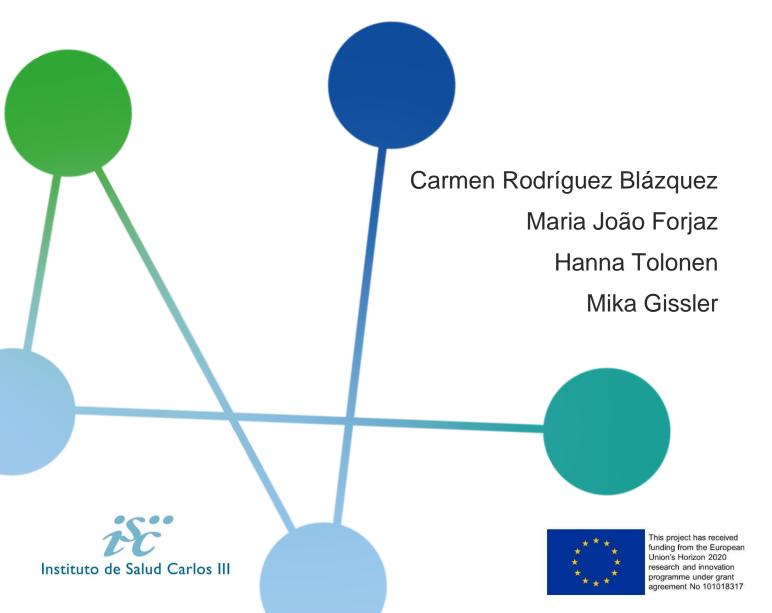


# **Case study report**

Use Case D, Deliverable 6.4, 24.06.2022

Changes in population mental health associated with the COVID-19 pandemic



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## **Executive summary**

**Population Health Information Research Infrastructure (PHIRI)** aims to facilitate and support open, interconnected, and data-driven research through the sharing of cross-country COVID-19 population health information and exchange of best practices related to identification of data sources, access, assessment and reuse of data on COVID-19 determinants, risk setting and outcomes. In this context, Work Package (WP) 6 intends to conduct research through use cases of immediate relevance for public health policies and management of the COVID-19 pandemic, and to facilitate further research by making scalable, reproducible methods available within PHIRI.

These use cases are fed with health data for secondary use. They pursue to pool and/or reuse data in a distributed way across Europe to produce information for action in public health crisis. This report shows monitor changes in population **mental health** associated with the COVID-19 pandemic (**use case D**). The methodology included several phases, starting from a research question: "Has the mental health status (depression/anxiety) of the general population changed during the COVID-19 pandemic?". A common data model (CDM) was defined to guide the metadata collection. Two surveys were consecutively administered to participant data hubs, a first questionnaire to assess their technical capabilities and data accessibility, and a second questionnaire to identify gaps in the availability of specific variables of the CDM, which was refined and revised accordingly. Finally, the analytical scripts were produced and published together with the CDM, the PHIRI app Docker version and the instructions, in an open repository (Zenodo).

The docker was deployed by 15 data hubs, from which, two were able of providing results for this use case (Wales and Finland), showing some effects of COVID-19 pandemic in diagnosis of depression and anxiety and in healthcare provision. Main difficulties in accessing data were related to the lack of expertise and capacity in data hubs, limited access to individual data, number of different data holders, fragmented data, and variation in used data sources and their coverage by countries that hampered cross-country comparisons.

Despite these limitations, we can conclude that the use case D facilitates research by making scalable, reproducible methods available within PHIRI. Building a common data model is a time consuming, iterative process and will require harmonization of regional/national data sources. It is not a closed research, as other data hubs will continue the ongoing analysis and the process and results will be disseminated through a variety of activities.

# **Key points**

- Preliminary results suggest that data on mental health impact of COVID-19 pandemic can be re-used in a distributed manner across Europe.
- Use case methodology is feasible and will allow cross-country comparisons.
- Some limitations may make the process complicated and time consuming.



# PHIRI: Case study report - use case D

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# I. Introduction

The COVID-19 pandemic, the measures to contain it, and their consequences, have caused an increase in the risk factors that lead to mental health problems: inequality, unemployment, loneliness, unhealthy lifestyles, etc. The effects on mental health were already evident during the first phase of the pandemic, when Holmes et al. (Holmes et al., 2020) warned about a rise in anxiety and depression symptoms and self- ham and suicidal behaviours in the general population in UK and launched a call for action to address this challenge. Some groups, such as children, older people and healthcare workers, are especially vulnerable to the psychological consequences of the pandemic, but there is also clear and reliable evidence of mental health deterioration in the general population in several European countries (Fiorillo et al., 2020; González- Sanguino et al., 2020; Pierce et al., 2020). A study using the WHO-5 instrument found a decline in mental well-being in the EU since summer 2020 (EUROFUND, 2021), with 64% of younger people (18-34 years old) at risk of depression. Literature suggest that the mental health problems increased during the lockdown, decreased in the immediate phase after it (summer 2021), and experienced an increase as the pandemic lengthened (Richter et al., 2021).

However, in many European countries, the increase of mental health disorders has not been parallel to healthcare provision. In fact, the pandemic disrupted the provision of public services and unmet mental health needs existed for around 20% of European citizens (EUROFUND, 2021).

In this situation, the World Health Organization has recommended countries to monitor changes in mental health at population level through valid, standardized and comparable measures and instruments (WHO- EUROPE, 2021). Routinely collecting data and indicators is key to monitor the performance and to improve the quality of mental healthcare services, but there is a need of harmonization to allow the comparability between the different levels and regions. In addition, the pandemic has highlighted the necessity of a structured European mechanism for COVID-19 exchange to organize and share information between countries in the area of population health. Population Health Information Research Infrastructure (PHIRI) aims to facilitate and support open, interconnected, and data-driven research through the sharing of cross- country COVID-19 population health information and exchange of best practices related to identification of data sources, access, assessment and reuse of data on COVID-19 determinants, risk setting and outcomes. The PHIRI project follows best ethical and data protection practices that ensure patient privacy without hindering research when sharing sensitive health and genomic data for research reuse (for example ELSI practices; https://rd-connect.eu/what-we-do/elsi) and promoting the capacity of computational systems to find, access, interoperate, and reuse data with none or minimal human intervention (FAIR principles; https://www.go-fair.org/fair-principles). In this context, Work Package (WP) 6 intends to conduct research through use cases of immediate relevance for public health policies and management of the COVID-19 pandemic, and to facilitate further research by making scalable, reproducible methods available within PHIRI.

These use cases are fed with health data for secondary use (e.g. administrative and survey data). They pursue to pool and/or reuse data in a distributed way across Europe to produce information for action in public health crisis. This report shows monitor changes in population mental health associated with the COVID-19 pandemic **(use case D)**.



# II. Approach (methodology):

Use case D included several phases:

#### A. Research question:

A research question was agreed with the 15 data hubs (responsible experts from regional or national public health institutions owning or allowed for requesting secondary use of health data). This case study focused on changes in population mental health associated with the COVID-19 pandemic. Specifically, the research question (RQ) in this Use Case D was:

# Has the mental health status (depression/anxiety) of the general population changed during the COVID-19 pandemic?

This RQ was planned to be addressed in two ways:

- 1. Register data: using indicators such as prescription of antidepressants and anxiolytics, visits to primary care or specialist care with an episode of depression/anxiety, etc.
- 2. Survey data: indicators of depression/anxiety of the general population based on validated rating scales or self-reported depression/anxiety.

The focus was on national level, 2020-2021 data, using 2017-2019 years for trend comparisons.

#### **B. Two-round questionnaire**

A <u>1<sup>st</sup> round questionnaire</u> (Appendix 1) was sent to partners to identify relevant information on the technical capabilities and data accessibility of the data hubs. The questions were referred to technical/IT expertise ("are you capable of using R, Docker, Python?"); access to data ("do you host any data?"; "do you have easy access to external data?"; "are data available at an aggregated level?").

A <u>2<sup>nd</sup> round questionnaire</u> (Appendix 2) was sent to the participating data hubs to obtain specific information (metadata) about available data items of each use case, to start off the process of harmonising data collection throughout a common data model (see next section).

#### C. Development of the Common Data Model (CDM)

After the <u>1<sup>st</sup> round questionnaire</u> was completed, a CDM was designed to guide the metadata collection (Appendix 3). CDM included the name, description and characteristics of the set of variables and the cohort description together with the inclusion and exclusion criteria applied.

The <u>2<sup>nd</sup> round questionnaire</u> was an availability survey to figure out what were the gaps between what is able to be provided and the original CDM. At this stage, it was assessed whether there were enough available data to carry out the use case. Next, the CDM was reviewed and discussed among the data hubs and the lead institutions (Spanish Health Institute Carlos III, ISCIII; and the Finnish Institute for Health and welfare, THL). CDM was adapted according to the results of the questionnaire.

#### **D. Analytical scripts**

The data hubs agreed relevant variables available for the mental health research questions. They reported the availability of those variables for their region/country. All those meaningful variables selected were then categorised by availability across data hubs as "required", "recommended" and "optional". General metadata were planned to be uploaded to the open platform Zenodo (<u>https://zenodo.org</u>).

The CDM also specified that the level of stratification should be at minimum by sex and age. The inclusion criteria were the following:



- Age 18 years old or older
- Had a contact with the healthcare system during 2017-2020 (2021 whenever possible)
- Washout period of one year for new cases

The included diagnoses were codes F32-34 (ICD-10), 296, 300.4 and 311 (ICD-9 MC) or 46206005, 370143000, 712823008 (SNOMED) for <u>depression</u>; and codes F41 (ICD-10), 300.00, 300.01, 300.02, and 300.09 (ICD-9 MC) or 197480006 and 21897009 (SNOMED) for <u>anxiety</u>. For drug prescription, the Anatomical Therapeutic Chemical-(ATC) codes N06A (depression medications) and N05B (anxiolytic drugs) were used. For coding visits to primary care, hospital unit or emergency, International Classification of Primary Care (ICPC) codes were used.

A pilot R script was developed to produce plots showing trends changing by month and comparing the pandemic year 2020 with previous years. The R script was generated using a synthetic dataset. Some countries owning or with direct access to electronic health records (actual datasets) developed their own R scripts training the common data model. A common R Markdown script was again shared in Zenodo (Aldridge et al., 2022).

#### E. Meta-analyses

A further step will use the common script by the participating data hubs with their datasets formatted according to the common data model. The results produced from this process will be comparable and suitable to pool in a meta-analysis.

#### F. Interface with WP7

The use case outputs will be processed in an interoperable way by formalising data models, data management processes and analytical pipelines, all of which are part of the client-server PHIRI federated infrastructure implemented as here: 10.5281/zenodo.6483177.

## **III. Results**

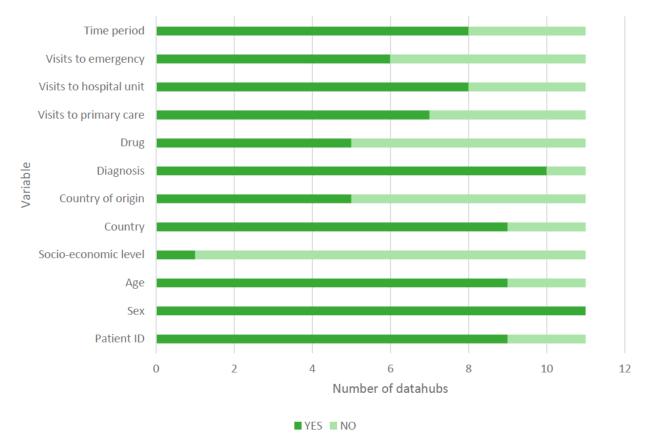
#### **Process related results:**

The research question was agreed with the data hubs, based on the previous literature and the availability of data. This case study measures changes in population mental health associated with the COVID-19 pandemic. Specifically, the research question (RQ) in this Use Case D was:

Has the mental health status (depression/anxiety) of the general population changed during the COVID-19 pandemic?

The CDM was designed and refined after reviewing the answers to the 2nd round questionnaire. This questionnaire was responded by 11 data hubs, and the results are displayed in Figure 1.





### Can you comply with common data model specifications for ...?

Figure 1. Mental health variables selected by the data hubs according to their importance and availability.

The data hubs agreed on 14 variables for the last version of the CDM, after assessing the availability of those variables for their region/country. Patient id, sex, age, country (residence), diagnosis and date of diagnosis were classified as "required" variables (Appendix 3). Country (origin), psychoactive drug, date of prescription, number of visits to primary care, number of visits to hospital unit, number of visits to emergency and date of visit were not easily available for some countries. For this reason, those variables were categorised as "recommended" for data extraction. Data hubs found desirable to report socioeconomic status, but information was not available for most of them. Due to its relevance it was included for data recovery as "optional". These metadata are publicly available at the platform for Open Science Zenodo (Rodriguez-Blazquez and Tolonen, 2022).

#### **Description of analytical scripts**

Two of the data hubs (Wales –UK and Finland) owning or with direct access to electronic health records have developed R scripts to produce some plots showing trends changing by month and comparing the pandemic year 2020 with the previous years 2018 and 2019. Spain developed their R scripts using a synthetic dataset. Researchers from the three countries made available in Zenodo an R Markdown script together with a synthetic dataset build following the specifications from the Use Case D Common Data Model, and an HTML interactive report produced by performing the analyses proposed within the R Markdown using the synthetic dataset (Aldridge et al., 2022).

#### **Participant data hubs**

Appendix 4 shows the final list of participant data hubs. By June 3rd 2022, 15 data hubs had deployed the Docker and are testing the R-scripts using the synthetic datasets.



#### **Results by data hub**

#### Finland

Finland obtained results on mental health services from the years 2019, 2020 and 2021. Information was gathered from the Hospital Discharge Register (HILMO) and the Primary Health Care Register (AvoHILMO). Those registries have population level-data. Thus, the Finnish data hub estimated rates (number of cases by 10,000 population) of depression and anxiety by month provided by specialised mental health services (Figure 2).

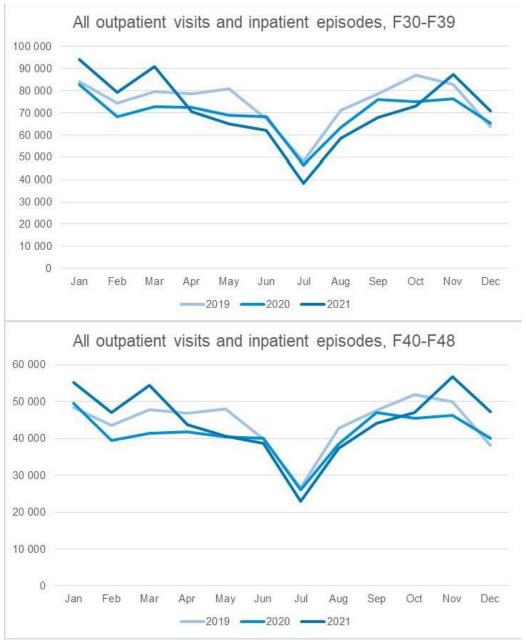


Figure 2. Rates of depression (upper panel) and anxiety (bottom panel) for outpatients and inpatients of Finnish hospitals.

Finnish contributors found a decrease of a 7% of rates between years 2019 and 2020 for depression and anxiety, respectively. Increasing trends were reported of a 3% for depression between 2020 and 2021; and an 8% for anxiety. Finnish contributors interpreted these trends as the pandemic having



a small effect in the use of specialised mental health services. From exact numbers, it can be concluded that:

- Depression (F30-F39 ICD-10 codes) during March-May 2020 decreased of 10% in visits compared to 2019.
- Anxiety (F40-F48) during March-May 2020 decreased of 4% in visits compared to 2019.
- The number of new patients increased in 2020, but 2021 only for depression.

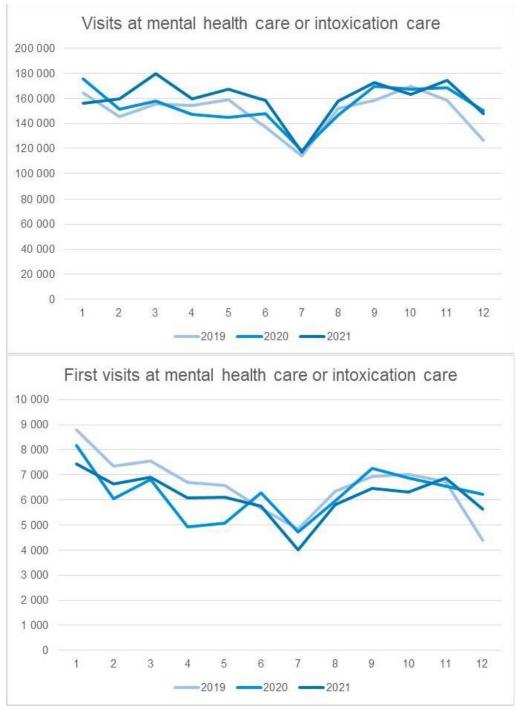


Figure 3. Rates of depression (upper panel) and anxiety (bottom panel) for outpatients and inpatients of Finnish hospitals.

At the level of primary care, the pandemic had also a small effect in the use of primary mental health services (Figure 3):

• No decrease in visits compared to 2019 was found for depression and anxiety during March- May 2020.



• The number of new patients decreased in 2020 and 2021.

The Finnish data hub acknowledged an underestimation of diagnosis at the level of primary care. Data on diagnoses were only provided if a physician was involved in the care and the codes were correctly reported to the register. Unfortunately, no data on patient's socioeconomic background were available. THL has access to such data until 2014, but no more recent data were available when completing these analyses.

#### Wales (UK)

Wales obtained results on mental health services to account for changes in health care utilisation regarding GP, hospital and emergency room visits (2017 to 2020). In addition, an analysis was conducted to determine if the pandemic affected existing patterns of inequalities in health by comparing fifths of the population according to the local area deprivation index, called the Wales Index of Deprivation. The ratio of the most to the least deprived fifths were calculated.

Cases of depression (Figure 4) and anxiety (Figure 5) are presented disaggregated by sex (years 2017 to 2021).

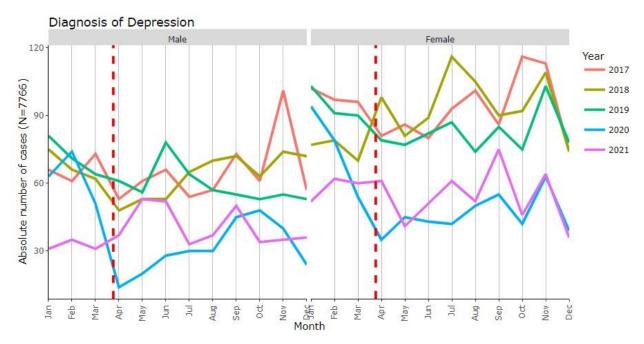


Figure 4. Diagnosis of depression absolute number of cases in Wales. Men (left panel) and women (right panel).



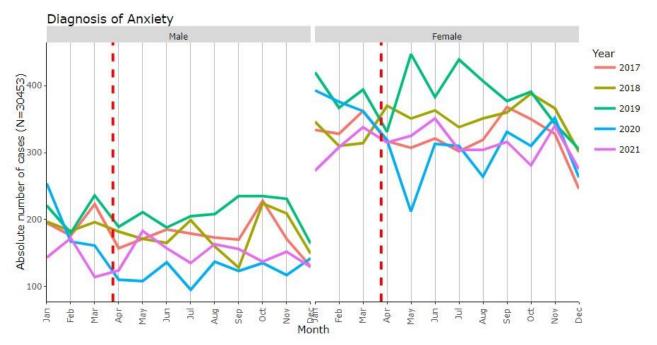
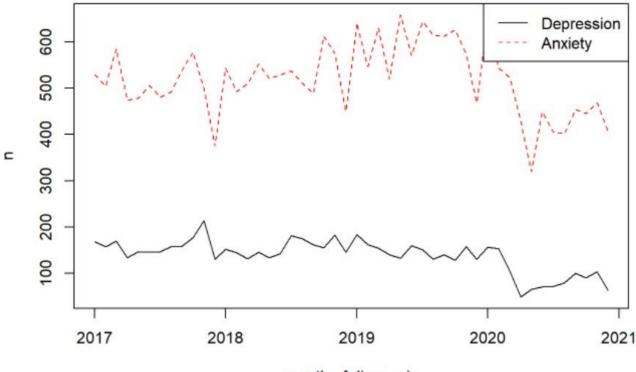


Figure 5. Diagnosis of anxiety absolute number of cases in Wales. Men (left panel), and women (right panel).

The observation of absolute number of cases for depression and anxiety diminished dramatically just after lockdown implementation (Figure 6).



month of diagnosis

Figure 6. Monthly absolute number of cases for diagnosis of depression and anxiety in Wales (UK) (2017-2021).

Wales observed a descending trend for the ratio between the number of patients with highest deprivation score and those with lowest deprivation score (Figure 7). This requires further investigation, but one potential reason could be that – due to a supply side shock in the respective country's health system – all groups of patients were affected similarly. Especially for mental health care, which in many countries is subject to high out-of-pocket payments (OECD and European



Union, 2020) or scarcely available, this supply side shock may have meant that socio-economic resources could not compensate for the gaps in availability of mental health care, e.g. due to shifts in health care resources towards COVID-19 patients (Schmidt et al., 2021).

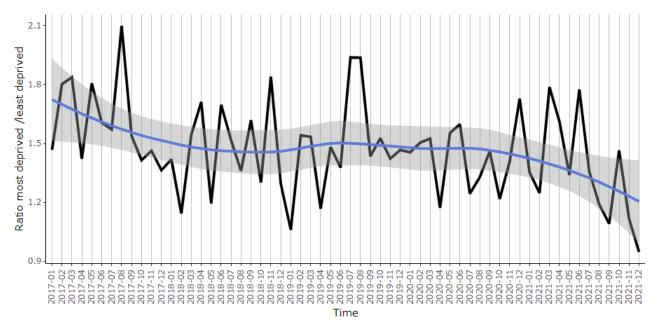


Figure 7. Monthly ratio for patients diagnosed for depression and/or anxiety in Wales (UK) comparing those living in the quintile most deprived versus those living in the quintile least deprived (2017-2021).

#### **Results meta-analyses:**

At this stage, cross-comparisons were not possible due to the lack of results from other data hubs.

# **IV.** Implications and limitations

#### Implications

The PHIRI use case D is a pilot exercise that has explored the consequences of COVID-19 pandemic in mental health outcomes of the European population. The results have relevance for public health policies and clinical management of COVID-19 impact.

The use case D has demonstrated how health data for secondary use can be pooled and reused in a distributed way to facilitate the exchange of information and to generate scientific evidence.

Results of the use case D showed a decrease in diagnoses of depression and anxiety in 2020-2021 in participant countries compared with previous years. This trend was observed also in visits to primary care or emergency admissions due to depression or anxiety.

The added values of this use case are:

- a) Translation into actionable outcomes: the FAIRified use case analyses results focusing on comparisons between countries and provide actionable outcomes to guide policy makers in preparedness and response scenarios.
- b) The use case D facilitates research by **making scalable**, **reproducible methods** available within PHIRI.



### **Sustainability**

Sustainability is based on two pillars:

- Pilot activities for the benefits and added value of a research infrastructure by bringing together data from different European countries.
- Build capacity in each data hub to provide use case data and analysis capabilities for a long term.

#### **Future perspectives**

The next step will be to use the common script by the participating data hubs with their datasets formatted according to the common data model. The results produced from this process will be comparable and suitable to pool in a **meta-analysis**.

In addition, the evaluation of the availability of **survey data** on the impact of COVID-19 in mental health could be a future approach for this use case D.

#### Limitations

Main limitations were related to the lack of expertise and capacity in data hubs, especially IT; the limited access to (individual) data; the number of different data holders and the existence of fragmented data, governance and legal requirements; and the variations in used data sources and their coverage by countries that hampered cross-country comparisons. To solve some of these difficulties would have needed a longer time span than expected.

#### Lessons learned

- Building a common data model is time consuming, iterative process and will require harmonization of regional/national data sources.
- Health systems differ substantially across countries, thus further analysis of the mechanisms of dealing with the pandemic are required (e.g. what is the role of primary care vs. other forms of care, which eligibility rules apply to access mental health care, which services are included etc.)
- Infection rates and pandemic management were not homogeneous either and will be contrasted with the results in a next step.
- Learnings from re-using administrative data for secondary purposes: (i) agree on common definitions, (ii) plan enough time to obtain data etc.

# V. Outlook

With this report, the activities in WP6 and the research use cases have not come to an end. Until the end of the PHIRI project in October 2023, a large number of **dissemination activities** will be carried out and the analyses will be continued.

Our **roadmap** foresees that both - the technical details of the federated approach and the research results of the use cases - will be shared with different target groups through various communication channels. For this purpose, it is planned to host a **stakeholder meeting** with representatives of the European Commission together with the implementation of the research infrastructure in WP7 in order to present the latest achievements. In addition, it is important to involve similar European initiatives and projects (e.g. TEHDAS, HealthyCloud) as well as their scientific community as one of the main stakeholders to discuss and share the results and experiences. **Scientific publications, webinars and trainings** would be suitable to disseminate the technical aspects of our exercise, while the research results of the use cases have to be shared to a broader audience (e.g. public health community, policy makers, journalists) and can be disseminated through factsheets, policy briefs, interactive dashboard(s) (on the Health Information Portal) and presentations at important **conferences** (e.g. Public Health Forum Gastein, European Public Health Conference).



In addition to the dissemination activities, the **analyses** within the individual use cases will be ongoing. As we are in an asynchronous process, where all use cases and their analytical pipelines are already deployed, but some data hubs have not yet been able to contribute data due to challenges causing delays, some partners will run the analyses and send their results to the use case leads for comparisons and meta- analyses. This implies that neither the analyses within the use cases nor the help desk in the coordination hub, that is receiving queries from the data hubs mainly meant to solve deployment problems that are addressed as soon as received, are closed. Thus, the partner countries still have the chance to join and feed their results into the analytical pipeline.

Building on the experience of the PHIRI federated approach and the orchestration of the use cases, an **evolution and upgrade of the PHIRI infrastructure** (task 7.5) for an integration into the European Health Data Space 2 (EHDS2) will be performed to enhance sustainability of the activities.

## **VI.** Conclusions and recommendations

They use cases methodology to pool and/or reuse data in a distributed way across Europe can be used to produce information for action in public health crisis. The Use case D aims to monitor changes in population mental health associated with the COVID-19 pandemic. Starting from a research question ("Has the mental health status (depression/anxiety) of the general population changed during the COVID-19 pandemic?"), a common data model (CDM) was defined to guide the metadata collection and an iterative process was developed to produce analytical scripts that was integrated in the PHIRI federated infrastructure. By June 3rd 2022, most data hubs had deployed the Docker and two data hubs were able of providing results for this use case (Wales and Finland), showing some effects of COVID-19 pandemic in diagnosis of depression and anxiety and in healthcare provision.

Despite some limitations, mainly related to the availability of data, we can conclude that the use case D facilitates research by making scalable, reproducible methods available within PHIRI. Building a common data model is a time consuming, iterative process and will require harmonization of regional/national data sources. Future steps will imply including other data hubs in the analysis, generating meta-analysis and cross-comparisons between countries, expanding the methodology of use cases to other data sources (for example, surveys) and disseminating the Use case D through a variety of activities.



# References

Aldridge, S., González-Galindo, J., Estupiñán-Romero, F., Garriga, C., 2022. PHIRI - WP6 - Use Case D scripts for local analyses (R Markdown). Zenodo. <u>https://doi.org/10.5281/ZENODO.6377112</u>

EUROFUND, 2021. Living, working and COVID-19 (Update April 2021): Mental health and trust decline across EU as pandemic enters another year, Publications Office of the European Union. Eurofound, Luxembourg.

Fiorillo, A., Sampogna, G., Giallonardo, V., Del Vecchio, V., Luciano, M., Albert, U., Carmassi, C., Carrà, G., Cirulli, F., Dell'Osso, B., Nanni, M.G., Pompili, M., Sani, G., Tortorella, A., Volpe, U., 2020. Effects of the lockdown on the mental health of the general population during the COVID-19 pandemic in Italy: Results from the COMET collaborative network. Eur. Psychiatr. 63, e87. <u>https://doi.org/10.1192/j.eurpsy.2020.89</u>

González-Sanguino, C., Ausín, B., Castellanos, M.Á., Saiz, J., López-Gómez, A., Ugidos, C., Muñoz, M., 2020. Mental health consequences during the initial stage of the 2020 Coronavirus pandemic (COVID-19) in Spain. Brain, Behavior, and Immunity 87, 172–176. https://doi.org/10.1016/j.bbi.2020.05.040

Holmes, E.A., O'Connor, R.C., Perry, V.H., Tracey, I., Wessely, S., Arseneault, L., Ballard, C., Christensen, H., Cohen Silver, R., Everall, I., Ford, T., John, A., Kabir, T., King, K., Madan, I., Michie, S., Przybylski, A.K., Shafran, R., Sweeney, A., Worthman, C.M., Yardley, L., Cowan, K., Cope, C., Hotopf, M., Bullmore, E., 2020. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. The Lancet Psychiatry 7, 547–560. https://doi.org/10.1016/S2215-0366(20)30168-1

OECD, European Union, 2020. Health at a Glance: Europe 2020: State of Health in the EU Cycle, Health at a Glance: Europe. OECD. <u>https://doi.org/10.1787/82129230-en</u>

Pierce, M., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., Kontopantelis, E., Webb, R., Wessely, S., McManus, S., Abel, K.M., 2020. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. The Lancet Psychiatry 7, 883–892. https://doi.org/10.1016/S2215-0366(20)30308-4

Richter, D., Riedel-Heller, S., Zürcher, S.J., 2021. Mental health problems in the general population during and after the first lockdown phase due to the SARS-Cov-2 pandemic: rapid review of multi-wave studies. Epidemiol Psychiatr Sci 30, e27. <u>https://doi.org/10.1017/S2045796021000160</u>

Rodriguez-Blazquez, C., Tolonen, H., 2022. PHIRI - WP6 - Use Case D Common Data Model. https://doi.org/10.5281/ZENODO.6358187

Schmidt, A.E., Rodrigues, R., Simmons, C., Steiber, N., 2021. A crisis like no other? Unmet needs in health care during the first wave of the COVID 19 crisis in Austria. (Preprint).

WHO-EUROPE, 2021. Action required to address the impacts of the COVID-19 pandemic on mental health and service delivery systems in the WHO European Region: recommendations from the European Technical Advisory Group on the Mental Health Impacts of COVID-19. WHO Regional Office for Europe, Copenhagen.



# **Appendices**

Appendix 1. Data hubs' technical capabilities and data accessibility survey.

11/1/2021

WP#6&7 - Data Hubs' technical capabilities and data accessibility

# WP#6&7 - Data Hubs' technical capabilities and data accessibility

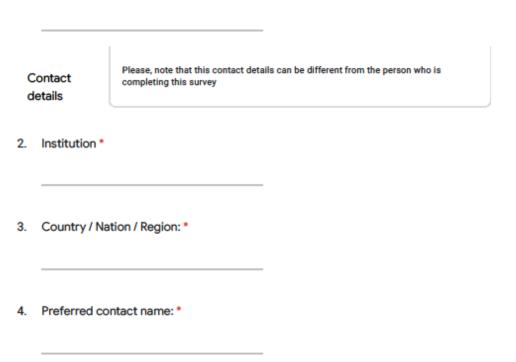
As you know, WP 6 and WP7 are working together in the development of the PHIRI federated research infrastructure. In this, there are three pillars to build: 1) the characterisation of the data hubs, 2) developing technical interoperability, and 3) developing common data models.

This survey is intended to provide WP6 and use case leaders (Tasks 6.1 to 6.4) and WP7 technical pilot leaders (Task 7.1) with relevant information on the first two pillars.

The institution that you represent is expected to act as a Data Hub within the PHIRI federation, so you are expected to complete tasks regarding data extraction, data management and data analysis.

A level of technical expertise on the development, adaptation and deployment of analytical pipelines in the form of open source software scripts is required for a proper participation. In addition, a knowledge on the health and health care data sources availability and access is also required for successful achievement of the tasks. \*Required

Email address \*

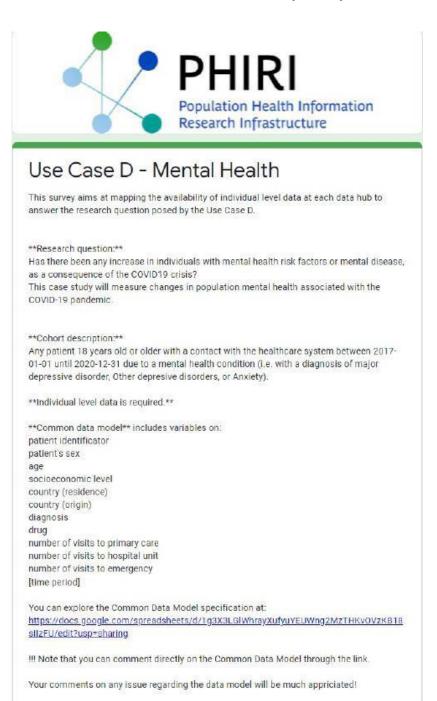


https://docs.google.com/forms/d/1yllmrbaxY8WYqJiL5RXHUUV707PCceTYGSaoi\_PSG54/edit

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Appendix 2. Use case D common data model availability survey.



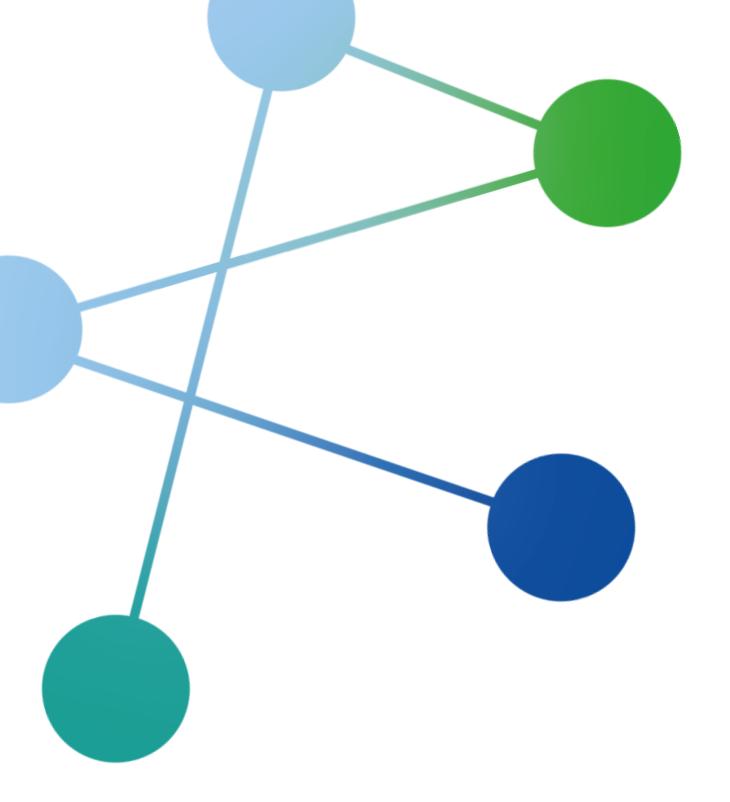


#### **Appendix 3.** Final version of the common data model of use case D.

Data model entity				Data Quality Assessment	ETL					
Associated entity in ERD	Label (var_label)	Name (var_concept)	Level (required/recommended /optional)	Classification/Encoding	Units	Format	Description	References to validation rules	Transformation at origin	Observations
patient	patient_id	patient identificator	required	private key ciphering function	none	string	patient pseudonymized identificator	SHA256	double hash function applied following SHA256 protocol (see patient cohort definition in next sheet)	field calculated at individual level
patient	sex	patient's sex	required		none	integer	patient's sex	man=0; woman=1		field calculated at individual level
patient	age_nm	age	required	none	years	integer	patient's age at the moment	3-digits; min 18; max 80	it might need to be calculated from 'birth_dt'	field calculated at individual level
patient	socecon_lvl_cd	socioeconomic level	optional	quintile	quintiles	integer	patient's socioeconomic level (quintile)	min 1; max 5	it might need to be calculated from 'income_lvl' or approximated through a combination of 'education_lvl and other variables	field calculated at individual level. Variable as available in the register, at individual level. Categorize it if possible
patient	country_cd	country (residence)	required	ISO3166	none	string	patient's country of residence	ISO3166-3	conformance with ISO3166-3	field calculated at individual level
patient	country_origin_cd	country (origin)	recommended	ISO3166	none	string	patient's country of origin	ISO3166-3	conformance with ISO3166-3	field calculated at individual level
patient	diagnosis	diagnosis	required	icd-10/icd-10_mc/icd-9-mc/SN	none (	string	patient diagnosis	codes icd-10_mc/icd-9- mc/SNOMED		field calculated at individual level. Express ICD- 10 codes as 1- or 2-digit as available in the register
date	dx_date	date of diagnosis	required	dd-mm-yyyy	date	integer	date of diagnosis	dd-mm-yyyy		field calculated at individual level
prescription	drug	drug	recommended	ATC	none	string	patient's prescription	codes ATC		field calculated at individual level.
date	drug_date	date of prescription	recommended	dd-mm-yyyy	date	integer	date of prescription	dd-mm-yyyy		field calculated at individual level
visit (contact w healthcare service)	prim_visit	number of visits to primary care	recommended	ICPC	visits	integer	number of visits to primary care	no negative values allowed	ICPC codes	field calculated at individual level
visit (contact w healthcare service)	hosp_visit	number of visits to hospital unit	recommended	ICPC	visits	integer	number of visits to hospital unit	no negative values allowed	ICPC codes	field calculated at individual level
visit (contact w healthcare service)	emer_visit	number of visits to emergency	recommended	ICPC	visits	integer	number of visits to emergency or unplanned visits	no negative values allowed	ICPC codes	field calculated at individual level
observation period	visit_date	date of visit	recommended	dd-mm-yyyy	date	integer	date of visit	dd-mm-yyyy		field calculated at individual level

#### **Appendix 4.** Final list of participant data hubs:

UCC	PARTNERS PARTICIPATION (GRANT AGGREEMENT)	PARTNERS DATA AVAILABILITY (SURVEY)	PARTNERS PHIRI-APP DEPLOYMENT (DEVELOPERS 'FORUM)	POTENTIAL PARTICIPATION	Short name	Participant Organization name	Country
SCIENSANO	Р	N	D	N	Sciensano (BEL)	SCIENSANO	Belgium
GÖG	Р	Y	D	Y	GÖG (AUT)	GESUNDHEIT ÖSTERREICH GMBH	Austria
FBiH	Р	Ň		N	FBiH (BIH)	ZAVOD ZA JAVNO ZDRAVSTVO FEDERACIJEBOSNE I HERCEGOVINE	Bosnia and Herzegovina
CIPH	P	N	D	N	CIPH (HRV)	HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO	Croatia
UZIS			D	?	UZIS (CZE)	USTAV ZDRAVOTNICKYCH INFORMACI A STATISTIKY CESKE REPUBLIK	Czech Republic
NIHD	Р	?	D	Y	NIHD (EST)	TERVISE ARENGU INSTITUUT	Estonia
THL	L	Y	D	Y	THL (FIN)	TERVEYDEN JA HYVINVOINNIN LAITOS	Finland
AEEK	Р	?		?	AEEK (HUN)	ALLAMI EGESZSEGUGYI ELLATO KOZPONT	Hungary
SISS/UNIVPN	Р	Y	D	Y	ISS (ITA)	ISTITUTO SUPERIORE DI SANITA	Italy
CDPC	Р	Y	D	Y	CDPC (LVA)	SLIMIBU PROFILAKSES UN KONTROLES CENTRS	Latvia
RIVM			D	?	RIVM (NLD)	RIJKSINSTITUUT VOOR VOLKSGEZONDHEID EN MILIEU	Netherlands
NIPH/HD	Р	N		N	HD (NOR)	HELSEDIREKTORATET	Norway
DGS/UNL	Р	Y	D	Y	DGS (PRT)	MINISTERIO DA SAUDE - REPUBLICA PORTUGUESA	Portugal
INSP			D	?	INSP (ROU)	INSTITUTUL NATIONAL DE SANATATE PUBLICA	Romania
NCZI	Р	N		N	NCZI (SVK)	NARODNE CENTRUM ZDRAVOTNICKYCH INFORMACI	Slovakia
NIJZ	Р	?	D	?	NIJZ (SVN)	NACIONALNI INSTITUT ZA JAVNO ZDRAVJE	Slovenia
ISCIII	L	Y		2.40	ISCIII (ESP)	INSTITUTO DE SALUD CARLOS III	Spain
IACS		Y	D	0.58	IACS (ESP)	INSTITUTO ARAGONES DE CIENCIAS DE LA SALUD	Spain
FoHM			D	?	FoHM (SWE)	FOLKHALSOMYNDIGHETEN	Sweden
SU	Р	Y	D	Y	SU (GBR)	SWANSEA UNIVERSITY	United Kingdom
	15	8	15	7			



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