EUROPE BIOBANK WEEK 2020

17 – 20 November | Virtual Conference

BIOBANKING FOR GLOBAL CHALLENGES

the new Lifelines dataplatform

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OUR MISSION

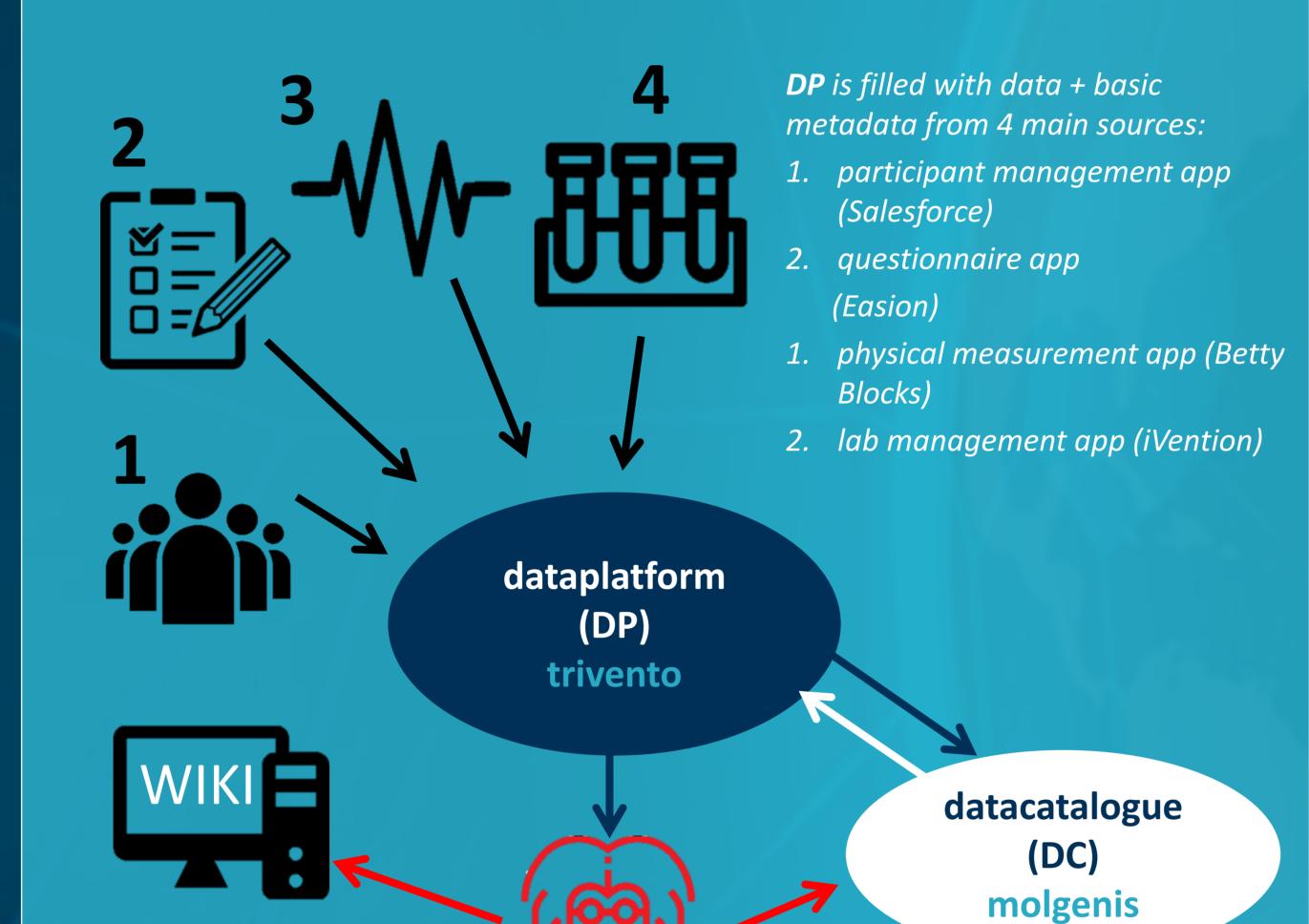
- Lifelines Cohort Study and Biobank collects longitudinal DATA and SAMPLES from >167,000 inhabitants of the northern Netherlands (including children and elderly)
- our mission is to make our rapidly expanding collection available for all researchers working in the field of HEALTHY AGEING
- our OPEN PROTOCOL allows
 researchers to collect additional
 data and samples from
 participants, to gain knowledge
 of healthy ageing

LINKS

https://data-catalogue.lifelines.nl

http://wiki-lifelines.web.rug.nl

OUR INFRASTRUCTURE



DC is filled with metadata from DP

• WHAT: list of variables

WHO: list of participant-s

WHEN: list of assessments

WHO x WHEN crosstable

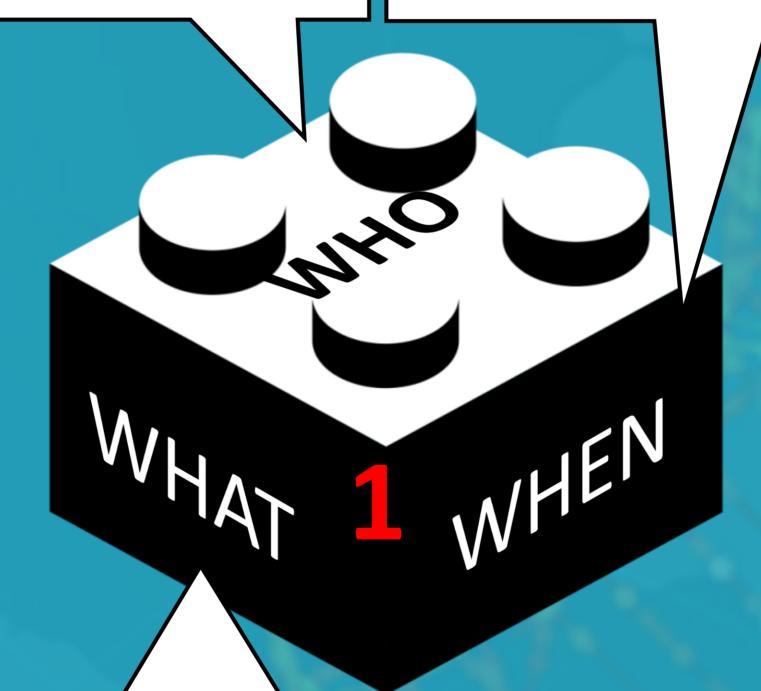
• WHEN x WHAT crosstable

researcher:

- -> prepares project using the WIKI
- -> selects a set of variables
- (using the WHO / WHEN filters)
 -> order is submitted from DC to DP
- -> DP automatically generates tables
- -> tables are released in the workspace

OUR DATA MODEL

participant-ID: 123456 Sex: female DOB: 01-01-1991 subcohort: UGLI, DAG3 date: 11-12-2013
 assessment: 2A
element: questionnaire 1
variant: 18-64y/digi/v2



THE "WHEN" DIMENSION

ASSESSMENT:

data/sample collection (project) with a common goal

ELEMENT:

part of an assessment taking place on 1 day/date

- > 1 visit
- > 1 questionnaire

VARIANT:

part of an element with a highly standardized protocol

- > 1 set of selection criteria
- > 1 set of variables
- > 1 method

assessment a element 1 variant 1 variant 1 variant 2 variant 2 variant 3 variant 3

assessment b

variant 4

variant 4

element 1

variant 1

variant 2

variant 2

variant 3

variant 3

variant 4

variant 4

(FAIR) AIM 1

to provide researchers in advance with a **COMPLETE OVERVIEW** of:

- our available participants/subcohorts
- our available assessments
- our available variables
- the number of participants per subcohort x assessment x variable
- our (rationale for certain) protocols

(FAIR) AIM 2

to practice **DATA MINIMALIZATION** by:

- building datasets that are customized ondemand
- helping researchers to filter out participants or subcohorts (by profile) and/or assessments
- allowing researchers to select individual variables (not fixed sets)

(FAIR) AIM 3

to STRUCTURE our datasets to facilitate analyses, including info about:

- missing vs. not collected data
- responders vs. non-responders
- "hidden" protocol changes
- basic (must-have) metadata for each participant & variable
- protocol description for each variant

(FAIR) AIM 4

to RAPIDLY INCORPORATE incoming data collections, including:

- regular data from our 4 main sources
- linked data from other registries
 (e.g. via postal codes)
- secondary (coded, sum-scored) data
- cleaned & qc'd datasets
- data from new sources, e.g. apps

SUPPORT

Lifelines is supported by:

UMC Groningen
Groningen University
Dutch Ministries of Health, Welfare &
Sports / Economic Affairs

3 Northern Provinces: Drenthe, Friesland and Groningen

Molgenis is supported by:

EUCAN-connect (H2020-824989)

EOSC-life (H2020-824087)

7G-07

2024407