

#### **SWEDISH RESEARCH COUNCIL**

The Register Utilisation Tool

A Practical implementation of GSIM as support in register-based research

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#### Register based research

- Sweden has many government registers, biobanks, health registers containing population based data.
- Data has been collected for decades and the registers are a valuable research resource.
- Time spent to grasp the meaning of the register variables and to communicate with the register owners before disclosure can sometimes add up to two years.

# Swedish research Council Government Comission

Improve the conditions to use register data in research by:

- Establishment of a Register Data Board
- II) Provision of information, advisory and education functions for register-based research
- III) Improved access to registers for research purposes via the coordination of data delivery

### Challenges for the researcher

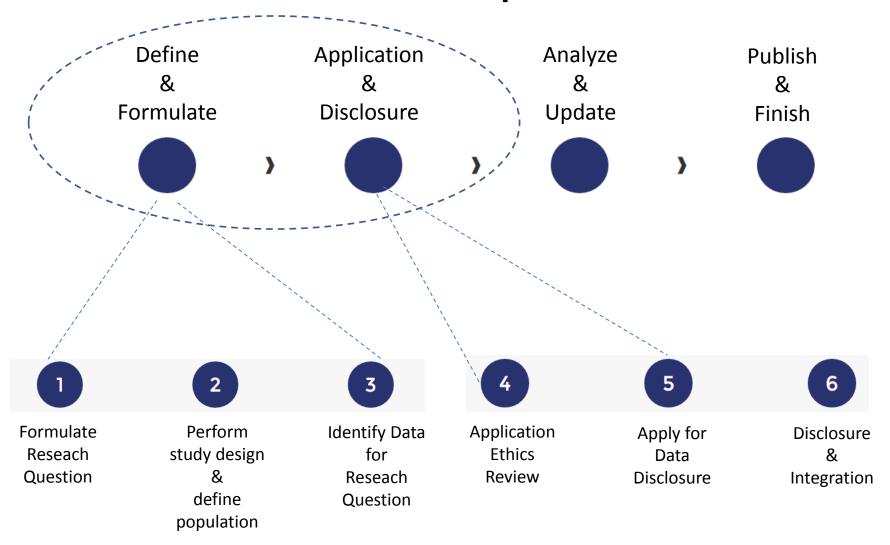
Before starting a register based research project you might need an answer to some questions:

- Can register data be used to answer my research question?
- What data are there?
- What registers holds the appropriate data?
- What do the register variables mean?
- Are the meaning similar enough between registers?
- Can data from the registers be linked?

### Register Utiliser Tool

- Decreases the researchers "Time-To-Data"
  - time spent to grasp the meaning and representation of the register variables
  - time spent evaluating variables
  - time spent to communicate with the register owners before disclosure

# RUT in the register-based research process

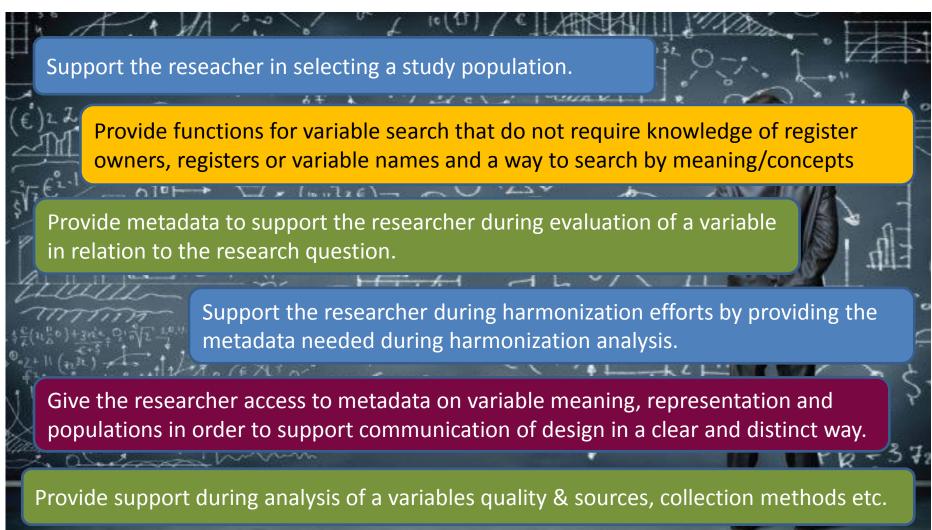


#### **REQUIREMENTS**

### Prerequisite

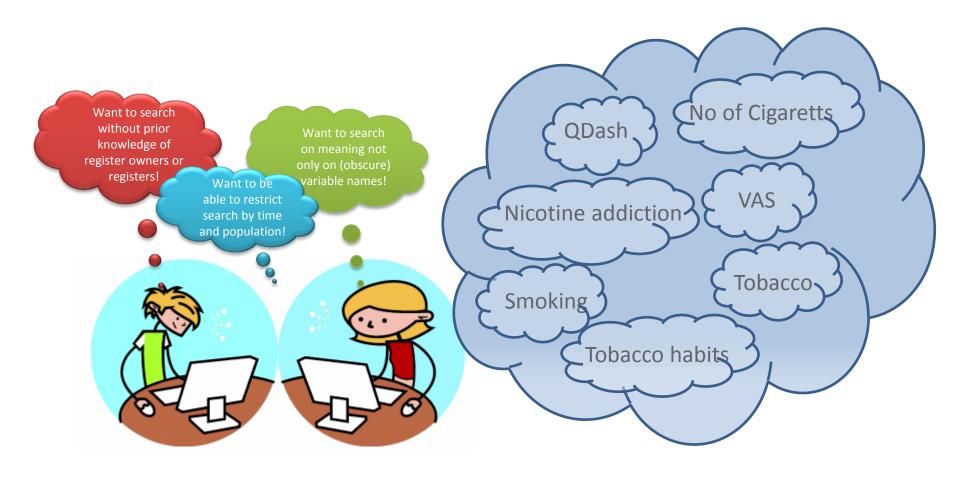
The separation of metadata and data because of legal constraints.

# High-level Functional Requirements



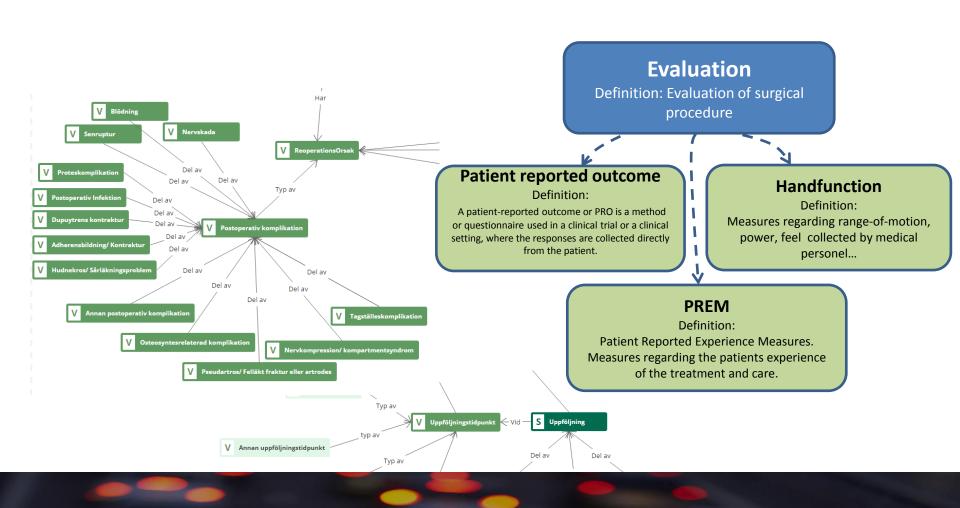
#### Search

- Without previos knowledge



#### Search

Through Concepts/ConceptSystems



#### ...to variables

#### **Patient reported outcome**

Definition:

A patient-reported outcome or PRO is a method or questionnaire used in a clinical trial or a clinical setting, where the responses are collected directly from the patient.

#### **Function Household Duties**

Definition:

Ability to perform heavy household duties such as laundry, washing floors, cleaning windows

#### **PREM**

Definition:

Patient Reported Experience Measures.

Measures regarding the patients experience
of the treatment and care.

#### **Experience of treatment in clinic**

Definition:

Patient Reported Experience Measures.

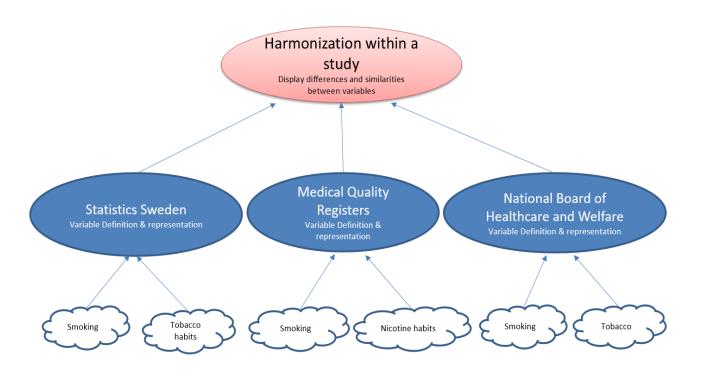
Measures regarding the patients experience of the treatment and care.

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VAS\_10

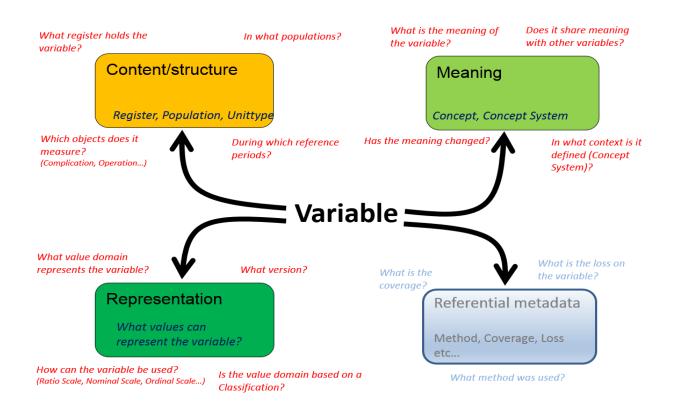
#### Harmonization Efforts

- Display differences & Similarities



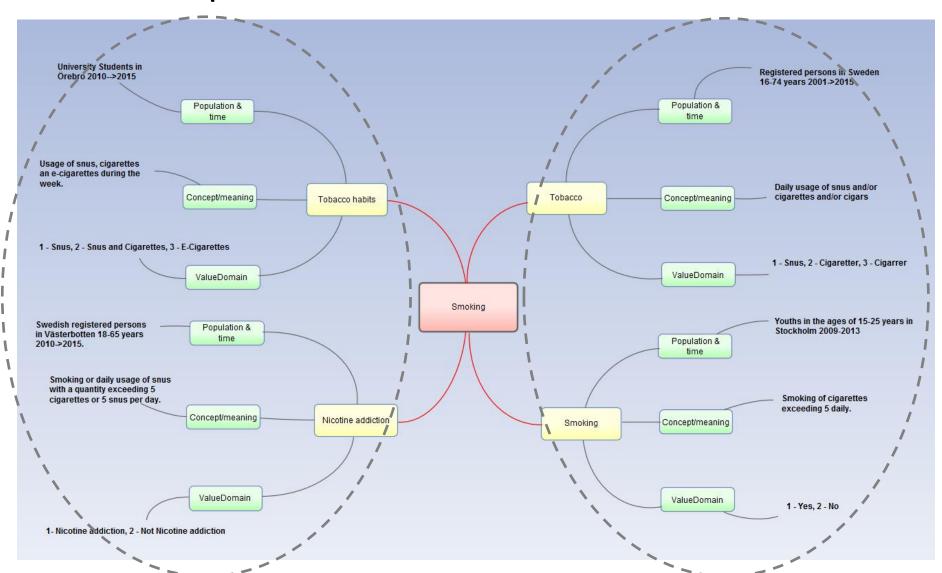
#### Harmonization Efforts

Perspectives on Differences & Similarities



#### Harmonization Efforts

Perspectives on Differences & Similarities



#### **EVALUATION**

#### **Evaluation**

- in relation to the project requirements

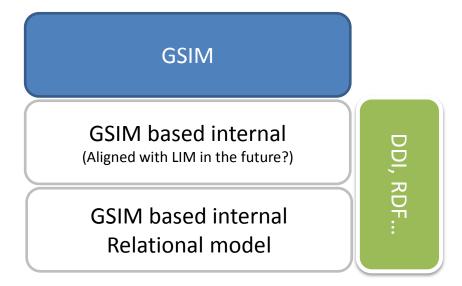
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GSIM
Neuchatel
ISO11179
DWB
DDI
SDMX
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#### **SELECTION**

### Conceptual standardized framework -The choice of GSIM

- Separation of meaning from representation.
  - Provides a foundation for implementing search by variable meaning.
  - Enables the conceptual support that the researchers need during evaluation of a variable and harmonization efforts (same meaning different names and vice versa).
- Enabling comparison of variables and parts of variables.
  - Comparing parts of a variable during evaluation and harmonisation efforts.
- Strong support for administration of valuedomains/codelists/classification.
  - During evaluation of a variable and harmonisation efforts.
- Large degree of Business Domain independence
  - The register holders that provide the metadata come from a wide variety of business domains.
- Common language when communicating researchers metadata needs with register owners.
  - Model based and on conceptual level.
- Providing a structure to incorporate referential metadata.
  - Quality, sources and collection methods etc. For Collection Cycles, Populations, Variables etc.

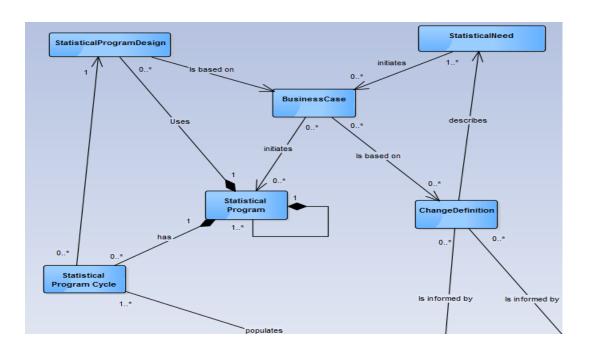
### Logical, Physical & Exchange



#### **GSIM Selection**

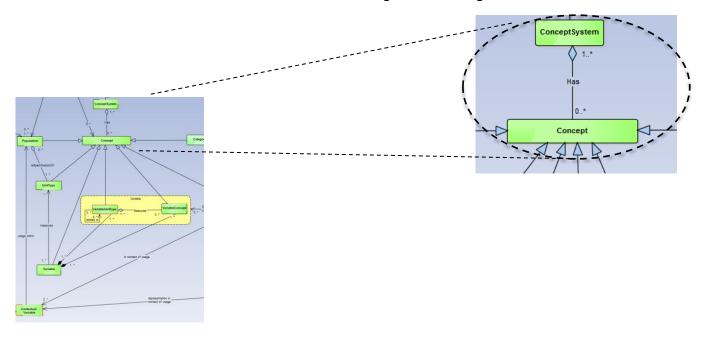
Mainly GSIM Concepts Group, some addition from the Business Group.

# Objects regarding register, variants and change



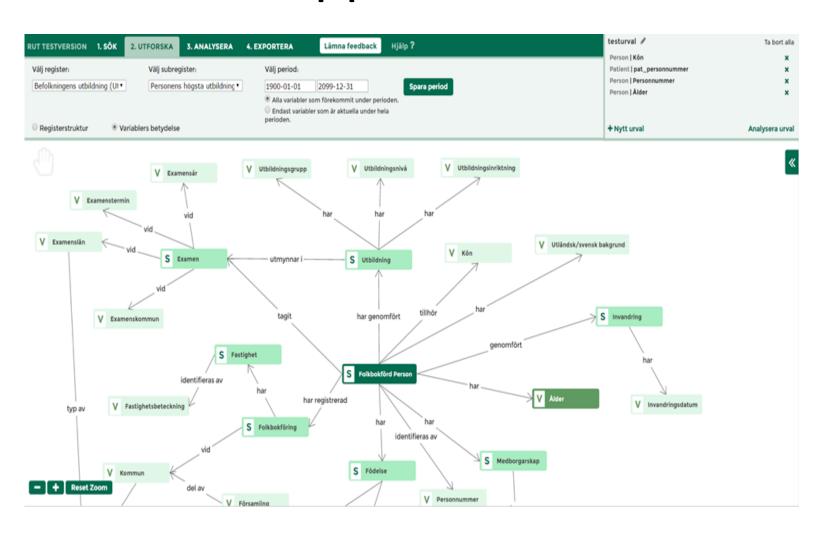
We added an association between "Statistical Program Cycle" and "Population" in order to express our usage of the Information Objects more clearly.

#### **Concept System**

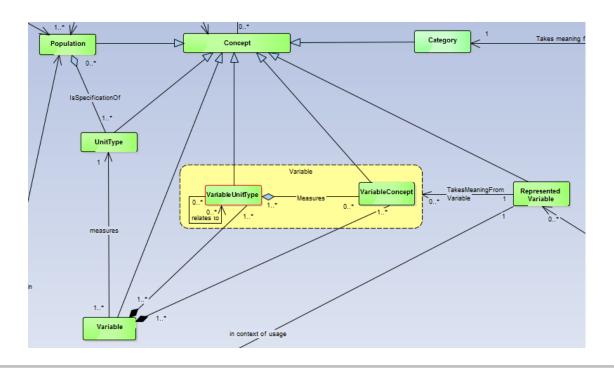


Gives the register holder an opportunity to present different perspectives of its Concepts in order to give the researcher an understanding of the intended meaning. Supports search and harmonisation efforts.

## Presenting a Concept System in the application

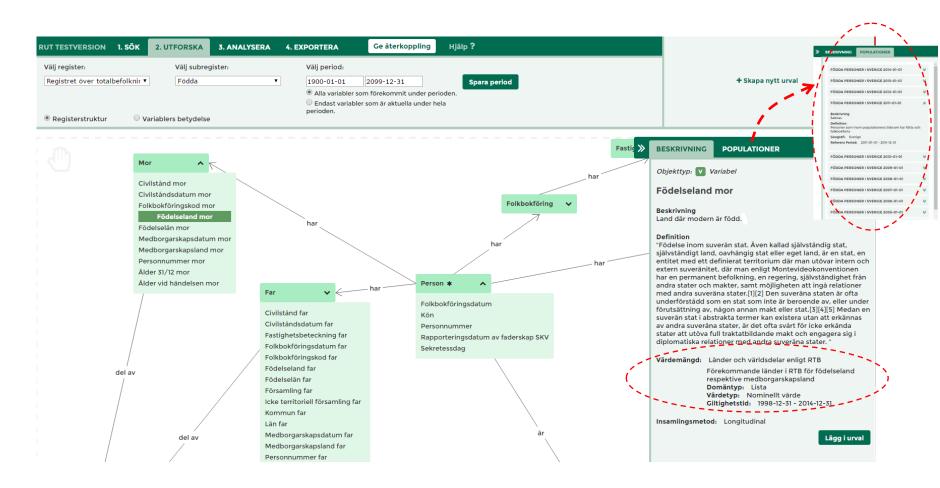


## Concept specializations (Population, Unit Type, Variable)



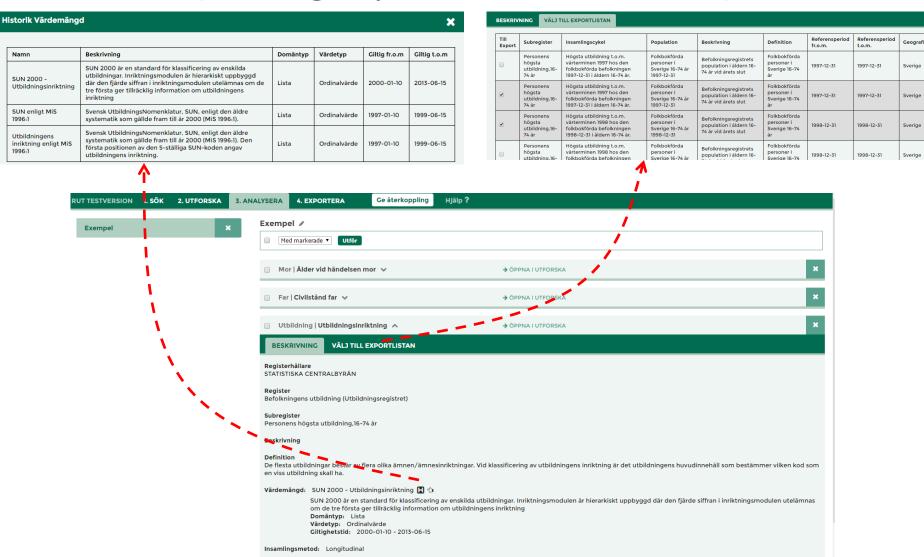
Variable in detail. We wanted to provide more detail to the GSIM variable to be able to visualize the variable as two parts, the "Variable UnitType" and the "Variable Concept", e.g. Father [Variable UnitType] + Income [Variable Concept].

### Presenting variables in the application



We then get the opportunity to provide a visualization of the logical grouping of Variable Concepts within Variable UnitTypes.

## Evaluating & selection variables (Adding representation & time)



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