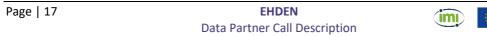


APPENDIX 1. APPLICATION FORM

Question	Hints/Options
Data Source Description	
Please state the exact name of the legal	
entity that would sign the grant agreement if	
your application is successful.	
Provide a brief description of the data source	Provide the data source introduction you would
(max 250 words)	normally use in a publication.
Provide links to max of 5 publications or	
publicly available links that describe the data	
source and demonstrate its use.	
From which country is the data originating?	
Describe the geographic coverage.	For example, a certain region or city
Is the data source containing patients with a	For example, Medicaid is a state and federal
specific socioeconomic status?	program that provides health coverage if you
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	have a very low income.
Is the data source containing patients from a	We refer here to all the patients in the data
specific health system (insured/uninsured,	source, e.g. a private insurance data source.
public vs. private)	
. ,	
What care setting(s) are covered?	Inpatient (hospital) care
	Outpatient general practitioner care
	Outpatient specialist care
	Long term/ skill nursing facility care
	Pharmacy care
	Other (free text)
What data capture process(es) are used?	Insurance/administrative claims
	Outpatient electronic health records
	Inpatient hospital electronic health records
	Inpatient hospital billing systems
	Registries
	Biobank
	Other (free text)
Specify the inclusion criteria for patients to	
enter the population, if any.	
When did the data collection start?	
Is there any lag in the data capture?	
What is the frequency of source data	
updates?	
Which of these age categories are included in	infants and toddlers (0 days to 23 months)
your data source?	• children (2 to 11 years)
,	adolescents (12 to 17 years)
	• 18 to 45 years
	• 46 to 65 years
	66 years and over





What is the gender of the data source	Male	
population?	Female	
	Both	
What is the approximate total (cumulative)		
number of subjects in your data source?		
What is the current approximate number of		
active patients?		
What is the average follow-up period per		
patient in years?		
Specify all data domains that are covered by	Person	
your source database.	Observation Period	
	Visit Occurrence	
	Visit Details Condition Convergence	
	Condition Occurrence Death	
	Drug Exposure	
	Procedure Occurrence	
	Device Exposure	
	Measurement	
	Observation	
	Specimen	
	Survey	
	Provider	
	Location	
	Care Site	
	Payer Plan Period	
	• Cost	
Door the data course contain for a tant?	If was	
Does the data source contain free text?	If yes: In what language is the free text?	
	Explain how you are using the free text in your	
	current studies.	
Are there any data domains not described		
above you like to include?		
Data Source Governance and Ethics		
Is your institute the data custodian?	Please explain if you are the "Owner" of the	
,	data source or acquired the data source from	
	another party, or simply have access to it	
Information about the Governance Board pro	 cedures for federated data analysis.	
including timeliness.		
Do you have an ethical committee /		
governance board?		
Do you have a publicly available document		
that details the procedure by which approval		
can be requested?		
Describe briefly the process of obtaining		
approval		
What is the average duration of the approval		
process?		
<u> </u>	1	

Page | 18

EHDEN

Data Partner Call Description

efpta

Which studies have to be registered to ENCePP?	
Are there any areas of use or research that have been explicitly barred by approval bodies or participants?	
	5 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
Are you allowed to use this data in	For example, mention if this is only allowed with
collaboration with external parties?	academics
Are you authorized to share aggregated	
analysis results for research purposes?	
Are you able to contact the health care	
provider to obtain additional information	
about the patient?	
Are you able to contact the patient to obtain	
additional information?	
Are you able to obtain biological samples	
from the patient?	
Are you able to gather additional information	
about the patients (for example,	
environmental data documenting the air	
pollution in the area where the patient lives)	
Technical Details	
What database management system is used	
for your data source?	
Are all your data currently co-located in one database?	
Do you have a document available that	If yes, can you share this document. If yes,
describes the database structure?	please upload the document.
	If no, please explain why not.
Which terminology systems are used in your	For example, ICD9, ICD10, local coding system
database?	etc.
Are you willing to share the Extraction	
Transform and Load Document for your data	
transformation with the EHDEN project?	

If possible, we like to obtain information about the structure of the source database using a profiling tool called <u>White Rabbit</u>. This tool will extract all the table names, their fields, and most frequent $values\ in\ the\ fields.\ Your\ data\ needs\ to\ be\ stored\ in\ a\ single\ relational\ database\ management\ system$ that is supported by the tool. If you need support send us an email: applicants@ehden.eu

Note that if you are not able to execute the tool or share its results, this will not by definition exclude your data source from the program. It would however be very useful for the committee to understand the complexity of your data source.

Are you able to execute the tool?	If not, please explain why
Are you able to share the results of the tool?	If not, please explain why. If yes, please upload.

Interest and ability to participate in distributed research

EHDEN will maintain a public database catalogue that contains contact information and meta data. This meta data consists of information like the governance procedure, but also aggregated data such

Page | 19 **EHDEN** efpia **Data Partner Call Description**



as total number of patients over time, cumulative patient time etc. We like to know what information		
you are able to share.		
Do you want to share contact information?		
Please specify what type of aggregated data		
can be shared.		
Do you intend to ask research questions and		
design network studies to generate evidence		
from the rest of the network? Please explain.		
Do you intend to use the OHDSI tools to		
conduct research locally?		
Do you plan to participate in network studies		
lead by others in the network?	DD 4.1.	
What type(s) of staff at your site are	DB Admins data managers	
commonly used to conduct database analyses	data managersinformaticians	
and would likely be involved in federated	statisticians	
research?	epidemiologists	
	clinical researchers	
	other (free text)	
	other (nee text)	
Are you already involved in the OHDSI		
community? If so, please describe how.		
, , , ,		
Activity selection		
Select the activity you are applying for.	For more details see the Call Description	
	Document	
	Create new Data Transformation and	
	Analytical Infrastructure	
	 Revise Existing Data Transformation and Analytical Infrastructure 	
	Inspect Completed Data Transformation	
	and Analytical Infrastructure	
	,	
For the last two options additional questions ar	e asked:	
Describe which tables have already been		
populated in your OMOP-CDM.		
Describe the status of the source code		
mapping for the domains you have		
populated.		
Explain how you like to revise or extend the		
existing data transformation.		
Do you have documentation of the current	If yes, can you share this document. If yes,	
data transformation?	please upload the document.	
	If no, please explain why not.	
	Which OHDSI tools and methods libraries are	
Describe the current status of the analytical		
Describe the current status of the analytical infrastructure.	currently used on your data?	
•		
infrastructure.	currently used on your data?	
infrastructure. Describe who implemented the Extraction,	currently used on your data?	

Page | 20

EHDEN

Data Partner Call Description

efpta



Describe who were the south for finencial	T
Describe why you want to apply for financial	
support.	
Signature	
Are you able and willing to go through the EHDEN application evaluation procedure,	
described in the call text?	
Declaration	Check box: i am fully authorized to submit this
	application on behalf of the data partner.
Do you confirm you agree with the Terms of	Check box: I agree
Service and Privacy Policy?	
Do you agree with the Terms of Service?	Check box: I agree
Can we add you to our newsletter so you will	
be notified of major milestones of EHDEN and	
future open calls.	
Signature	Fill in the full name of the applicant





