# New concept proposal

# Death

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| **Project** | General interest | **Contact** | DCC |
| **Dataset release** | 2024.1 | **Consulted expert** | - |

## 1 Rationale

Currently, the information that a patient has died can be represented in two different and independent data concepts: *Death Status* and *Death Date,* which are not connected. Further the death status has only 1 value in the value set which is death. This poses the risk of false results when querying for the number of patients who died in a given time period. In addition, it is necessary to represent further metadata related to death, such as the cause of death. The new *Death* concept provides the possibility to link all death-related information and adheres to the guiding principle of concept design “a meaning defined only once”.

## 2 Comparison to other standards/data models

### 2.1 UMLS

In UMLS, there are two definitions available for *cause of death* with the UMLS Concept Unique Identifier (CUI) C0007465:

Factors which produce cessation of all vital bodily functions. They can be analyzed from an epidemiologic viewpoint. **(MSH)**

The circumstance or condition that results in the death of a living being. **(NCI)**

### 2.2 HL7 FHIR

Death reporting via FHIR is a topic in the US, see https://hl7.org/fhir/us/vrdr/2019May/. LOINC as well as SNOMED CT Codes are used to express related information, e.g. SNOMED CT code 308646001 |Death certification (procedure)|.

## 2.3 OMOP

There is a DEATH table in OMOP linked to PERSON but no such element as death status (living patients should simply not contain any information in the DEATH table).

## 2.4 OpenEHR

There is an archetype *cause of death* defined in the OpenEHR Knowledge manager, which refers to direct cause (The disease, condition or injury that directly led to, or occurred closest to, the time of death.) and cause (Identification of an antecedent disease, condition or injury that directly contributed to the 'Direct cause'.)

Source: https://ckm.openehr.org/ckm/archetypes/1013.1.5606

## 3 Concept information

| Concept or concept compositions or inherited | General concept name | General description | Contextualized concept name | Contextualized description | Type | Standard | Value set or subset | Meaning binding | Cardinality for composedOf |
|---|---|---|---|---|---|---|---|---|---|
| **concept** | Death | cessation of all vital bodily functions | Death | cessation of all vital bodily functions | | | | SNOMED CT: 419620001 \|Death (event)\| | |
| **composedOf** | report datetime | datetime the concept was reported | report datetime | datetime death was reported | | | | | 0:1 |
| **composedOf** | date | date of death | death date | date of death | Death Date | | | | 0:1 |
| **composedOf** | circumstance code | coded information specifying the circumstance associated to the concept | death circumstance | circumstance that led to death, e.g. death by fire | Code | SNOMED CT, ICD 10 | for SNOMED CT : descendant of: 419620001 \|Death (event)\| | | 0:1 |

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|---|---|---|---|---|---|---|---|---|---|
| **composedOf** | condition code | coded information specifying the condition associated to the concept | death condition | condition that led to death, e.g. myocardial infarction | Code | SNOMED CT, ICD 10 | for SNOMED CT: descendant of: 64572001 \|Disease (disorder)\| | | 0:1 |

| General concept name | Cardinality for concept to Administrative Case | Cardinality for concept to Data Provider Institute | Cardinality for concept to Subject Pseudo Identifier | Cardinality for concept to Source System |
|---|---|---|---|---|
| Death | 0:1 | 1:1 | 1:1 | 1:1 |

## 4 Impact on the SPHN Dataset

The *Death Status* concept needs to be deprecated.

## 5 Discussion

An alternative design has been discussed allowing the separation between direct and indirect cause of death. However, it appeared that the two layers of information, 1. direct, indirect; 2. circumstance, condition would result in a design forcing the decision if a circumstance or condition is direct or indirect. As this information is not always available the alternative design has been discarded.

## 6 Example

Death example 1:
- report datetime: 13.01.2022
- death datetime (Death Date)
  - Year: 2021
  - Month: 06
  - Day: 05
  - Time: 23:11
- circumstance code: 287192004 |Suicide - drowning (event)|
- condition code: -

Death example 2
- report datetime: 13.01.2022
- death datetime (Death Date)
  - Year: 2021
  - Month: 06
  - Day: 05
  - Time: 23:11
- circumstance code: -
- condition code: 22298006 |Myocardial infarction (disorder)|