PHIRI

Population Health Information Research Infrastructure

Case Study Report

Use Case A, Deliverable 6.1, 24.06.2022

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Executive summary

Can include the following:

- Contains the purpose of the paper,
- definition and description of the problem,
- evaluation of solution alternatives,
- Conclusions and recommendations.

Key points

The most important ideas are summarised in key point by using direct quotes of key words, phrases, or sentences.

Key points include implications to public health, public health policy and public information systems.

PHIRI: Case study report. Use case A

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I. Introduction

COVID-19 has had a major impact on countries across the world including their health systems and economies. As of end of May 2022 there have been more than 525 million cases globally with more than 6 million deaths, of which 221 million cases and just over 2 million deaths have been in the WHO European region[1].

The absence of vaccines and safe antiviral treatments at the outset led to a number of public health prevention and control measures including advice on handwashing, ventilation, social distancing, self-isolation of cases and contacts, border closures, travel restrictions and national lockdowns. Apart from the direct effects of the COVID-19 disease on sickness, hospitalisation and deaths there have been huge indirect effects on a number of sectors including healthcare. Early studies identified a huge drop off in primary care contacts in the UK for a wide range of physical and mental health conditions[2]. A variety of other studies have shown marked reductions, for example, in expected cancer diagnoses[3], cardiovascular services[4], respiratory disorders [5,6] and surgical activity[8].

However, there is a dearth of European studies utilising common definitions and data models to inform policy makers on the indirect impact of COVID-19 on aspects of population health, including important conditions and health service resilience. There is also a need to ensure that vulnerable populations are as well protected as possible. Vulnerability may be due to ageing, the presence of specific health conditions or adverse social conditions.

Analysis and validation of linked infection, primary care, secondary care, and mortality data identified a number of clinical risk factors that have been used to prioritise access to vaccines and anti-viral therapies[9,10]. These studies also identified relative socioeconomic disadvantage as a risk factor for hospitalisation and death.

The use of routinely collected population data to derive intelligent indicators of the health of the public is key to monitoring the performance and improving the quality of healthcare services and population health. However, this is not a simple task as variations in design, coverage and ontologies means there is a need for harmonization to allow 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 the best ethical practices that protect patient privacy without hindering research when sharing sensitive health and genomic data for research reuse (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 no 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.

In order to improve knowledge of the indirect effects of COVID-19 on a variety of conditions, Use Case A focused on the impacts on hospitalisations with a particular emphasis on how known socio-economic inequalities in health were affected by the pandemic. This was designed to complement the other use cases B-D, which will focus on breast cancer, perinatal health, and mental health.

II. Approach

Methodology:

Use case A included several phases:

Research question

Several potential research questions were proposed to the data hubs (responsible experts from regional or national public health institutions owning or allowed for requesting secondary health data). The aim was to maximise the ability of hubs to participate. Early on it became clear that there were large differences in the availability, depth and breadth of data and its timeliness across the data hubs. Given the absence of linked primary care data from many systems it was decided not to repeat the UK studies on clinical risk factors and to focus on indirect impacts of the pandemic on hospitalisations for selected conditions.

Research Question: Has the COVID19 pandemic changed existing patterns of non-COVID-19 health care utilisation for the general and socio-economically vulnerable populations within and between countries?

Use Case A addresses four sub questions

Has the pattern of hospital treatment for heart attacks and strokes for the general population changed during the COVID-19 pandemic?

Has the pattern of hospital treatment for hip and knee replacements for the general population changed during the COVID-19 pandemic?

Has the pattern of hospital treatment for serious trauma for the general population changed during the COVID-19 pandemic?

Have there been changes in any of the above groups by socioeconomic status?

These three groups of conditions were chosen to reflect different aspects of health care provision. Heart attacks and strokes are medical emergencies that should be treated at hospital, but patients may be reluctant to attend hospital during pandemics due to fear of contracting the condition or not to add to health service pressures during extremely busy times. Hip and knee replacements are elective or planned procedures that may be put off due to system pressures or patients being reluctant to attend health care premises during pandemics. The incidence of trauma may be affected during pandemics as people change travel and work patterns. Reduced incidence of road traffic and work-related injuries would be expected with an increase in injuries occurring at home. As bed availability and differences in treatment approaches between countries impact on admissions to treat trauma it was decided to utilise a definition of severe trauma that has been agreed by international experts as always requiring hospitalisation [11].

Many countries did not have access to linked hospitalisation/socio-economic status data to address question 4. Different systems are used in countries where there are socioeconomic data and hence it is not possible to combine such data in meta-analyses. Nevertheless, the use of ratios over time to compare changes in the most deprived to the most affluent individuals or areas or by income or educational status can be very helpful. In this study we have characterised individuals by local socio-economic status and compared the most deprived fifths to the least deprived fifths of the population in Wales and took similar approaches in other data hubs.

Two round questionnaire

A 1st round questionnaire (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 2nd round questionnaire (Appendix 2) was sent to the participant data hubs to obtain specific information (metadata) of each use case, to start off the process of harmonising data collection throughout a common data model (see next section).

Development of the common data model

The first common data model produced consisted of 3 separate cohorts corresponding to heart attack and stroke, hip or knee replacement surgery, and trauma. These included demographic details along with details regarding the incident or treatment.

The questionnaires revealed what data was available from each country/region, along with the form it took and any limitations/restrictions in place. All those meaningful variables selected were then categorised by availability across data hubs in "required", "recommended" and "optional". These metadata were planned to be uploaded to the open platform Zenodo (https://zenodo.org/record/6483177).

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

- Men and women of all ages
- With Any of the conditions listed
- For trauma patients, only the first record of injury is reported
- Had a contact with the healthcare system during 2017-2020 (2021 when possible)
- A washout period of one year was used to identify new cases of each type of incident and exclude starting analysis within a healthcare event. Each patient can be recorded against each type of event, however in the case of a repeat event (e.g. a second hip surgery), the patient must have a separation of 365 days since the previous recording of that type.

The diagnoses and procedure codes included were:

Cohort 1: ICD-10 codes I21 (stroke), I60-I164 (heart attack)

Cohort 2: OPCS codes W37 – W42. (OPCS is a coding system for procedures e.g. hip and knee replacements)

Cohort 3: ICD-10 codes S720 – S723, S063, S272, S360, S361

The final common data model was condensed to one table that held patient data for all three of the cohorts, recording only the first event of each type per patient.

Analytical scripts

A pilot R script was created by the team based at Swansea University in Wales using a cohort of real patients from the SAIL databank and shared with the rest of the team. This was developed further by colleagues to produce a script suitable for running within the Docker that would generate a summary report of the European age standardized rates combined with the aggregated data needed for further analysis. The R Markdown script was again shared in Zenodo.

Meta-analyses

Future analysis will use the aggregated data provided by participating countries to perform a meta-analysis and establish statistical significance across a pool of European populations. We will also investigate the extent of changes in hospitalisations related to the stage and extent of local COVID-19 infection rates.

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 (RQ) was defined based on the previous literature and the types of data available from each of the data hubs surveyed. The case study investigates changes in health care utilisation associated with the COVID-19 pandemic, and is defined as:

> *Has the COVID-19 pandemic changed existing patterns of non-COVID-19 health care utilisation for the general and socio-economically vulnerable populations within and between countries?*

The final common data model was reached after feedback from the 2nd questionnaire. This final round of questions was answered by 11 data hubs, the responses are displayed in Figure 1.

The common data model was finalised in response to 11 countries answers to the 2nd questionnaire. The SARS-COV-2 variable was disregarded and the following 16 variables were included as

- **Basics:** Patient ID, Age, Sex, Observation Period
- **Cohort 1:** Heart event (ICD10 codes), Date of heart event, Stroke (ICD10 codes), Date of stroke
- **Cohort 2:** Type of surgery (OPCS code), Type of hip surgery (OPCS code), Type of knee surgery (OPCS code)
- **Cohort 3:** Trauma admission (ICD10 codes), Date of admission

- **Optional:** Level of education achieved, socioeconomic score, Country code, Country of origin code, District code

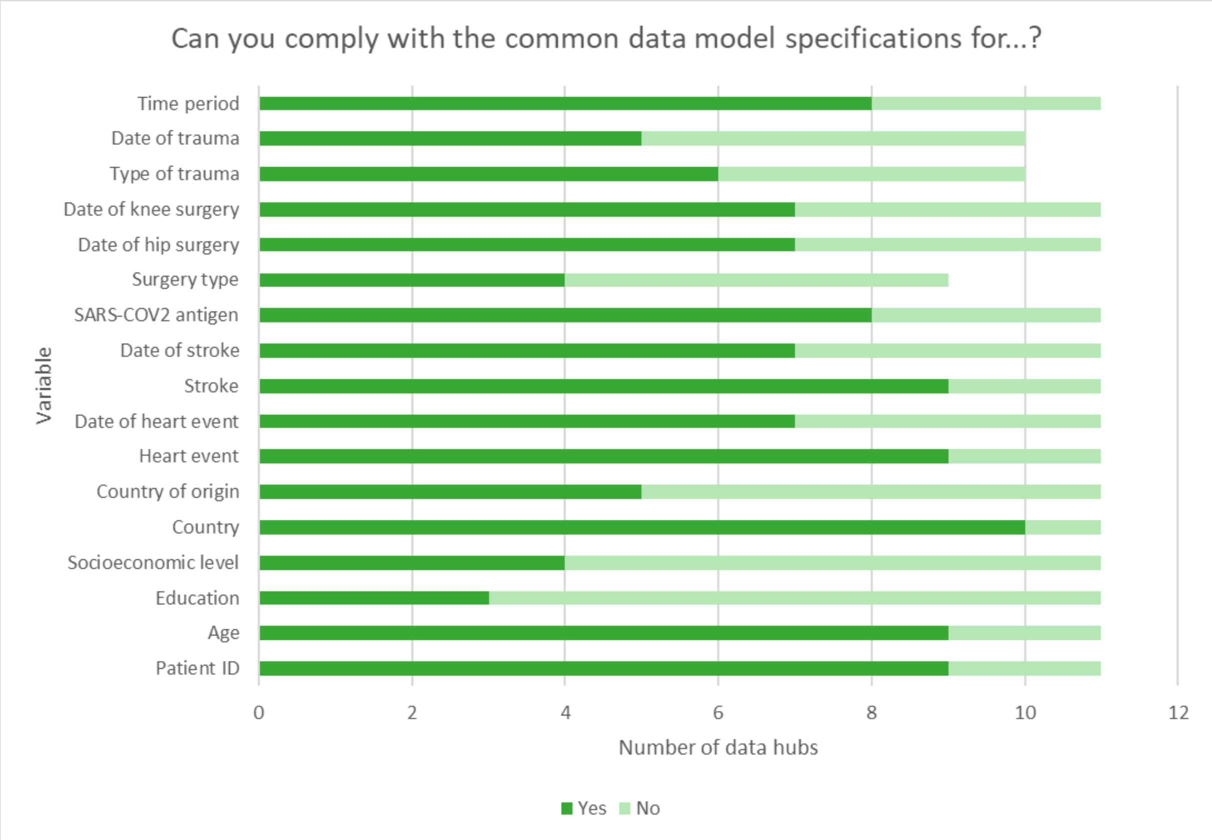


Figure 1. Health care utilisation variables and their availability among participating countries.

Description analytical scripts

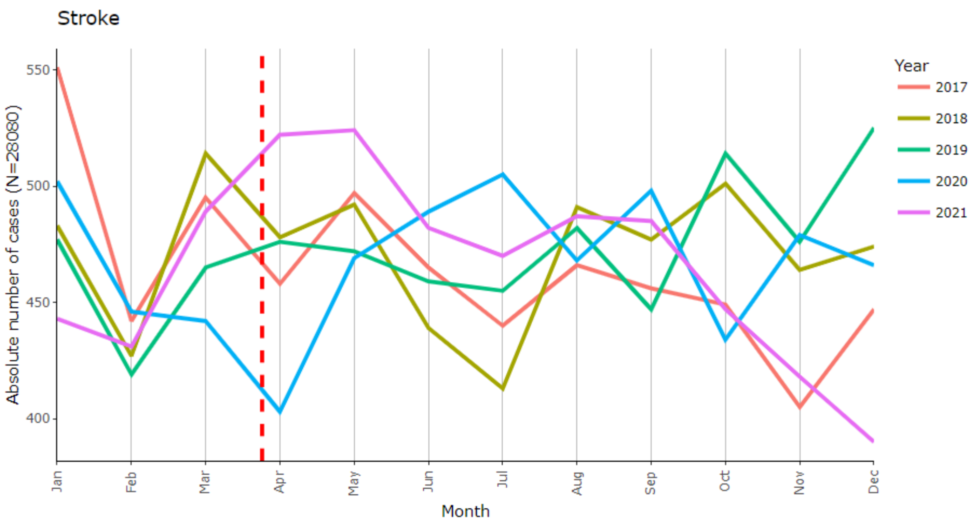
Analytical scripts were initially developed in UK using Welsh electronic health data records. These were created using R markdown to generate HTML summary reports plotting trends in health care utilisation in Wales during 2017-2021. These scripts were modified by researchers in Spain and incorporated into the DOCKER package available at Zenodo for use by participating data hubs. Four data hubs were able to implement the scripts by the deadline: Wales, UK; Austria; Finland; and Croatia.

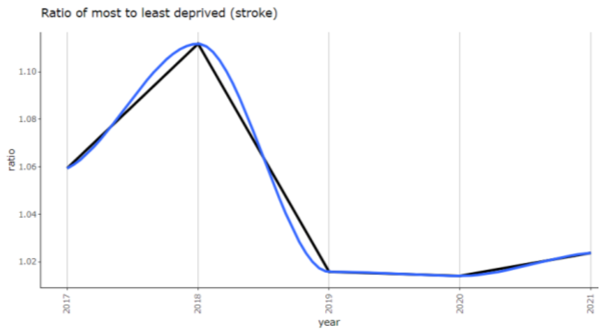
Results by data hub

1. Wales, UK

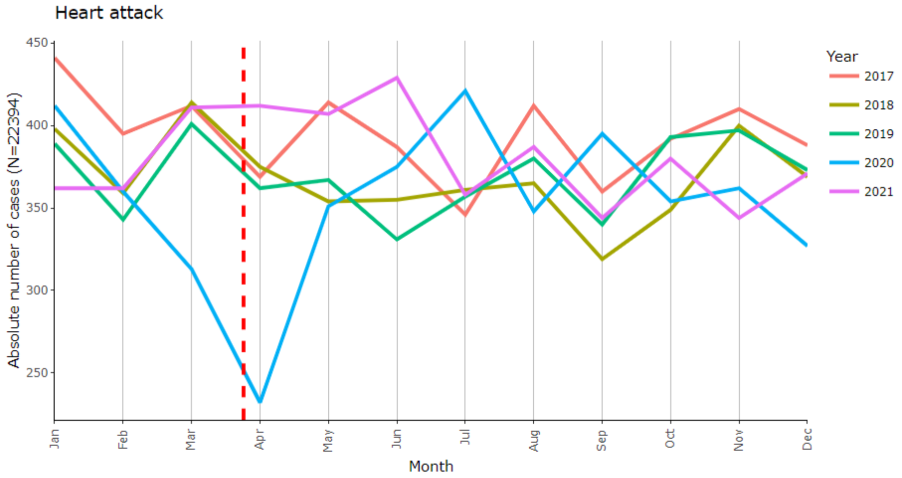
Wales was in national lockdown through 2020 and 2021 as a result of COVID-19 through 23rd Mar 2020 – 1st June, 23rd Oct – 9th Nov, 26th Dec – 13th Mar 2021.

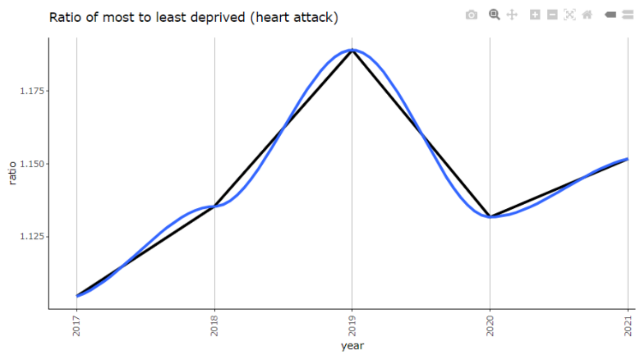
Stroke



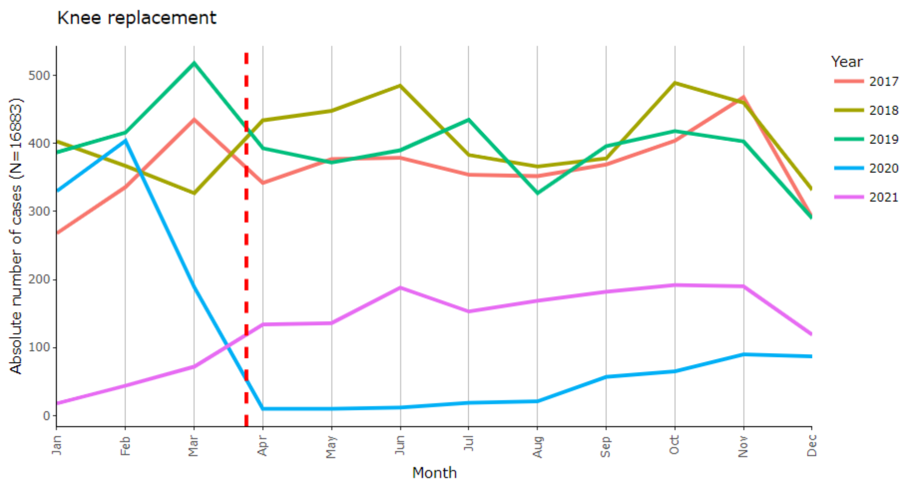


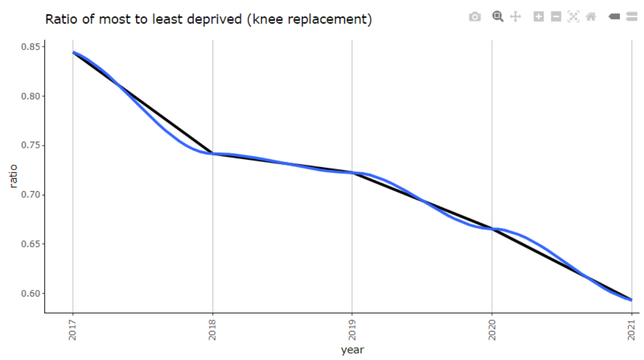
Heart attack



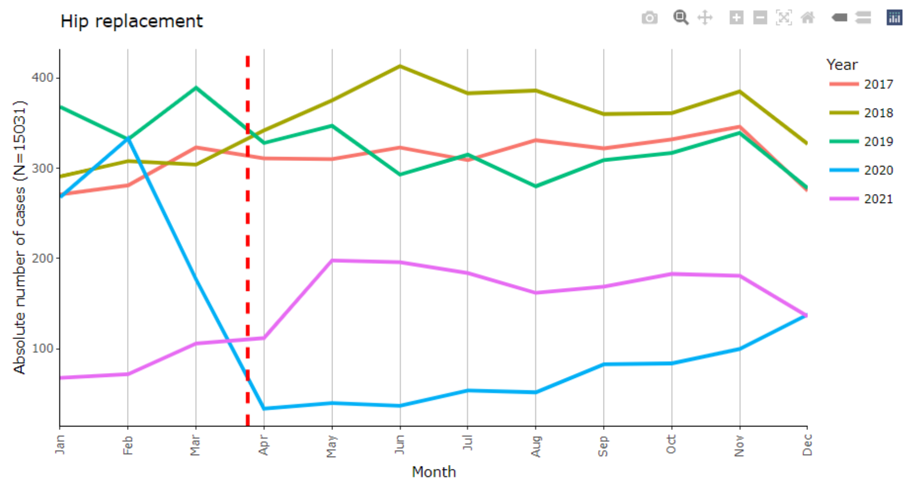


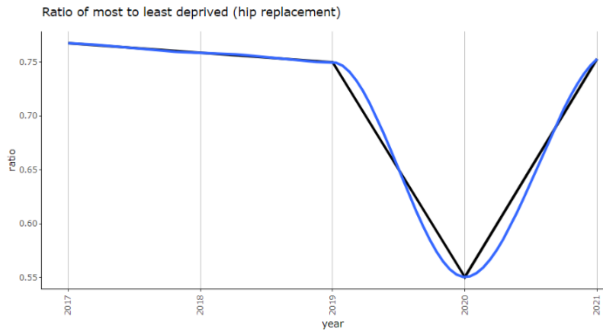
Knee replacement surgery



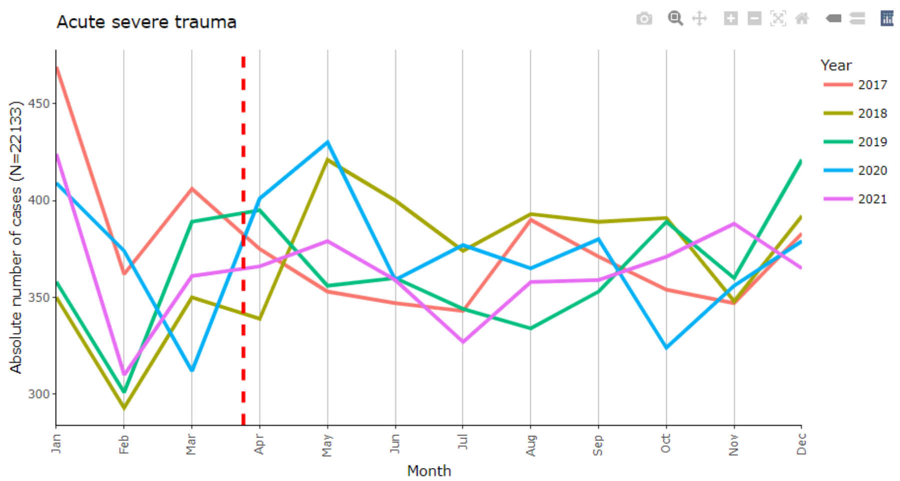


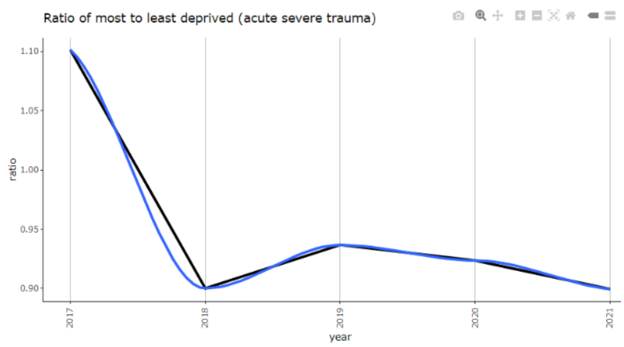
Hip replacement surgery





Severe trauma

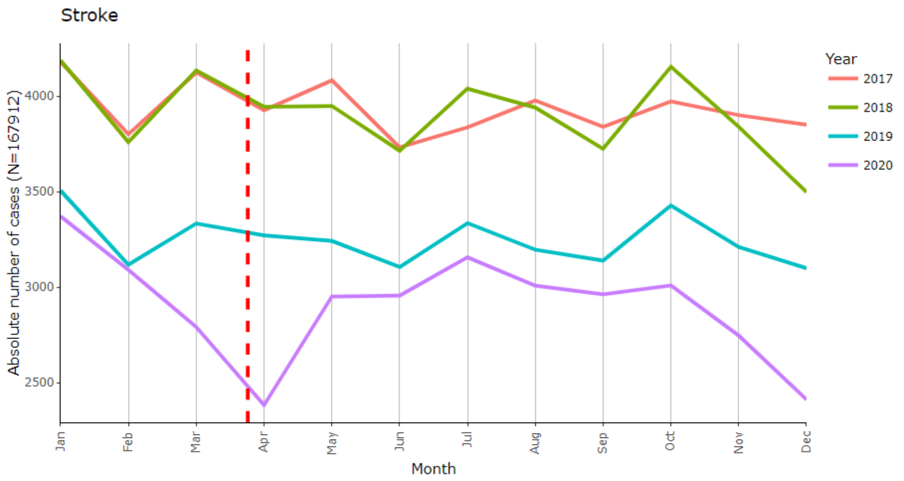




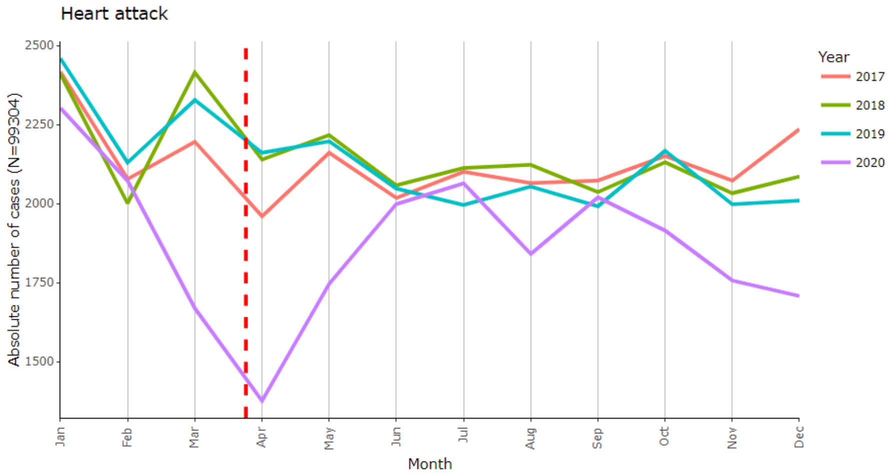
2. Austria

Austria was in national lockdown in 2020 as a result of COVID-19 during 16th Mar – 17th May, Nov 17th – Dec 26th – Feb 8th 2021.

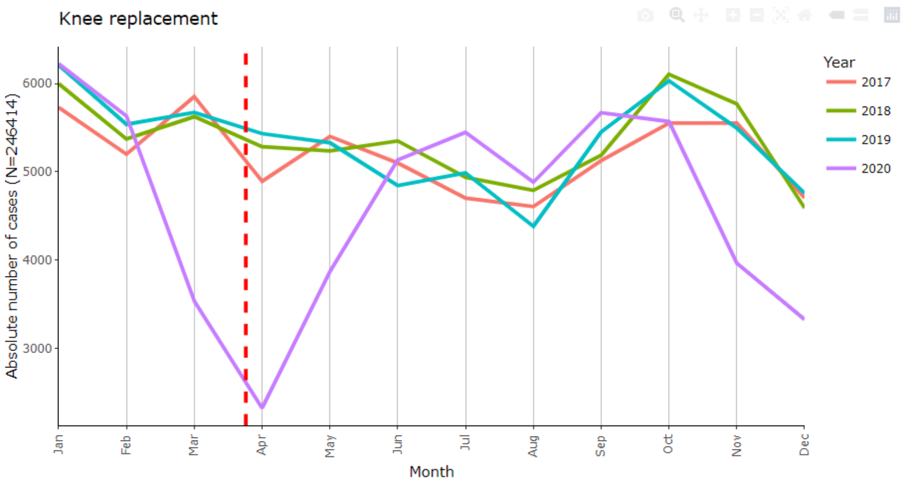
Stroke



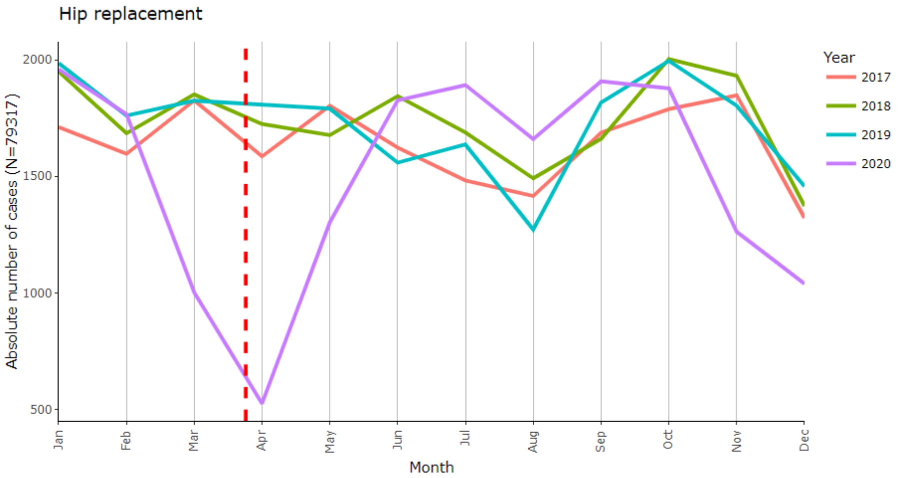
Heart attack



Knee replacement surgery



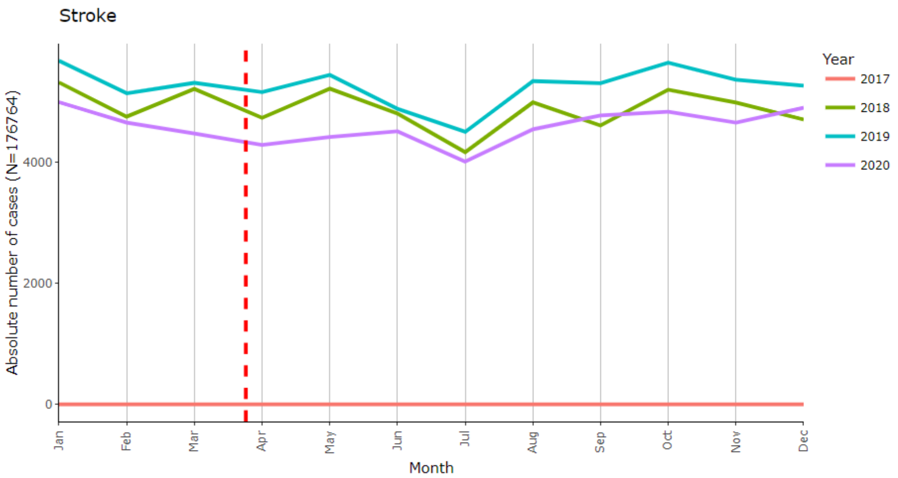
Hip replacement surgery



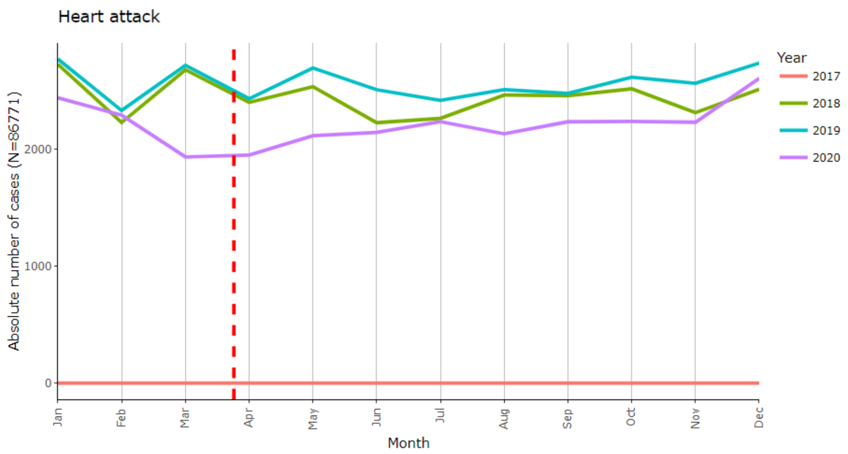
3. Finland

Finland never went into a national lockdown, but did issue a state of emergency on 16th March, implementing measures to close schools, government run facilities, increase healthcare capacity and restrict movement into Finland. On 27th March movement within Finland was further restricted when the borders to the Uusimaa region were closed. Data from 2017 were not available for this analysis.

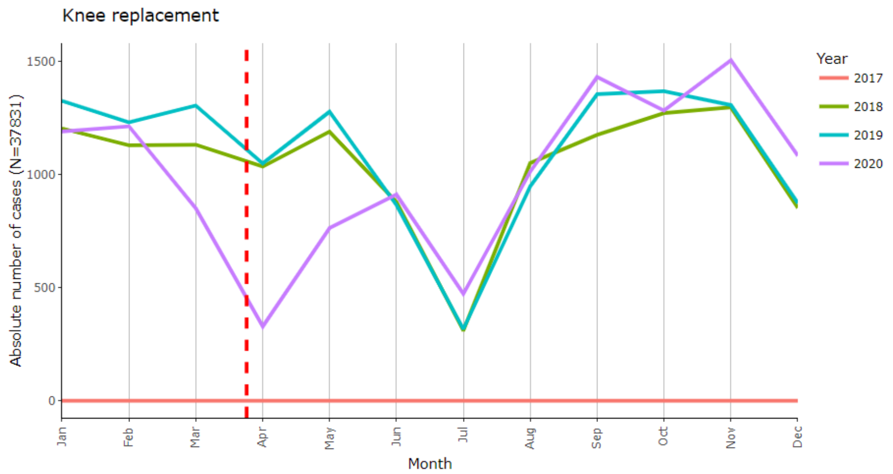
Stroke



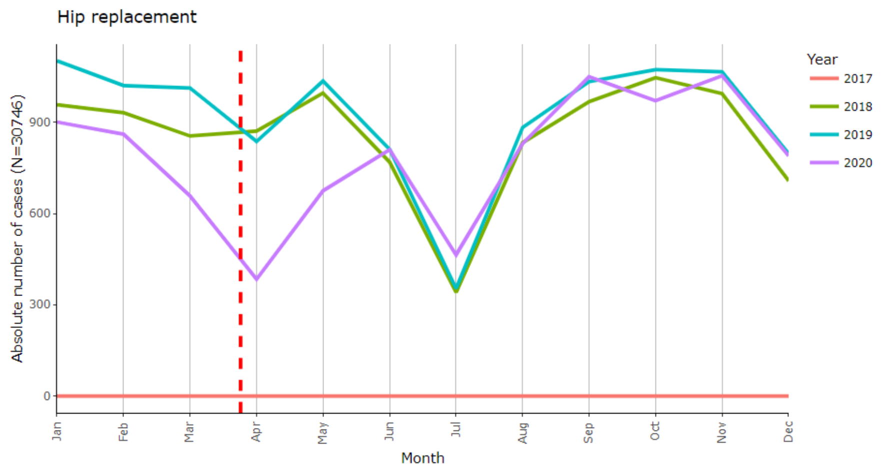
Heart attack



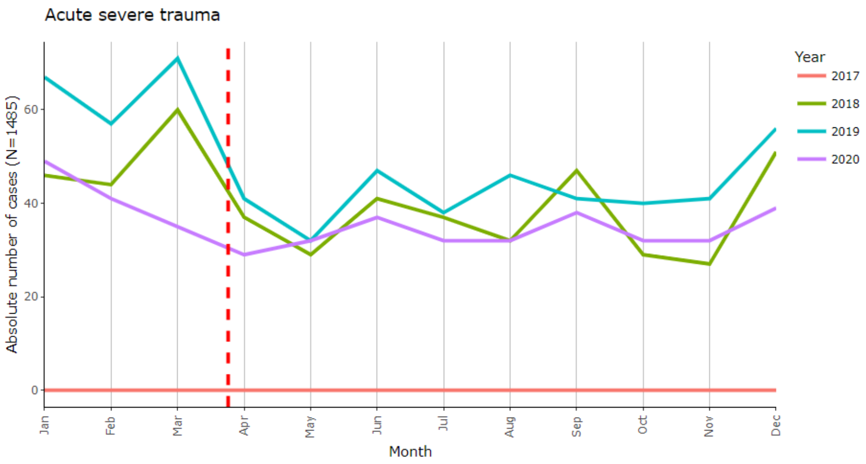
Knee replacement



Hip replacement



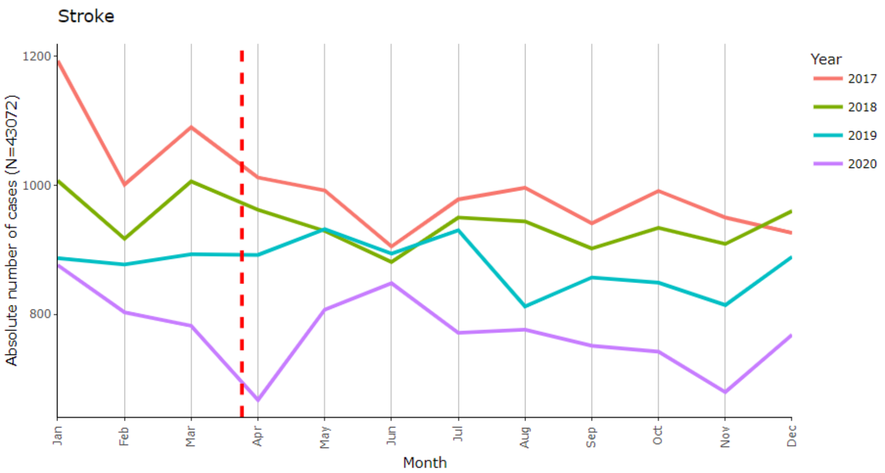
Severe trauma



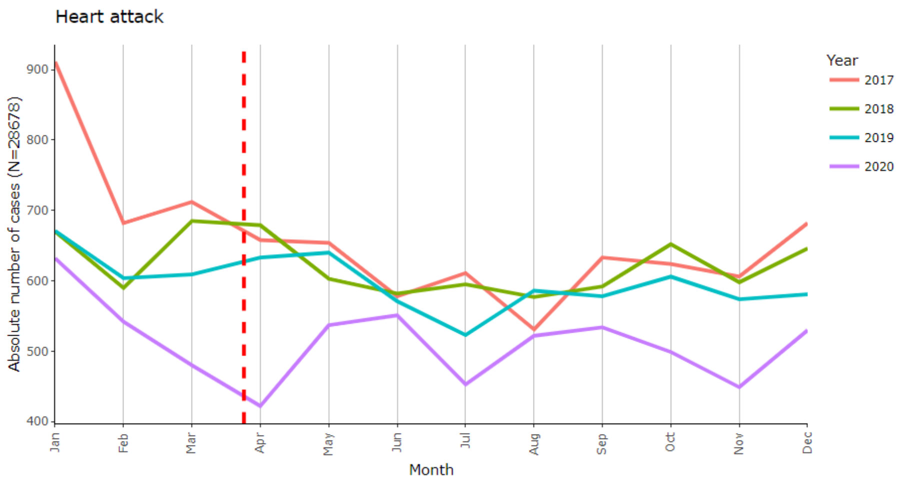
4. Croatia

Croatia went into a national lockdown on 23rd March until 27th April 2020.

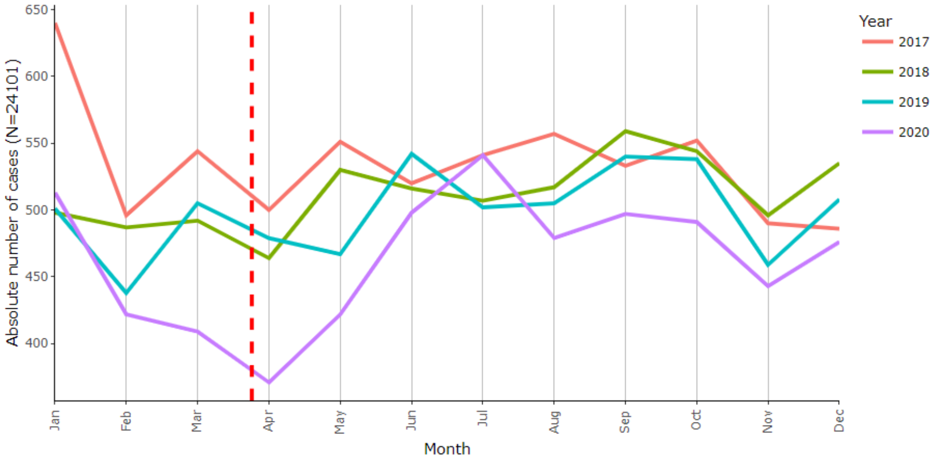
Stroke



Heart attack



Hip and knee replacements



IV.Implications and limitations

Use Case A demonstrated that it was possible to develop, agree on, and implement a common data model across European countries around the impact of COVID-19 on hospital care for acute medical and trauma care indicators and elective care for major joint replacements. There were quite different patterns of disruption to care pathways in the different jurisdictions, from which policy makers can learn considerably. This was our first foray into this pattern of working. At this point in time comparisons are limited to four countries. Future developments will include investigation of the timing and extend of COVID-19 in the different countries and the relationship with health service disruption and population age standardisation to account for population differences. Before the end of the project, we also expect to finalise analyses in Spain, Norway, Czech Republic, Bosnia, and hopefully other countries.

V. Conclusions and recommendations

Given the complexity of data hubs and working practices across Europe, with some PHIRI investigators having direct access and others having to engage with one or several data providers it is not surprising that clarification of what data are available takes some time to complete. It was important to spend a considerable amount of time with data providers and researchers working out which countries or data hubs could provide the necessary variables. As can be seen from the graphs in the results section data on 16 variables were requested. Between 3 and 10 data hubs were able to access each variable. This necessitated some reformatting of the research question and making data on the entire period or socioeconomic position optional.

Four countries were able to complete the analysis of the data using the DOCKER solution and 5 countries are still in the process of investigating or implementing the DOCKER solution. When more countries have completed the analysis and the additional step of providing results not just by counts but also by European Age Standardised Rates (EASRs) we will continue with more detailed comparison of the impacts in each data hub or country and how these relate to the prevalence of infection over the time period.

The pattern of disruption to health care for the index conditions varied by jurisdiction.

Overall, there is a clear pattern with reductions in admissions prior to the implementation of national lock downs or responses. This is likely due to patients' fear of attending hospitals once numbers of cases rose quickly across Europe. Planned surgery for hip and knee replacements also tails off prior to lock downs and is likely due to planning to make beds available for care of COVID-19 patients and perhaps patients' reluctance to receive care at that time. There are some differences between countries in the extend and timing of changes.

In Wales, there was a profound impact in stroke admissions in Wales in March and April 2020, and an even larger reduction in admissions due to myocardial infarctions. Knee replacement surgery fell by an even greater amount and remained suppressed until late 2021 when there was a partial improvement, but rates remain below normal. The pattern for hip replacement is similar.

The pattern for severe trauma admissions is quite different from all the others. There was an initial major dip prior to lockdown, which is probably related to reductions in exposures when people were travelling less and staying away from others but would need confirmatory sub-analyses by cause of injury. This was followed by a fairly quick return to usual or even elevated rates. It may be that reductions in physical activity from social distancing and increasing frailty may have increased the number of home injuries but again this is speculation which requires further, more detailed investigation.

The results in Austria show a similar picture to that in Wales in relation to the initial disruption to health services for treatment for strokes and heart attacks. The time taken to recover capacity for hip and knee replacements appears to be considerably shorter.

The data from Finland demonstrate a different picture. Disruption to acute services for stroke, heart attacks and trauma appear to be much smaller than in Wales or Austria, if they exist at all. The impact on elective hip and knee replacements was more noticeable and similar to the pattern in Austria with a return to usual levels by June 2020.

The picture in Croatia is also slightly different from the others. The numbers of strokes and heart attacks admitted in 2020 appears lower than other years but further analyses using confidence intervals is needed to determine if the change is within yearly fluctuations. Hip and knee replacement surgery returned to normal levels by the end of June 2020.

Socio-economic analyses.

Wales was the only country able to analyse data by socio-economic status by the deadline. Socioeconomic status was derived by dividing some 2000 small areas called Lower Super Output Areas (LSOAs) and ranking these into fifths based on the Welsh Index of Multiple Deprivation (WIMD).

In Wales, the patterns of admission by socio-economic status changed a little during the pandemic. Ratios above 1 show higher incidence in the most deprived fifth of the population than the least deprived. The well-known higher rates of stroke, heart attacks in deprived communities changed little during the pandemic. Hip and knee replacements are less common in deprived communities and access to these services appears to have worsened during the pandemic for the most deprived groups. However, further work is needed to check the statistical significance of any changes.

As more countries come on board and implement the DOCKER solution we plan to extend the analyses, comparing the relationship between infection rates and hospital admissions for the conditions in Use Case A between and within countries, using European age standardised rates and confidence intervals.

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Appendices

Appendix 1. Data hubs technical capabilities and data accessibility survey

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

1. Email address *

____

Contact details

Please, note that this contact details can be different from the person who is completing this survey

2. Institution *

____

3. Country / Nation / Region: *

____

4. Preferred contact name: *

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Appendix 2. Use case A common data model availability survey

PHIRI
Population Health Information
Research Infrastructure

Use Case A - Vulnerable population groups

This survey aims at mapping the availability of individual level data at each data hub to answer the research question posed by the Use Case A.

Research question:
Has the COVID19 pandemic changed existing patterns of non-COVID-19 health care utilisation and mortality for vulnerable populations within and between countries?
This is based around answering the indirect effects of the pandemic on population health.

Cohort description:
Any patients 18 years old or older, with a hospital episode with a main diagnosis of any of the conditions included in the cohort definition (i.e. heart attack, stroke, hip or knee replacements, or severe trauma) from 2019-01-01 until today.

Individual level data is required.

Common data model includes variables on:
patient identificator
age
highest completed education level
socioeconomic level
country (residence)
district (residence)
country (origin)
major vascular event - heart attack
first date - heart attack
major vascular event - stroke
first date - stroke
diagnostic antigen test for SARS CoV 2 detection
[time period]
type of treatment
elective surgery, hip joint replacement
elective surgery, knee joint replacement
hospital admission for trauma based on serious injuries
date of admission

You can explore the Common Data Model specification at:
https://docs.google.com/spreadsheets/d/14P8ax05T_Y-Mm3xgCfoUxlB2NJbqSBUOR-ApEz-CjWA/edit?usp=sharing

!!! Note that you can comment directly on the Common Data Model through the link.

Your comments on any issue regarding the data model will be much appriciated!

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Appendix 3. Final version of the common data model of use case A

	A	B	C	D	E	F	G	H	I
1	**Case study**	**Data model entity**	**Variable**						
2		**Associated entity in ERD**	**Label (var_label)**	**Name (var_concept)**	**Classification/Encoding**	**Units**	**Format**	**Description**	**Observations**
3		patient	**patient_id**	patient identificator	private key ciphering function	none	string	patient pseudonymized identificator	field preferably calculated at individual level
4	basics	patient	**sex**	sex					
5		patient	**age_nm**	age	none	years	integer	patient's age as of 2019-01-01	field preferably calculated at individual level
6		observation period	**period**	[time period]	none	month	integer	natural month	
7									
8		heart event	**acute_event_heart**	major vascular event - heart attack	ICD10:I21				field preferably calculated at individual level
9	cohort 1	date heart event	**date_event_heart**	date - heart attack	date	date_DMY_nr	YYYY-mm-dd		field preferably calculated at individual level
10		stroke event	**acute_event_stroke**	major vascular event - stroke	I60-I64				field preferably calculated at individual level
11		date stroke event	**date_event_stroke**	date - stroke		date_DMY_nr	YYYY-mm-dd		field preferably calculated at individual level
12									
13		procedure	**ttm_type_cd**	type of treatment	types of treatment referred	none	integer	type of treatment received by the patient	field preferably calculated at individual level
14	cohort 2	procedure	**surgery_elective_hip**	elective surgery, hip joint replacement	OPCS codes in UK W37-W39				field preferably calculated at individual level
15		procedure	**surgery_elective_knee**	elective surgery, knee joint replacement	OPCS codes in UK W40-W42				field preferably calculated at individual level
16									
17	cohort 3	condition	**acute_event_trauma**	hospital admission for trauma based on	ICD10: S720, S721, S722, S723,	none	string	Based on scientific analysis by New	field preferably calculated at individual level
18		Date of event	**date_event**	date of admission	date	date_DMY_nr	YYYY-mm-dd	date of admission	field preferably calculated at individual level
19									
20		**Optional:**							
21		patient	**educ_cd**	highest completed education level	quintile or top/bottom	quintiles	integer	patient's highest completed education	field preferably calculated at individual level
22		patient	**socecon_lvl_cd**	socioeconomic level	quintile or top/bottom	quintiles	integer	patient's socioeconomic level (quintile)	field preferably calculated at individual level
23	optional	patient	**country_cd**	country (residence)	ISO3166	none	string	patient's country of residence	field preferably calculated at individual level
24		patient	**district_cd**	district (residence)	e.g. Eurostat NUTS				
25		patient	**country_origin_cd**	country (origin)	ISO3166	none	string	patients' country of origin (country of	field preferably calculated at individual level

Appendix 4. Final list of participating hubs

Update May 2022		PARTNERS PARTICIPATION (GRANT AGREEMENT)	PARTNERS DATA AVAILABILITY (SURVEY)	PARTNERS PHIRI-APP DEPLOYMENT (DEVELOPERS' FORUM)	POTENTIAL PARTICIPATION	Short name	Participant Organization name	Country
		P	N	D	N	**Sciensano (BEL)**	SCIENSANO	Belgium
		L	Y	D	**Y**	**GÖG (AUT)**	GESUNDHEIT ÖSTERREICH GMBH	Austria
Contact correct	Seila got back to	P	N		**N**	**FBiH (BIH)**	ZAVOD ZA JAVNO ZDRAVSTVO FEDERACIJEBOSNE I HERCEGOVINE	Bosnia and Herzegovina
Jakov	Jakov is working on the data			D	**?**	**CIPH (HRV)**	HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO	Croatia
Ondrej as lead, a	CZ is working on	P	?	D	**?**	**UZIS (CZE)**	USTAV ZDRAVOTNICKYCH INFORMACI A STATISTIKY CESKE REPUBLIKY	Czech Republic
		P	?	D	**?**	**NIHD (EST)**	TERVISE ARENGU INSTITUUT	Estonia
ppt in Nov 2021				D	**Y?**	**THL (FIN)**	TERVEYDEN JA HYVINVOINNIN LAITOS	Finland
		P	N		**N**	**RKI (DEU)**	ROBERT KOCH-INSTITUT	Germany
		P	?		**N**	**AEEK (HUN)**	ALLAMI EGESZSEGUGYI ELLATO KOZPONT	Hungary
		P	Y	D	**Y**	**ISS (ITA)**	ISTITUTO SUPERIORE DI SANITA	Italy
		P	Y	D	**Y**	**CDPC (LVA)**	SLIMIBU PROFILAKSES UN KONTROLES CENTRS	Latvia
		P	?	D	**?**	**RIVM (NLD)**	RIJKSINSTITUUT VOOR VOLKSGEZONDHEID EN MILIEU	Netherlands
Tricia.Larose@he	Tricia asked for a meeting on 9 or 1		Y		**?**	**HD (NOR)**	HELSEDIREKTORATET	Norway
				D	**?**	**DGS (PRT)**	MINISTERIO DA SAUDE - REPUBLICA PORTUGUESA	Portugal
		P	?	D	**?**	**INSP (ROU)**	INSTITUTUL NATIONAL DE SANATATE PUBLICA	Romania
		P	N		**N**	**NCZI (SVK)**	NARODNE CENTRUM ZDRAVOTNICKYCH INFORMACII	Slovakia
		P	?	D	**?**	**NIJZ (SVN)**	NACIONALNI INSTITUT ZA JAVNO ZDRAVJE	Slovenia
		P	Y		**Y**	**ISCIII (ESP)**	INSTITUTO DE SALUD CARLOS III	Spain
ppt in Nov 2021 covered Aragón region			Y	D	**-**	**IACS (ESP)**	INSTITUTO ARAGONES DE CIENCIAS DE LA SALUD	Spain
		L	Y	D	**Y**	**SU (GBR)**	SWANSEA UNIVERSITY	United Kingdom
		15			**5**	**CURRENTLY ENGAGED**		

Disclaimer

Disclaimer excluding Agency and Commission responsibility

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