Why "dummy data"?

Important in the euCanSHare Data Catalogue are:

- **The study descriptions**. These are entered directly into Mica and provide information on the study population, study design, study size etc. (See <u>the tutorial "How to upload data to Mica"</u>)
- **The variable descriptions.** These describe the data variables available from the studies. The variables are described in data dictionary files which are uploaded to Opal, and linked to Mica, as described in <u>the tutorial "How to upload data to Opal"</u>.
- Annotation of the variables according to Maelstrom "Areas of Information" and additional euCanSHare taxonomies. These make it possible to search for variables in specified areas of interest, across the studies. The annotations of the variables are also entered into Opal as a part of the data dictionaries. The annotation process is described in <u>the tutorial "Annotation of variables in Opal"</u> (login required).

If individual level *real* data are available in Opal, these can be linked to Mica so that the Catalogue shows the distributions of the variables. However, linkage of the real data to a publicly accessible Mica can be interpreted as violating the General Data Protection Regulation (GDPR).

Although the distributions of the variables cannot be shown in the euCanSHare Catalogue, it is possible to show the amount and reasons of missing data of the variables. This can be done by replacing the real variables by <u>dummy variables</u>, which provide information on the availability and unavailability of the real data values, but not on the actual measured values. As these "dummy data" do not convey information on the characteristics of the individuals persons, they are not "personal data" in the sense of the GDPR.

Although the "dummy data" are not as important in the euCanSHare Catalogue as the study descriptions, "real" data dictionaries and the annotations of the variables, they are useful to those searching data for research.

This document describes how to create and upload the dummy data into Opal and Mica.

For the "dummy data" (i.e. showing the missingness / availability information by variable), one has to enter

- 1. dummy data dictionary (Excel file) and
- 2. individual level dummy data (csv file), to Opal
- 3. update the dataset description in Mica.

How to code the dummy data?

Each study can define the dummy data categories according to what is relevant for the study and what metadata are available. There must be at least two dummy data categories (Valid value, Missing), but missingness can also be divided into multiple categories. For example, for the MORGAM studies, the following coding is used for all dummy variables:

1 = Valid value

2 = Missing, but replaceable to valid (Note: this typically relates to skip rules in data collection questionnaires. Be careful with this because it may reveal real values of the filter variable.)

3 = Missing (not by design) (Note: This typically refers to data which are not missing on purpose.)

4 = Missing by design 5 = Not applicable

Figure 1 shows the "Categories" sheet of the data dictionary Excel file <u>based on real data</u> and how the dummy data codes are derived from the metadata. However, please note that items EAGE and STOP are continuous and hence only the missing data categories are listed here.

table	variable	name	missing	label:en	Missing values and 2
MORGAM	DEXAM	99999999	1	insufficient data	wissing values, code 5
MORGAM	EAGE	99	1	insufficient data	
MORGAM	MARIT	1	0	single	
MORGAM	MARIT	2	0	married or cohabiting	
MORGAM	MARIT	3	0	separated or divorced	Valid values, code 1
MORGAM	MARIT	4	0	widowed	
MORGAM	MARIT	5	0	other	
MORGAM	MARIT	9	1	insufficient data	Missing values, code 3
MORGAM	EDLEVEL	1	0	university or college or equivalent	, ,
MORGAM	EDLEVEL	2	0	intermediate between secondary lev	ela Valid values code 1
MORGAM	EDLEVEL	3	0	secondary school	Valia Values, code 1
MORGAM	EDLEVEL	4	0	primary school only (or less)	
MORGAM	EDLEVEL	9	1	insufficient data	
MORGAM	SCHOOL	99	1	insufficient data	
MORGAM	CIGS	1	0	yes, regularly	•
MORGAM	CIGS	2	0	no	etc
MORGAM	CIGS	3	0	occasionally	• • •
MORGAM	CIGS	9	1	insufficient data	
MORGAM	NUMCIGS	888	1	irrelevant if CIGS = 2	•
MORGAM	NUMCIGS	999	1	insufficient data	
MORGAM	DAYCIGS	1	0	usually on one day a week or less	
MORGAM	DAYCIGS	2	0	usually on 2 to 4 days a week	
MORGAM	DAYCIGS	3	0	almost every day	
MORGAM	DAYCIGS	8	1	irrelevant if CIGS = 1 or 2	
MORGAM	DAYCIGS	9	1	insufficient data	
MORGAM	EVERCIG	1	0	yes, regularly in the past, but not no	W
MORGAM	EVERCIG	2	0	no	- · · · · · · -
MORGAM	EVERCIG	8	1	Irrelevant if CIGS = 1	Not applicable, code 5
MORGAM	EVERCIG	9	1	insufficient data	Missing value, code3
MORGAM	STOP	8888	1	irrelevant if CIGS = 1 or EVERCIG =	2 Not applicable, code 5
MORGAM	STOP	9999	1	insufficient data	Missing value, code3
	Variables	Categorie	s (+)		

Figure 1: Data dictionary for the real data; "Categories" sheet in the data dictionary Excel file (i.e. the values and labels of the categories). Codes for dummy data, as defined for MORGAM studies, are marked to the right

Figure 2 shows the individual level dummy data after transformation according to the 5 categories of dummy codes (example taken from MORGAM studies). Please note that STOP (the year when smoking was stopped) takes value 5, i.e. not applicable, if the subject did not smoke. The data transformation here was done programmatically using R and saved as a csv file.

н	Ι	J	К	L	М	N	0	Р	Q	R
SEX	DEXAM	EAGE	MARIT	EDLEVEL	SCHOOL	CIGS	NUMCIGS	DAYCIGS	EVERCIG	STOP
1	1	1	1	1	1	1	2	5	1	1
1	1	1	1	1	1	1	1	3	5	5
1	1	1	1	1	1	1	2	5	1	1
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	1	3	5	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	1
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	1
1	1	1	1	1	1	1	2	5	1	5
1	1	1	1	1	1	1	2	5	1	1
4	4	4	4	4	4	4	0		4	-

Figure 2: Individual level dummy data (to be saved as a csv file), example taken from MORGAM studies.

How to create a dummy data dictionary?

Dummy data dictionary Excel file is created similarly as described in <u>the tutorial "How to upload</u> <u>data to Opal"</u>, with these exceptions:

- 1. Dummy data dictionary "table" column must be named differently from the real data dictionary (this name is given in both sheets; "Variables" and "Categories"),
- 2. "Variables" sheet should contain 6 columns (table, name, valueType, unit, label:en, description:en) those can be copied from the real data dictionary Excel file (column "script" is not needed). For dummy data dictionary:
 - column "table" should be renamed, e.g. "xxx_dummy",
 - all valueTypes should be "integer" (if the 0,1,2,... are used for dummy codes), and
 - units are not needed (can be left empty).
- 3. "Categories" sheet must:
 - include the dummy codes for each variable (also for continuous / date / etc. variables) and the category values and labels are same for each variable,
 - $\circ~$ column "table" should include the dummy table name, e.g. "xxx_dummy", and
 - column "missing" should be 0 for categories indicating valid and replaceable to valid values, and 1 for categories indicating missingness.

See figures 3 ("Variables" sheet) and 4 ("Categories" sheet) for details (examples taken from MORGAM studies).

table	name	valueType unit	description:en	label:en			
FINRISK2401_dummy	DEXAM	integer	"See the specific descriptio	Date of examination (day, mo	onth, year)		
FINRISK2401_dummy	EAGE	integer	"See the specific descriptio	Age on the date of examination	on		
FINRISK2401_dummy	MARIT	integer	"See the specific descriptio	Marital status			
FINRISK2401_dummy	EDLEVEL	integer	"See the specific descriptio	"What is the highest level of e	ducation	ou have co	mpleted?"
FINRISK2401_dummy	SCHOOL	integer	"See the specific descriptio	"How many years have you s	pent at sch	ool or in fu	ll time study?"
FINRISK2401_dummy	CIGS	integer	"See the specific descriptio	"Do you smoke cigarettes nov	v?"		
FINRISK2401_dummy	NUMCIGS	integer	"See the specific descriptio	"On average how many cigare	ettes do yo	u now smo	ke a day?" "
FINRISK2401_dummy	DAYCIGS	integer	"See the specific descriptio	"On how many days a week d	lo you smo	oke cigarette	es?"
FINRISK2401_dummy	EVERCIG	integer	"See the specific descriptio	"Did you ever smoke cigarette	es regularly	y in the past	:?"
FINRISK2401_dummy	STOP	integer	"See the specific descriptio	"When did you stop smoking	cigarettes	regularly?"	Record the year (f
Variables	Categories	(+)				4	1

Figure 3: Variables for the dummy data dictionary (example taken from MORGAM).

table	variable	name	missing	label:en	
FINRISK2401_dummy	DEXAM	1	0	Valid value	
FINRISK2401_dummy	DEXAM	2	0	Missing, but replaceable to valid	
FINRISK2401_dummy	DEXAM	3	1	Missing (not by design)	
FINRISK2401_dummy	DEXAM	4	1	Missing by design	
FINRISK2401_dummy	DEXAM	5	1	Not applicable	
FINRISK2401_dummy	EAGE	1	0	Valid value	
FINRISK2401_dummy	EAGE	2	0	Missing, but replaceable to valid	
FINRISK2401_dummy	EAGE	3	1	Missing (not by design)	
FINRISK2401_dummy	EAGE	4	1	Missing by design	
FINRISK2401_dummy	EAGE	5	1	Not applicable	
FINRISK2401_dummy	MARIT	1	0	Valid value	
FINRISK2401_dummy	MARIT	2	0	Missing, but replaceable to valid	
FINRISK2401_dummy	MARIT	3	1	Missing (not by design)	
FINRISK2401_dummy	MARIT	4	1	Missing by design	
FINRISK2401_dummy	MARIT	5	1	Not applicable	
FINRISK2401_dummy	EDLEVEL	1	0	Valid value	
FINRISK2401_dummy	EDLEVEL	2	0	Missing, but replaceable to valio	
FINRISK2401_dummy	EDLEVEL	3	1	Missing (not by design)	
FINRISK2401_dummy	EDLEVEL	4	1	Missing by design	
FINRISK2401_dummy	EDLEVEL	5	1	Not applicable	
FINRISK2401_dummy	SCHOOL	1	0	Valid value	
 ♦ Variable 	s Catego	ories	+	<u></u>	

Figure 4: Categories for the dummy data dictionary (example taken from MORGAM).

The dummy data dictionary Excel file is uploaded to Opal as given in <u>the tutorial "How to upload</u> <u>data to Opal"</u> (the same project folder for real data dictionary can be used, when the table names are not the same).

How to import the individual level dummy data to Opal?

The individual level dummy data (csv file) is imported into Opal similarly as given in <u>the tutorial</u> <u>"How to upload data to Opal"</u> in the section "Raw file". Note that in the tutorial the example data file contains the real data values for individual level data, but using the real data in linking to Mica can be interpreted as violating the GDPR.

"Destination table" for the individual level dummy data ("raw data") should be the dummy dictionary table.

Linking a dummy Opal data table to a dataset in Mica

To show the dummy data summary statistics in the variable description pages of the catalogue, the dummy data table should be added to the Mica dataset. The dummy data table uploaded to Opal is linked to the Mica dataset by ticking the box "*This dataset is linked to a dummy table*", and adding the name of the project and table exactly as given in Opal - see figure 5 below. After saving, remember also move the dataset description "to under review" and click "publish".

Μ	lica Studies	Administration	Catalogue	Help
C	Collected Datasets / brianza0101			
•	Edit			
≡ 0	General Information			
	ame Brianza MONICA Cohort 01 Baseline MORGAM data			
A	cronym			
	Brianza0101_MORGAM			
D	escription			
E	ntity Type			
	Participant			
	This dataset is linked to a dummy table			
ſ	Brianza			
D	ummy Table			
	Brianza0101_dummy			
	Brianza0101_dummy Add a comment to describe the enanges.			

Figure 5: Link a dummy table to the Mica dataset.

Once a dummy table is linked to the Mica dataset and is published, the summary statistics for the variables in the dataset would be displayed as in figure 6 below. The top part, marked in red, displays the real data categories, while the section 'Summary statistics' (marked in blue) displays the summary according to the dummy data categorisation.

CIGS									
"Do you smoke	cigarettes now?	7"							
() "See the spe	cific description	of the variable i	n the MORGAM we	bsite.					
-		-							
Overview					Definitio	n			
Value type	Intege	er			Dataset		Friuli0101_N	IORGAM	
Nature	Categ	porical			Study		Friuli		
Entity type	Partic	lipant			Populati	on	Friuli MONICA St	udy Cohort 01	
Categories					Data Col	lection Event	Friuli MONICA St	udy Cohort 01 R	ound 01
Name	Label		Missing						
1	yes, regularly								
2	no			_					
3	occasionally								
0	insufficient da	ta	×	- 14	• Real	data dict	tionary		
Add to cart 📜									
Annotations									
Source	Quest	tionnaire							
Target	Target Participant								
Lifestyle and	Tobac	000							
behaviours									
Find similar var	tables Q								
Summary Stat	tistics								
N	1.880								
N with values	1,87	7							
N missings	3								
Frequencies								1 🗾 3	
Value	11	Frequency	% with 11 values	% missinas	11 11	11 Missing			
1 Valid value		1,877	100		00.84				
2 Missing, but re	placeable to	0	0		0				
valid									
3 Missing (not b)	y design)	3		100	0.16	~			
4 Missing by des	lign	0		0	0	~			
5 Not applicable		0		0	0	~			
N/A Empty values		0		0	0	~			

Figure 6: Summary statistics, with real categories marked in red, and dummy categories marked in blue.