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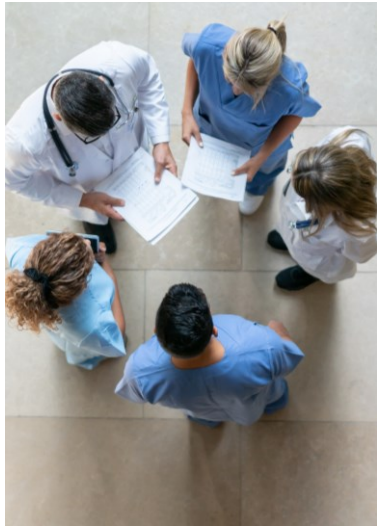
openEHR

Nordic openEHR Collaboration

PDL implementation guide- aggregated information from care processes in openEHR



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- Background – PDL implementation guide, aggregated information from care processes
  - The legislation has recurring wording regarding access, where the swedish terms for "care unit or within care process" is used to express allowance/restriction of access.
  - The PDL implementation guide has so far clarified the relationship between openEHR and the terms careunit (vårdenhet) and careprovider (vårdgivare), this work track aims to clarify the relationship and use of the swedish term for care process within openEHR

- Objective – better (legal) support for care personnel to relevant care process data
  - What health issues the patient are facing at the moment
  - What health issues they have had in the past
  - How health issues can be updated over time
  - How to split up a health issue, which turned out to be multiple health issues
  - How to merge multiple health issues, which turned out to be the same health issue

- Workspace: https://openehr.atlassian.net/wiki/spaces/healthmod/pages/1975287809

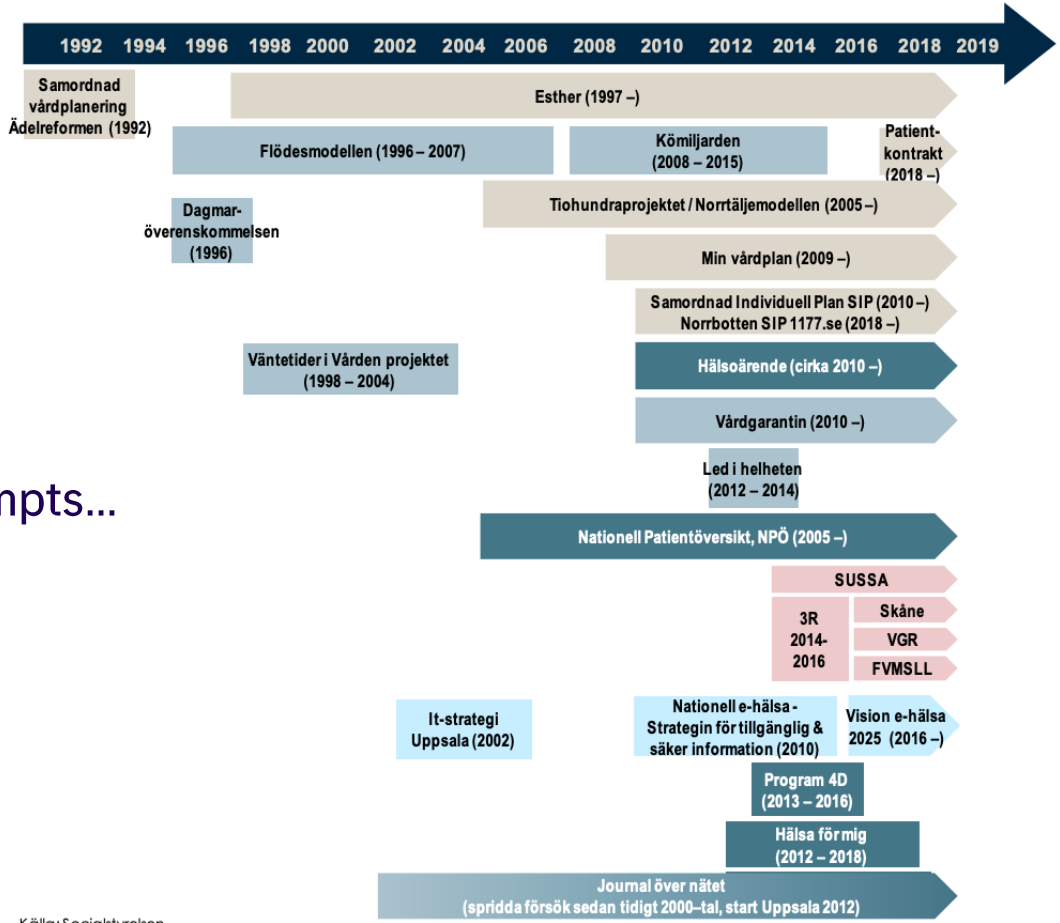
- Background: Since 2012, the Swedish Social board (Socialstyrelsen) has worked on being able to follow the patient's path through care using a process ID:
  - Described an identifier that can be introduced to mark different care events with the same process ID, in order to connect these events in a patient's individualized care process
  - Since a patient can have several different care processes at the same time with several care providers, there is a need to be able to identify these individually

- Social board research within health accessibility showed need for:
  - Easily accessible overview of the patient's various care processes
  - Structured overview of various events in care across care provider boundaries
  - Selection of information based on the patient's current state of health at a given time.
  - The healthcare professionals experience the current situation as "coming into the middle of a book and trying to understand what happened"

Main references:

- Patient data law https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientdatalag-2008355_sfs-2008-355
- Social board: Regulations on journaling and processing of personal data https://www.socialstyrelsen.se/kunskapsstod-och-regler/regler-och-riktlinjer/foreskrifter-och-allmanna-rad/konsoliderade-foreskrifter/201640-om-journalforing-och-behandling-av-personuppgifter-i-halso--och-sjukvarden/
- Social board: Health issue and process id: Prerequisites for coherent care and social care documentation within individualized care processes https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2015-2-2.pdf
- Social board: To be able to follow the patient's path through care: Ways to connect care events in the patient's care process https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-2-10.pdf
- e-health authority (E-hälsomyndighetens) codes for chief complaints https://ngs.ehalsomyndigheten.se/specifikation/soskodverk/sokorsak
- Regulations for interoperability within healthcare (RIVTA). Authorization model for care and social care: https://rivta.se/documents/ARK_0062/

Previous attempts...



Källa: Socialstyrelsen.

Method – online work meetings with a common documentation area

- Step 0: Determine scope, examination of references and relevant sources
- **Step 1: Minimal information to manage aggregated information from care processes**
- Step 2: Extend minimal set with purposeful information (if suitable found)
- Step 3: Management of health processes over time, from SnomedCT chief complaint (patient's description) to a health issue and coded contact reason (professional description), managing hierarchies and being able to split/merge health processes

… a lot of discussions on terminology, conceptual- and information models!

- Starting point - the Swedish main reference material from legislation, Social board, eHealth authority and national standardisation organisation Inera.
- We have asked follow-up questions about the reports and models available from the Social board
- Further clarification of process-support in national service interoperability standard

The patient data law and use of the concepts of care unit and care process.

Patientens möjlighet att begränsa elektronisk åtkomst för vårdsyfte

4 § Personuppgifter som dokumenterats för ändamål som anges i 2 kap. 4 § första stycket 1 och 2 hos **en vårdenhet eller inom en vårdprocess** får inte göras tillgängliga genom elektronisk åtkomst för den som arbetar vid **en annan vårdenhet eller inom en annan vårdprocess** hos samma vårdgivare, om patienten motsätter sig det. I sådana fall ska uppgiften genast spärras.

Vårdnadshavare till ett barn har dock inte rätt att spärra barnets uppgifter.

Uppgift om att det finns spärrade uppgifter får vara tillgänglig **för andra vårdenheter eller vårdprocesser**.

5 § En spärr enligt 4 § första stycket får hävas av en behörig befattningshavare hos vårdgivaren, om

1. patienten samtycker till det, eller
2. patientens samtycke inte kan inhämtas och informationen kan antas ha betydelse för den vård som patienten oundgängligen behöver.

Uppgift om **vårdenheter eller vårdprocesser** som spärrat uppgifterna ska i det fall som avses i 2 göras tillgängliga. Därefter får bara sådana uppgifter som kan antas ha betydelse för vården av patienten göras tillgängliga.

Källa: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientdatalag-2008355_sfs-2008-355

The patient data law and use of the concepts of care unit and care process.

(don't hang me for the translation ☺)

From chapter 4 – section The patient's ability to limit electronic access for care purposes

§ 4 Personal data documented for purposes specified in chapter 2, Section 4 first paragraph 1 and 2 at a **care unit or within a care process** may not be made available through electronic access to the person who works at another **care unit or within another care process** with the same care provider, if the patient opposes it. In such cases, the data must be blocked immediately.

However, guardians of a child do not have the right to block the child's information.

Information that there are blocked data may be available to other **care units or care processes**.

§ 5 A block according to § 4, first paragraph, may be lifted by a authorized executive at the healthcare provider, if

1. the patient consents to it, or
2. the patient's consent cannot be obtained and the information can be assumed to be important for the care that the patient inevitably needs.

In the case referred to in 2, information about care units or care processes that posses the blocked data must be made available. After that, only information that can be assumed to be important for the care of the patient may be made available.

source: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientdatalag-2008355_sfs-2008-355

So what is the role of the Swedish Social board?

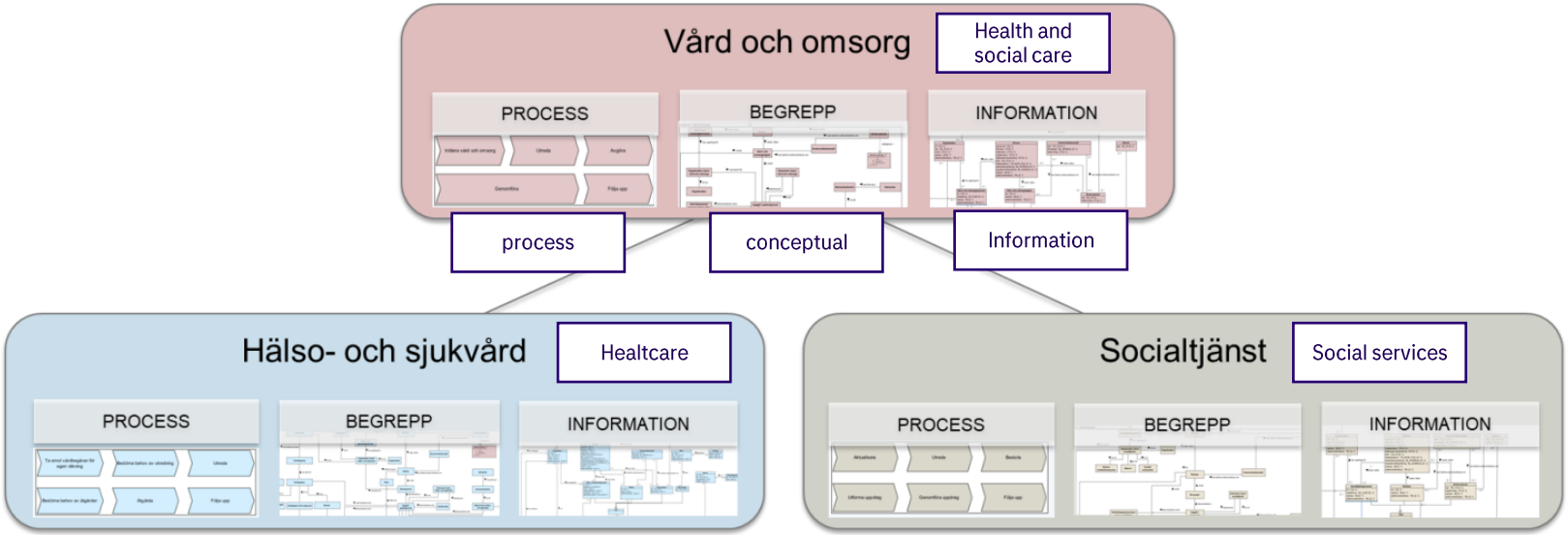
- Nationell informationsstruktur
- Snomed CT
- Hälsorelaterade klassifikationer
- Socialstyrelsens termbank

} Nationellt fackspråk

Instruction to the National Board of Health and Welfare Ordinance (2015:284)

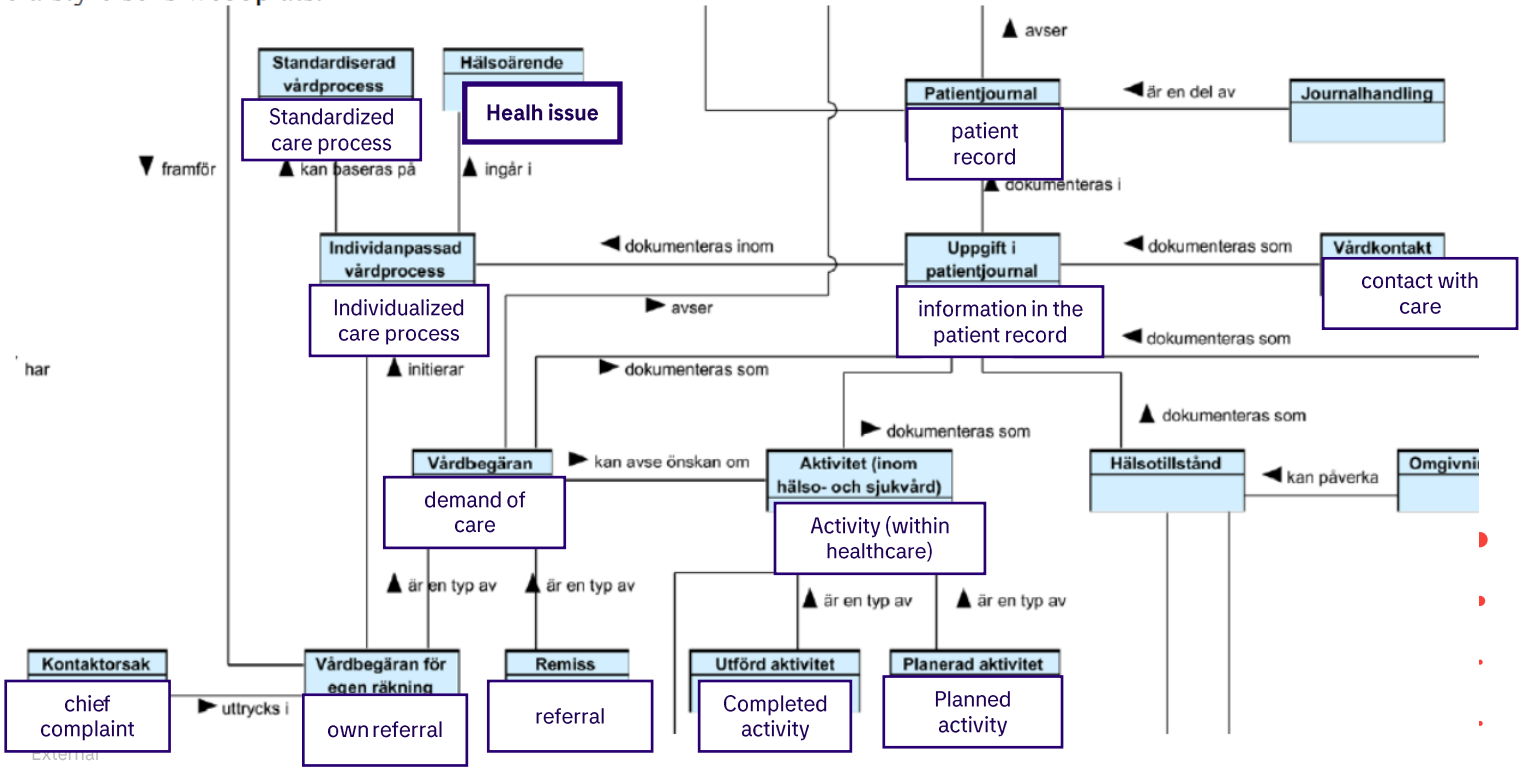
- create and provide uniform concepts, terms and classifications
- create, describe and provide an appropriate information structure

National Information structure - NI

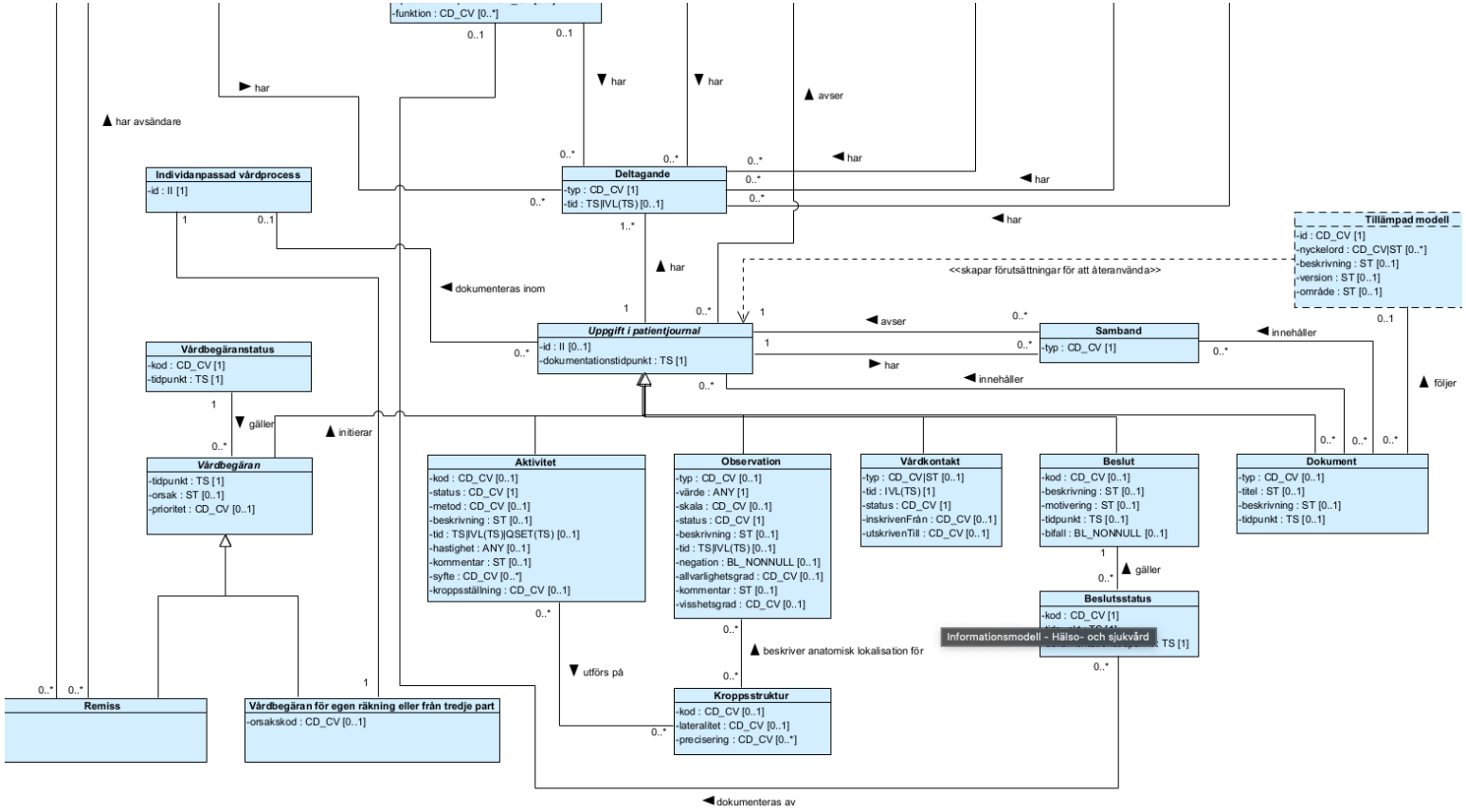


Ref. Social board – Health issue(Hälsoärende) and process id: Prerequisites for coherent care and social care documentation within individualized care processes

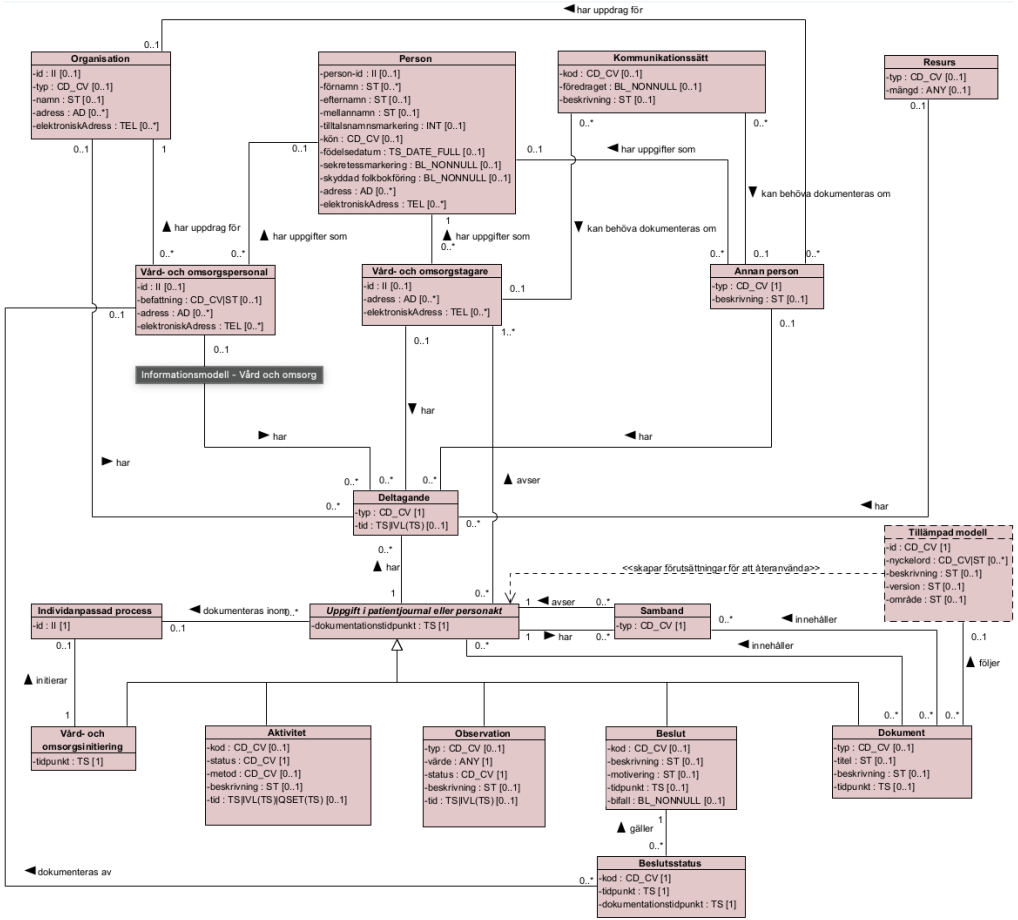
Figur 7: Utsnitt ur NI:s begreppsmodell för hälso- och sjukvård. Begreppsmodellen presenteras högupplöst på Socialstyrelsens webbplats.



Ref. Social board National Information model rev 2022 with health issue (hälsoärende) removed



Referens NI: informationsmodell vård och omsorg 2022

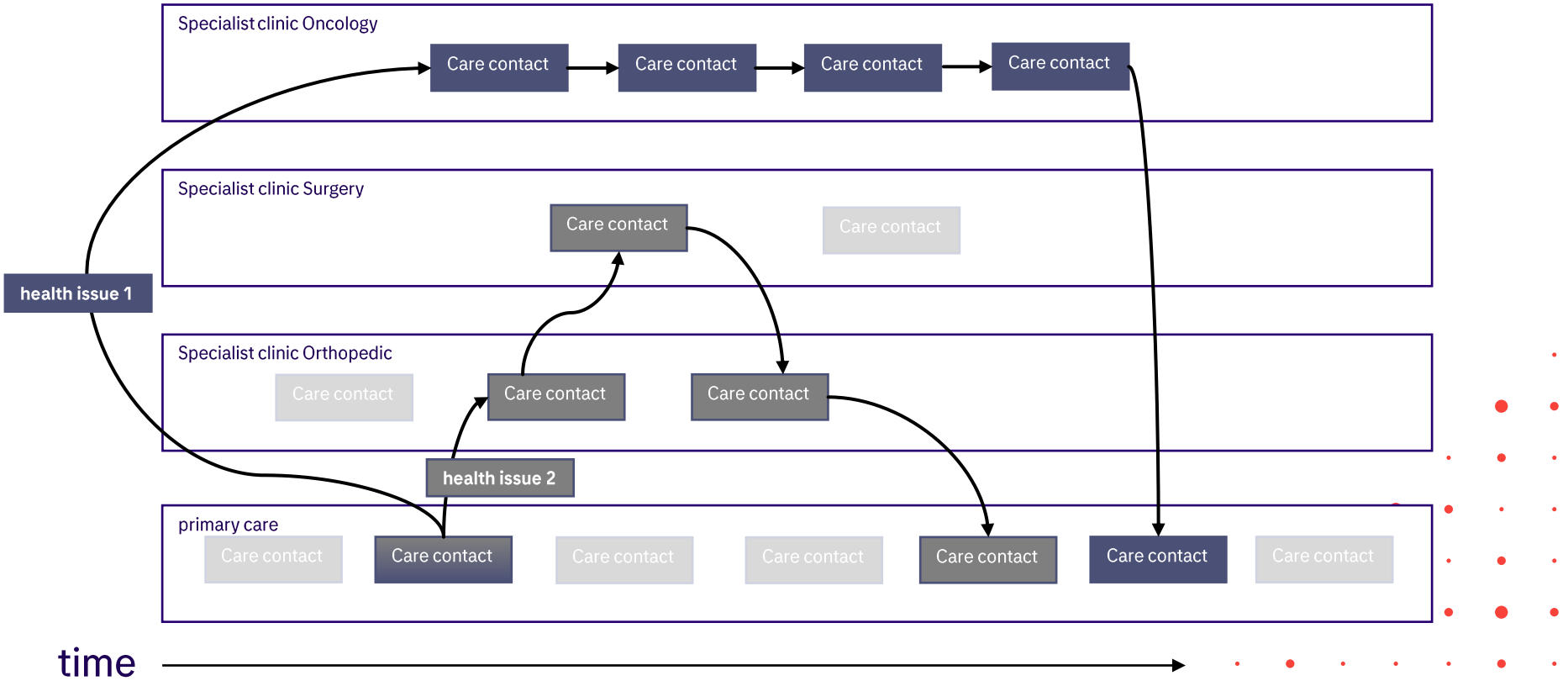


What happened to the concept of health issue (hälsoärende)? In later versions of the national models, the concept/term is removed. We asked the Social board what has happened with this term and got the response:

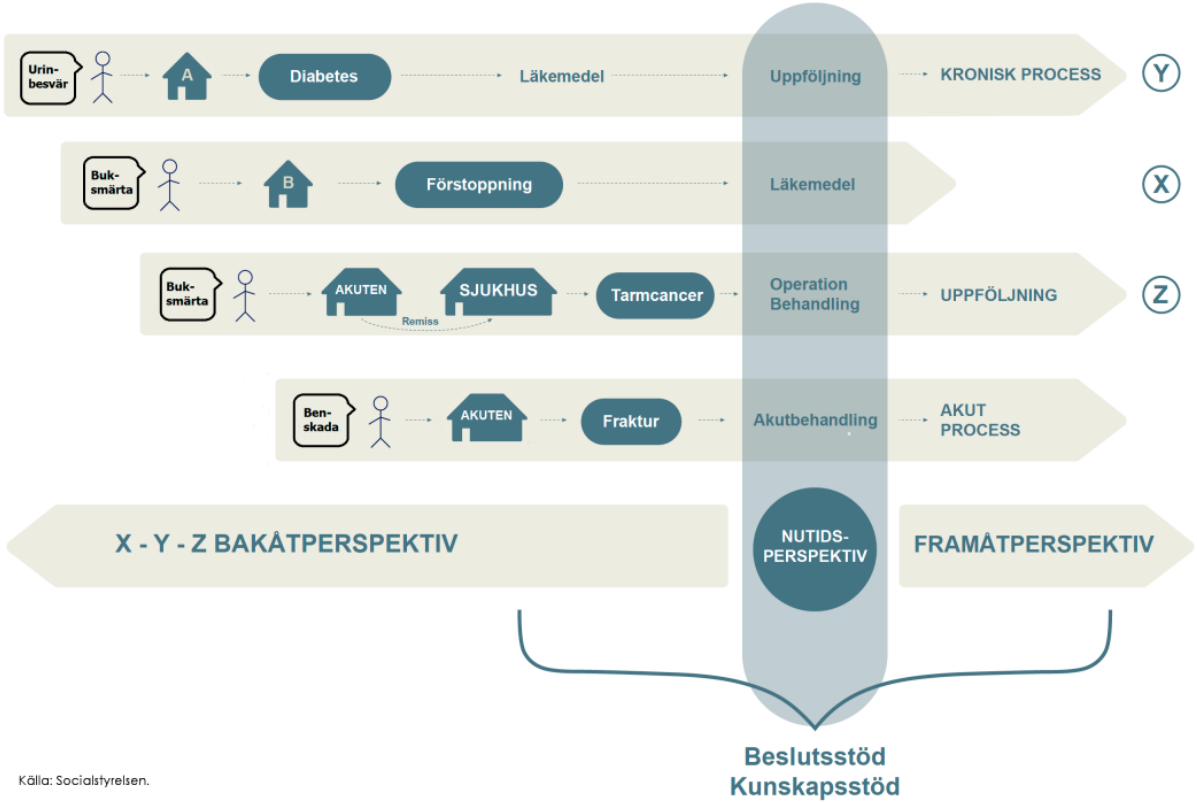
”Hälsoärende" is no longer handled within the national information (NI) models. The reason for this is that it is considered to be a technical solution.
Hälsoärende is a grouping of the individually adapted care processes that have started with the same reason for encounter/cause of contact.
NI does not handle this as an individual class, but this is a solution that the system must keep.

”Hälsoärende” hanteras inte längre inom NI. Anledningen till detta är att det bedöms vara som en teknisk lösning.
Hälsoärende är en gruppering av de individanpassade vårdprocesser som har startat med samma kontaktorsakstyp.
NI hanterar inte detta som en enskild klass utan detta är en lösning som systemet får hålla.”

Concept aggregated information from care processes



Concept aggregated information from care processes



Källa: Socialstyrelsen.

Reference PDL: authorization model for health care

Information Attributes:
- Patient
- Informationtype
- Organisation
- Care contact

Regelverk för behörighet

Authorization rules

Teknisk översättning

Infor-mation

Egenskaper
- patient
- informationstyp
- enhetstillhörighet
- vårdärende/kontakt

Regelut-värdering

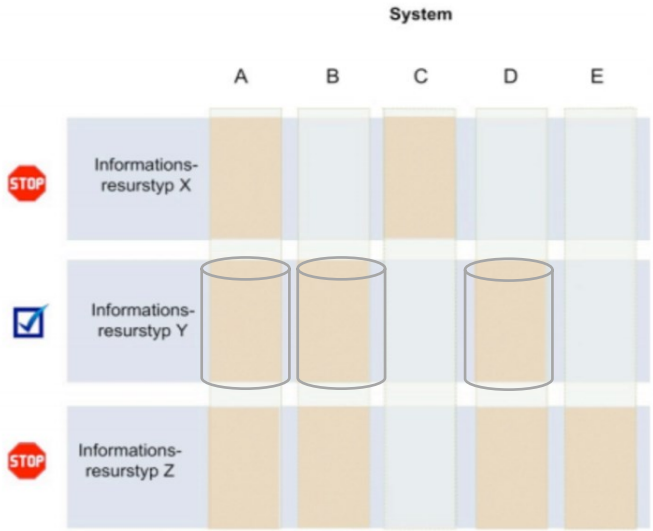
Tillåtet/ Otillåtet

Authorization evaluation

Person

Egenskaper
- personliga
- anställningsrelaterade
- uppdragsrelaterade
- situationsrelaterade

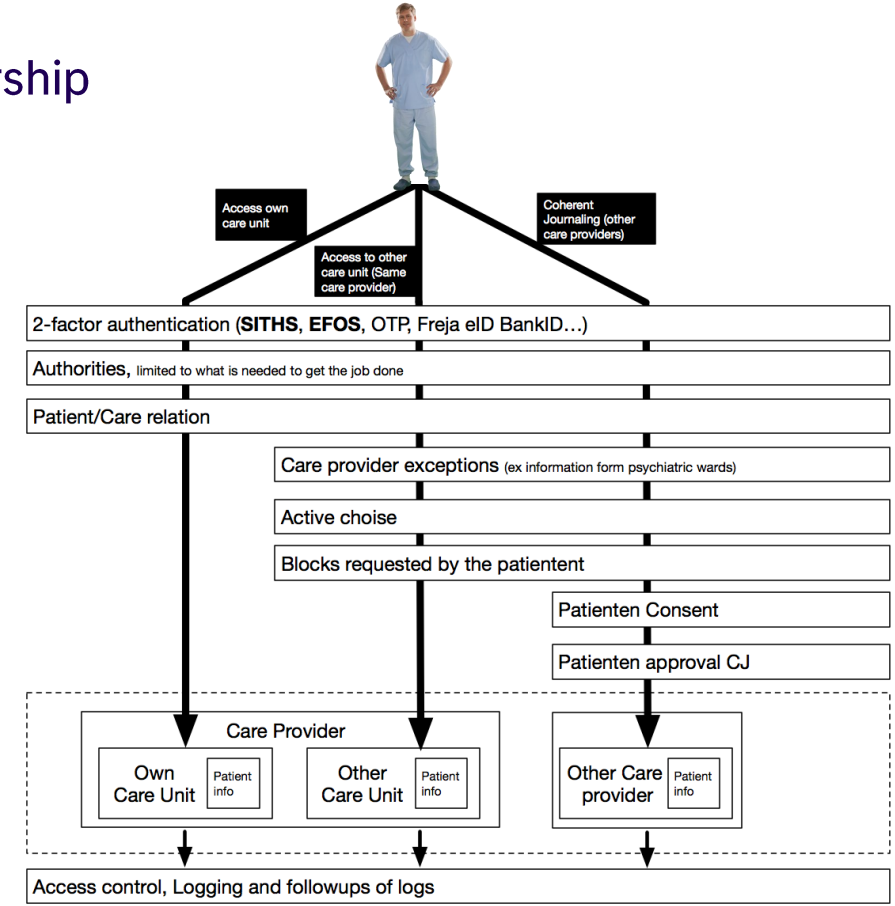
Personal Attributes:
- Personal
- Employment
- Role/mission
- Situation



Patient Data Law and information ownership

- Default – full access to own care unit
- Information can not be blocked within care unit
- Access of data from other care units require active choices and check for blocks *
- Access of data from other care provider is based on consent

* Benefit from utilizing the care process concept – Better knowledge/decision support by grouping of relevant information, allowing access of data from other care units, within the same care provider, without active choises for disclosure.



PDL aspects to investigate

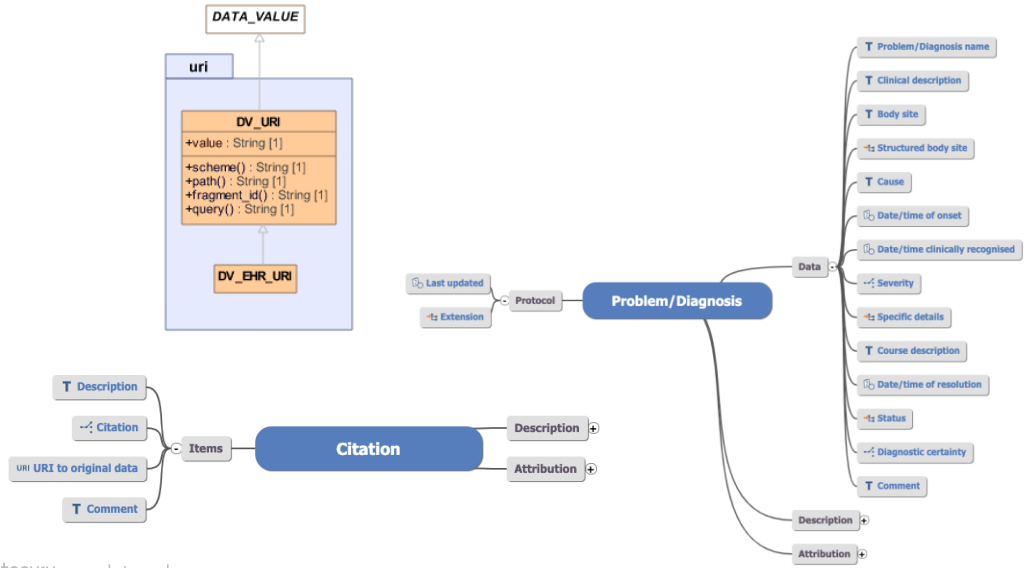
- Pre-requisits for listing care processes
- Relationship to coherent/aggregated journaling (sammanhållen journalföring)
- Consent and blocks of health issues (hälsoärenden)?
- Access and authorizations in relation to employee and situation, what defines a participant in a care process? What other factors should be taken into account, for example time of day and schedule or type of care being conducted?
- Write/read rights to care process
- Can a richer context provide better support for care processes?

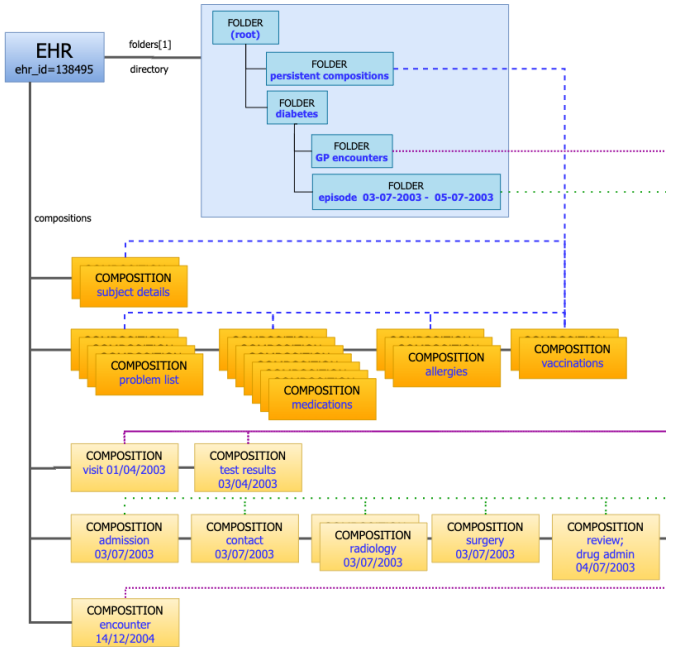
Draft – how to define a health issue (hälsoärende)

- A health issue is used to collect care documentation from one or more related individualized care processes, and can be initiated by either a clinical observation of the patient – a reason for encounter (kontaktorsak), or that a patient in contact with care provides a chief complaint (sökorsak).
- A health issue has a time of perceived onset which can subsequently be changed.
- A health issue can be closed, have an estimated end time and a manually confirmed end time.
- A health issue can be split and merged with other health issues.
- A medical record entry can be associated with one or more health issues.
- A health issue must be able to be linked to:
  - medical records and other objects in the openEHR CDR (Clinical Data Repository)
  - References to objects in other systems.
  - Actors (organisation, role and professionals/users)
  - Patient consent to aggregated records, as well as patient consent to access of blocked information in accordance with internal confidentiality
- A health issue must be able to be blocked
- Access to information related to a health issue may require consent

Possibilities within openEHR

- Problem/Diagnosis
- URI data types, EHR URI (references)
- Citation (references to information stored elsewhere)
- Folders (directories with references)





Discussions, questions (and maybe) answers!

Thank you!

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