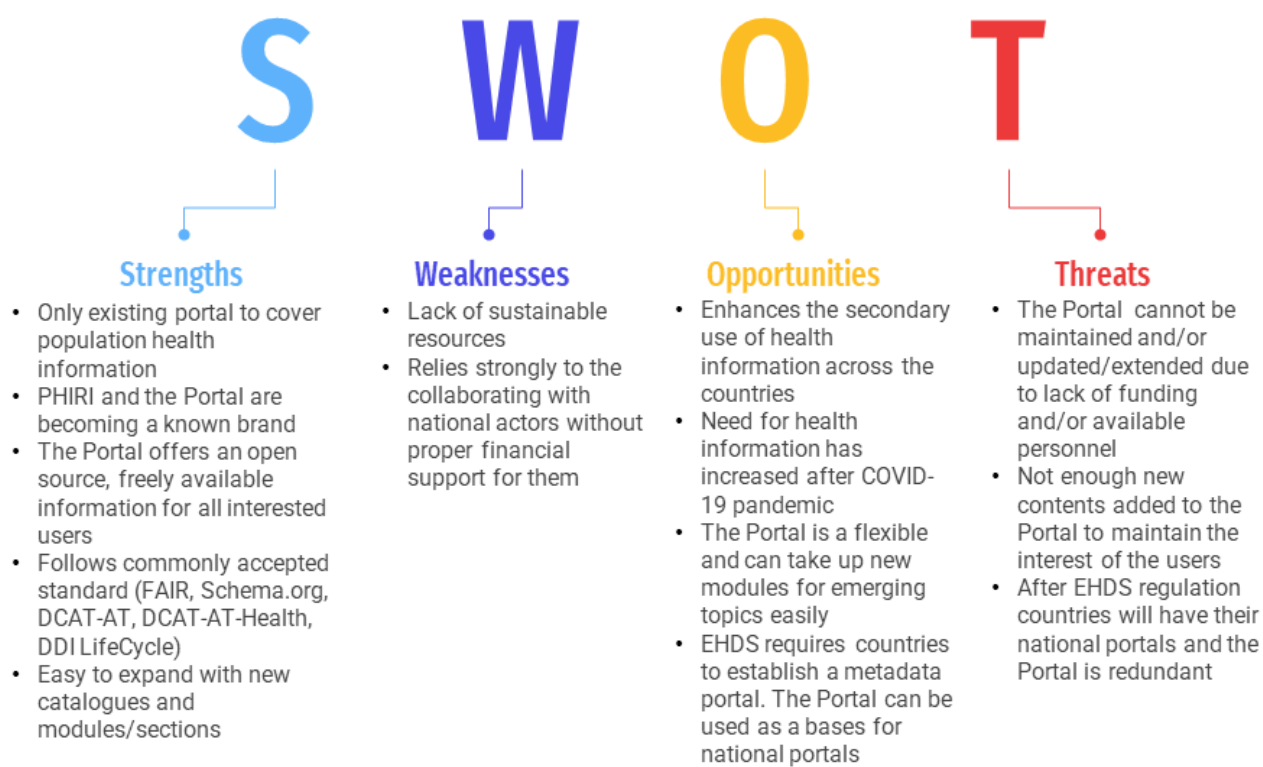


Figure 2. PHIRI stepwise approach for federated research infrastructure

The Portal offers an array of readily accessible tools tailored to cater to the needs of researchers seeking to undertake investigations involving the secondary use of observational data. These tools have undergone thorough implementation and testing, aimed at facilitating the execution of diverse research studies pertaining to the indirect consequences of the COVID-19 pandemic.

These tools represent digital resources that researchers have the ability to download, tailor to their specific research inquiries, and deploy in their investigations. Among the collection of digital assets, the Portal offers access to resources encompassing common data models [3-7], synthetic data sets [3-7], quality assessment scripts, and analytical algorithms [8-12]. Furthermore, the Portal features the PHIRI app [13]. Additionally, PHIRI has engineered an interactive demonstrator, affording users the opportunity to actively engage with one of the research projects within the PHIRI initiative [14].

III.Sustainability Assessment



B. Current efforts to ensure sustainability of the Portal

Horizon 2020 research and innovation program (Grant Agreement No. 101018317), draws to a close in October 2023, the resources dedicated to the maintenance and advancement of the Portal from this funding source are also reaching their conclusion. While Sciensano, Belgium, has graciously committed to maintaining the Portal on their server for the time being, their support will be primarily directed towards resolving issues and addressing minor updates.

To secure future funding for the continued development and maintenance of the materials on the Portal, several funding proposals have been diligently prepared for open calls under the EU Horizon Europe and EU4Health programs. These proposals are intended to harness the Portal for their specific objectives.

In the context of capacity building, Professor Luís Lapão's team at the Universidade NOVA de Lisboa, Portugal, has taken on the responsibility of periodically updating information and organizing an annual training school. This commitment ensures that the training materials hosted on the Portal will continue to expand and retain relevance for its user community.

A dedicated working group, composed of willing partners from the PHIRI consortium, will be established to oversee the ongoing progress of the Portal and to identify potential sources of funding.

Furthermore, PHIRI had considered the possibility for establishing itself as a legal entity, adopting the structure of a non-profit international organization with institutional members.

Membership fees are envisioned to be partially allocated to sustain the Portal, contributing to its long-term viability.

IV. Sustainability strategy

A. Key elements of the sustainability

To ensure the sustained functionality of the Portal, a set of pivotal elements has been identified, as illustrated in Figure 3:

1. **Continuous Data Updates:** Implement automated data and information collection tools, including web scraping and APIs, to acquire the most current information for existing catalogues, thereby keeping the content up-to-date.
2. **Semantic Interoperability:** Prioritize the establishment of semantic interoperability, enabling other portals and websites to seamlessly harvest information from the Portal, enhancing its reach and influence.
3. **Flexible Module Development:** Remain adaptable and responsive to the evolving needs of the user community by creating new sections and modules when new requirements arise.
4. **Collaboration Synergy:** Forge collaborations with other projects, fostering the transformation of the Portal into a shared platform, reducing the redundancy of multiple independent portals and websites.
5. **Long-Term Financial Security:** Secure enduring financial resources to underpin the longevity of the Portal, ensuring its uninterrupted operation.
7. **Sustained Visibility:** Guarantee the ongoing visibility of the Portal even after the conclusion of the PHIRI funding period by maintaining the PHIRI Newsletter and active social media accounts, while also facilitating its promotion through collaboration with other projects..



Figure 3. Key elements of the sustainability of the Portal

B. Sustainability strategy for difference existing sections

1. National Nodes

A National Node is a distinct organizational entity, often affiliated with a national institution or a governmental body, serving as a pivotal national liaison. It systematically assembles pertinent national stakeholders to facilitate coordinated efforts. These stakeholders may encompass entities such as the national statistical office, national public health institutes, representatives from various ministries (including health, research, and science), and other relevant bodies. Furthermore, a National Node functions as a discussion and advisory platform, addressing matters related to health data and information, both at the national and international levels.

National Nodes have assumed a central role within the PHIRI framework. They contribute essential information to the Portal, encompassing data sources, publications, and expertise, among other aspects. Simultaneously, they relay pertinent international information to their respective countries. To ensure the continued operation of the National Nodes and to facilitate the establishment of such entities in countries lacking them, it is imperative to conduct regular meetings and foster information exchange. This approach is fundamental to sustaining and expanding the network.

2. Data sources

To ensure alignment and compliance with the evolving European landscape, particularly in response to the European Health Data Space, the Health Information Portal is set to integrate the health extension of the DCAT-AP metadata standard. This extension is currently in development as part of the HealthData@EU project [15]. This strategic move equips European member states with a distinct advantage, as their metadata records hosted on the Portal will adhere to European standards. Such records will be readily accessible in a format that aligns with European requirements, simplifying harvesting and direct display on their respective national portals via the Portal's API. This step is especially significant, as EHDS regulations mandate the availability of a national metadata catalogue by Member States.

Furthermore, the Portal endeavors to incorporate data profiling into its processes, entailing a comprehensive review of source data for content and structural attributes. This facilitates the provision of information related to the data source's structure and content, encompassing details like variable names, coding, and data collection methods. There are also plans to furnish access to mock-up data and synthetic data in conjunction with metadata records.

To empower end-users in evaluating the quality of both metadata records on the Portal and the actual datasets, a quality label is in development. This label will be implemented within the Health Information Portal as part of the HORIZON project 'QUANTUM' (2024-2027).

Discussions on automated data harvesting from national portals have taken place, with plans for further testing and development. This effort is geared not only towards incorporating new data sources but also ensuring the ongoing maintenance of metadata for existing data sources to keep them up-to-date.

3. Capacity building

The possibility to automate the collection of information, specifically through web scraping, from established websites that maintain listings of capacity building activities, such as WHO and EUPHA, among others needs to be further investigated. This would enhance the accessibility and comprehensiveness of the Portal's resources.

Additionally, the Portuguese team plans to conduct a systematic review of new capacity building activities biannually. Any new and significant events that arise in the interim may also be included in the Portal between these scheduled updates.

Furthermore, the Portuguese team is committed to organizing an Annual Spring School on Health Information, with active participation from as many PHIRI partners as possible. Currently, this initiative relies on voluntary engagement and commitment until additional funding can be secured.

4. Ethical, legal, and societal issues (ELSI)

It is imperative to maintain vigilant oversight of legislative changes, not only at the European Union level but also within individual Member States, and their implications for the utilization and exchange of health information both nationally and internationally. Any emerging legal mandates should be promptly integrated into the Portal, while outdated requirements must be systematically removed to ensure the platform's ongoing relevance and compliance.

5. Publications

In the context of the publications section, it is advisable to include materials that are not readily discoverable through widely-used databases such as PubMed and Web of Science. This typically pertains to national reports, white papers, and similar publications that hold significance for researchers seeking in-depth insights into national matters. These resources are often challenging to locate on the websites of relevant organizations.

The task of uploading these publications to the Portal should be entrusted to the National Nodes, ensuring a systematic and comprehensive approach to making these valuable resources accessible to the research community.

6. COVID-19 section or section for other health crises

The COVID-19 section was initially established in response to the heightened demand during the pandemic. With the declaration of the pandemic's conclusion, there is limited ongoing necessity to extend the COVID-19 section. However, the establishment of this section has served as a valuable demonstration of how the Health Information Portal (HIP) can effectively promote and support initiatives related to emerging health crises.

Consequently, in scenarios involving new health crises or when there is a clear imperative to enhance actions and information exchange for pre-existing health issues, such as obesity or mental health, similar sections could be established through collaborative efforts involving National Nodes.

1. The essential steps involved in this process include:
2. Establishment of a governing body or working group tasked with monitoring emerging needs for new topic-specific sections.

3. After the identification of these emerging needs, effective communication with the National Nodes to secure consensus on the necessity for such information exchange.
4. Formation of the new section, with the assignment of a coordinator to oversee the operations.
5. Collection of section contents in an agreed-upon format, which may involve methods such as online questionnaires or regular meetings, among other approaches. This ensures the systematic and organized compilation of relevant information.

7. National and international projects

This section has been primarily dedicated to population-based COVID-19 projects, excluding clinical trials and surveillance systems which have been comprehensively documented elsewhere. In the event of new health crises, this section can be updated to incorporate pertinent ongoing national and international projects and research studies. The process for such updates aligns with the steps proposed for the COVID-19 section (steps 1-3).

In step 4, the content for this section is gathered systematically in a mutually agreed format through extensive online literature searches. These searches encompass reputable databases such as PubMed, Web of Science, and similar resources. Additionally, relevant documents can be sourced from institutional websites and research networks. To facilitate the regular and automated updates of this catalogue, the deployment of data collection tools, including web scraping, is recommended. This approach ensures the timely and comprehensive incorporation of new data into the section.

8. Required annual personnel resources

The table presented below (Table 1) provides a summary of the annual resources necessary for the upkeep and revision of material on the Health Information Portal (HIP). It is essential to note that the resources required for the addition of new modules and services to the Portal are not encompassed within this table.

Table 1. Summary of the required annual personnel resources for maintaining and minimal updating of the Portal

Section	Activity	Personnel resources (PM/year)		
		Central resources (coordination, support, etc.)	National resources	Other actors
National Nodes	Coordination	0.5 PM	0.5 PM	
Data sources	Coordination, support	1.0 PM	0.1 PM	
	Uploading new and maintaining existing data sources		0.2 PM	
Capacity building	Periodic update of capacity building activities	0.5 PM		
	Coordination and preparation of annual training school	1.0 PM		
	Lecturers of the training school			0.2 PM/lecturer

ELSI	Review and updating latest legislation changes	0.5 PM	0.1 PM	
Publications			0.2 PM	
COVID-19 (in case of new health crises section is added)	Coordination	1.0 PM		
	Contribution of substance		0.5 PM	
National and international projects (in case of new health crises section is added)	Setting of portal for new collection	0.5 PM		
	Web and literature search to identify relevant projects	1 PM	0.2 PM	
Technical maintenance of the Portal		2 PM		
Overall coordination of the Portal development		3 PM		
TOTAL		11 PM	1.8 PM	0.2 PM/ lecturer

V. Roadmap for sustainability of the Portal

The continued existence of the Portal is intricately intertwined with the presence of the PHIRI network, comprising a cadre of experts and national stakeholders. As a consequence, the sustainability of the Portal should be regarded as an integral component of the broader sustainability of the PHIRI network.

Both PHIRI and the Portal fulfill distinct functions that span across critical areas, encompassing network operations, research-supporting activities, and policy-making support. Consequently, a comprehensive roadmap for ensuring the sustainability of the Portal (and PHIRI) can be strategically formulated, taking into account different domains and a spectrum of potential scenarios.

A. Sustainability of the networks

As previously emphasized, the networks cultivated during the course of PHIRI and its precursors play a pivotal role in ensuring the sustainability of the Portal. These networks, comprised of population health information experts and national stakeholders, not only contribute information to the Portal but also serve as its primary users.

To preserve and fortify these networks, several distinct scenarios can be considered:

1. Informal Networks: Informal networks rely on the inherent interest and voluntary contributions of their members to foster collaboration and knowledge exchange without external financial support, often taking the form of in-kind contributions. In the short term, this approach is feasible for maintaining networks; however, over the medium and long term, waning interest, limited time, and dwindling resources may reduce participation, leaving only a handful of highly motivated members. Informal networks should serve as the groundwork

during a transition period, identifying potential funding opportunities and working toward more structured networks.

2. EU Cost Action Support: Leveraging EU Cost (European Cooperation in Science and Technology) Action funding presents an alternative to secure financial support for networking and capacity building in the population health information domain. Cost Action funding can facilitate the organization of meetings, workshops, conferences, short-term scientific missions, training schools, communication, dissemination of activities, and the provision of networking tools. This mechanism would enable the sustenance of networking and certain capacity building activities initiated during PHIRI and emerging in the future, while concurrently moving towards more formalized networks.

3. Establishment of a Non-Governmental Organization (NGO): Forming an NGO would confer legal status upon the PHIRI networks. Several funding models can be envisioned for an NGO:

- a. **No Membership Fees:** In this model, no membership fees are imposed, but small participation fees for NGO-organized activities such as training events and workshops are collected. These participation fees cover the event costs and contribute to overall coordination. While this approach encourages a broader spectrum of organizations to join the NGO, it may lead to funding uncertainty, as it depends on the number of events and participants.
- b. **Membership Fees:** In this model, participating organizations are required to pay membership fees, which fund overall coordination and potentially other activities, unless separate participation or service fees are levied for those activities. The collection of membership fees provides a steady financial basis for overall coordination but might restrict the number of involved organizations. To succeed, this model necessitates an attractive portfolio of services and tools offered to participating organizations as value for their membership fees.
- c. **External Funding:** As a legal entity, an NGO can also pursue external funding from various grant organizations. EU Operating Grants present one such alternative that could supplement project-based funding.

Each of these scenarios plays a distinct role in the roadmap for sustaining the PHIRI networks and, by extension, the Health Information Portal. The choice of scenario is contingent upon the specific needs, resources, and long-term objectives of the networks and the Portal.

B. Services supporting research

Presently, the Portal and PHIRI offer certain services, such as a metadata catalogue and a demonstrator for federated data analysis, aimed at supporting the research community. Since establishing, maintaining, and developing services to support research community in their work requires resources (personnel and technical), it won't be feasible to establish these as informal activities based solely on in-kind contributions by involved organizations.

It is important to recognize that these services must be designed to be appealing and beneficial to the research community, with users willing to pay for their utilization. For instance, the metadata catalogue should ideally remain open access, even if national metadata catalogues are generated using the metadata already available in the Portal. To

establish a formal Research Infrastructure (RI), it is necessary to create a comprehensive portfolio of services that support research.

The organization and continuation of these services to assist the research community can be realized through distinct scenarios, including:

1. Non-Governmental Organization (NGO): A non-governmental organization model could be employed, which allows these services to operate under the legal auspices of the NGO. This approach necessitates the allocation of resources, including personnel and technical support, to establish, maintain, and develop the services.

Establishing a NGO requires commitment from the key organizations providing the services, assuming that RI would be a distributed RI where different organizations provide different services. Especially when RI is established and not all potential customers have been identified, reached and engaged, contribution from involved organization is essential. Several funding models can be envisioned for an NGO:

- a. **Membership fees** which covers overall governance of the RI as well as to some level maintaining of the services.
- b. **User fees** for specific services.
- c. **External funding** through different funding bodies such as Horizon Europe and EU4Health.

2. ESFRI Roadmap and ERIC Status: An alternative route to establish a legal status for the Research Infrastructure involves aspiring to be part of the ESFRI (European Strategy Forum on Research Infrastructures) roadmap, with the long-term goal of obtaining ERIC (European Research Infrastructure Consortium) status. RIs interested in joining the ESFRI roadmap must apply during the ESFRI roadmap updating rounds. The previous ESFRI roadmap was last updated in 2021, and the next update is anticipated in 2025 (<https://www.esfri.eu/esfri-white-paper/32-esfri-roadmap>). When an RI gains acceptance on the ESFRI roadmap, it can evolve into a landmark project, often leading to ERIC status. ERIC status also confers legal entity status. The process of securing a spot on the ESFRI roadmap and obtaining ERIC status is an extended and competitive endeavor, often spanning up to 10 years. RIs must compete with other RIs vying for inclusion on the roadmap, introducing significant uncertainties regarding success. Therefore, careful planning and commitment from key organizations providing these services are essential to navigate this process effectively.

C. Activities supporting policy making

Numerous activities within the PHIRI and modules featured on the Portal are designed to provide support for policy-making endeavors. Notably, the work of entities like the Rapid Exchange Forum and Health Information System Assessments falls under this category. These activities are substantial and extend beyond the scope of simple networking. Although informal arrangements may suffice in the short term, sustaining them over the medium and long term can prove challenging due to the considerable resource requirements.

Consequently, it is imperative to consider various scenarios for activities supporting policy-making:

1. Non-Governmental Organization (NGO): Similar to networks, non-governmental organizations (NGOs) present a viable alternative for policy-supporting activities. These NGOs can be established with or without membership fees, depending on the extent of representation required from organizations and countries. Certain activities, like health information system assessments, could be transformed into services provided to countries for a nominal fee to offset costs.

2. Cost Action: For a transitional phase, EU Cost Action, akin to networks, can offer resources to sustain these activities in the short term, while solutions for the medium and long term are developed.

In sum, a multifaceted approach is necessary to address the complexities associated with activities that underpin policy-making. The choice of scenario should align with the specific requirements and objectives of each activity, recognizing the need for both immediate and enduring solutions.

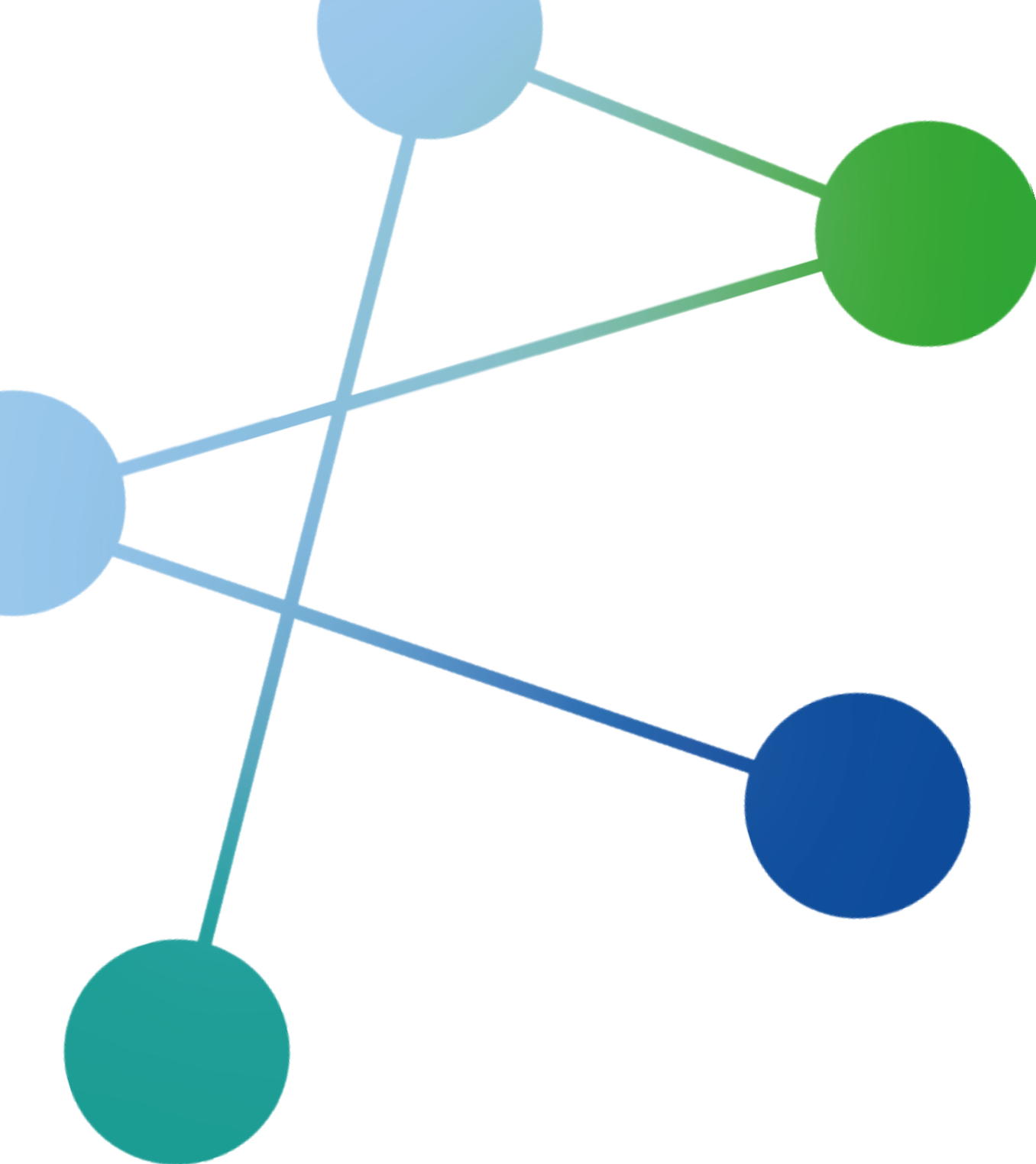
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