



A generic tool for disease-specific care plans

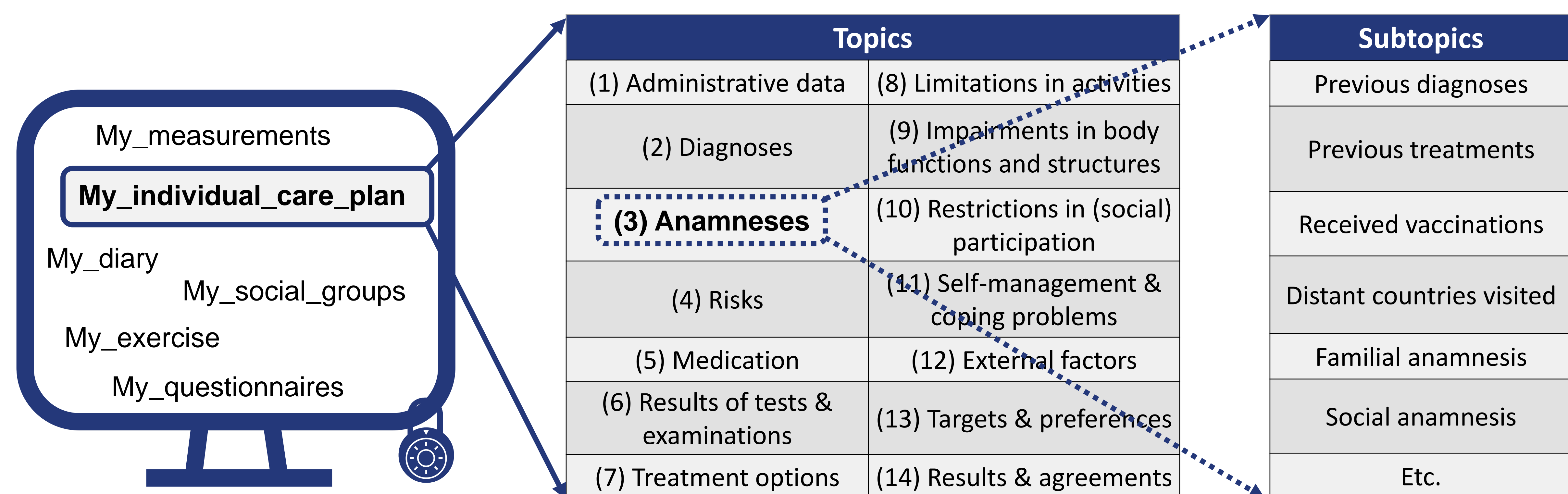
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Introduction

An individual care plan (ICP) is a dynamic set of data and agreements between professional care providers and the patient to support and facilitate shared decision making (SDM) and self-management. Ideally, every patient has a digital version of his individual care plan, that can be consulted and updated not only by the patient himself, but also by his care-givers irrespective of the location of their activity or work place. For this to happen is however more needed: interoperability of the ICT-systems of the hospitals the patient is visiting, secure data streaming, privacy assurance and the availability of interactive personal digital healthcare environments (PDHE).

An individual care plan should be part of a person's PDHE, that is a comprehensive up-to-date digital tool serving a variety of purposes (see scheme below). For common diseases like COPD or diabetes type 2, care plans are in use for several years already, though in old-fashioned paper-forms. The development of a care plan for a certain disease costs time and need to happen in consensus with patient-representatives and care-providers. In order to leverage the development of disease specific care plans, that are already suitable for digitization, we are developing a blueprint for a generic care plan for rare en genetic diseases. Using this blueprint, patient organizations and their centres of expertise will be able to construct disease-specific care plans and to integrate it into future PDHEs.



Personal Digital Healthcare Environment (PDHE)

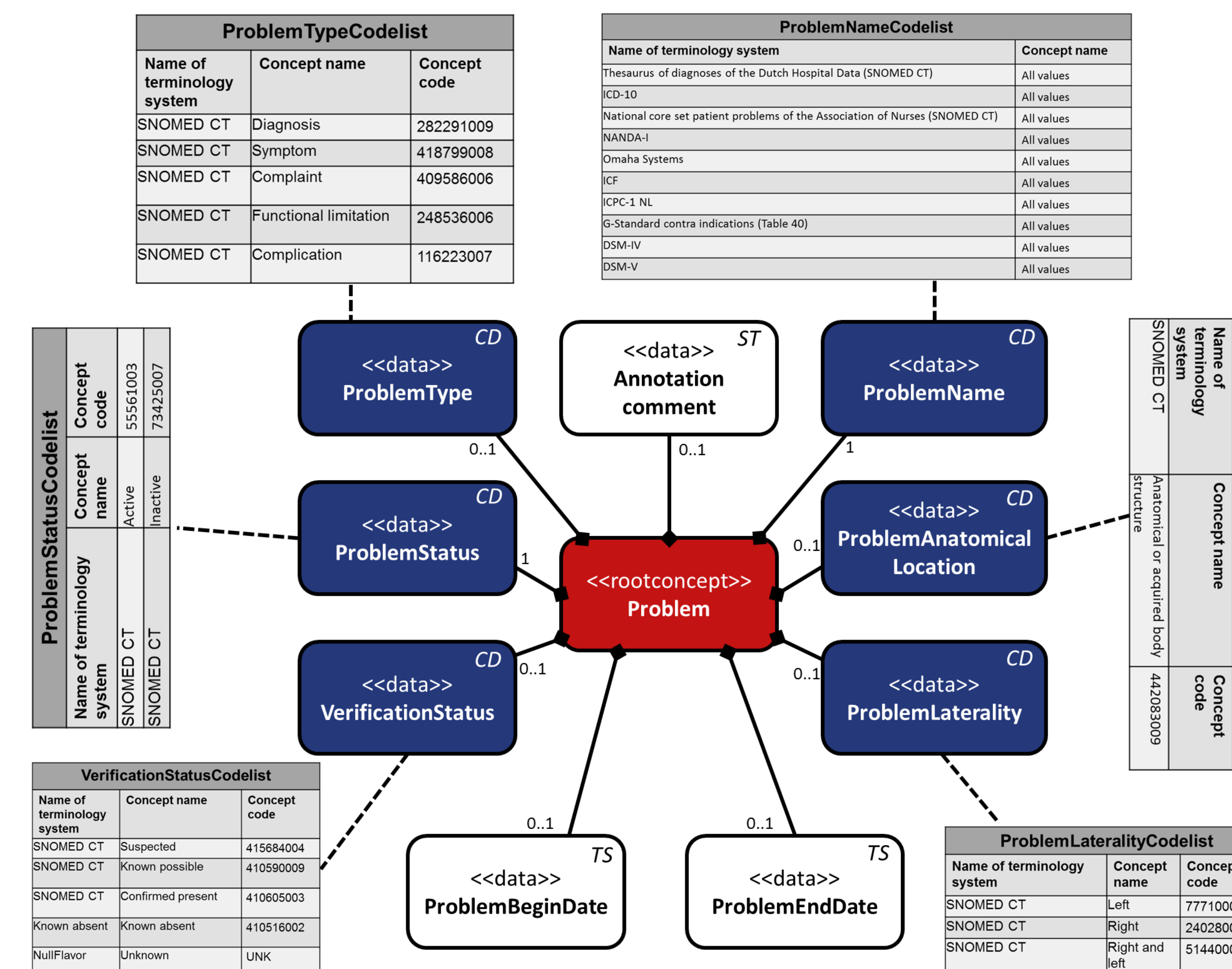
Table 1. Topics of a care plan for RD

Table 2. Several subtopics of the topic "Anamneses"

To be well-informed and in full charge of the own disease, it is crucial that patients have insight into their own data, among others lab-values, actual medication, allergies, problems in functions and so on. In the Netherlands, there is consensus about the topics that an individual care plan should cover [1]. We have adopted and slightly regrouped few of the topics of this national format and made it suitable for rare diseases (Table 1).

Future-proof care plans through standardisation

Semantic interoperability means ensuring that the precise meaning of exchanged information is understandable by any other system or application not initially developed for this purpose [2]. It implies that received data can be combined seamlessly with local data and processed homogeneously without loss of meaning. In particular, the standardization of clinical concept representation by the use of Detailed Clinical Models (DCM) is one of the major developments in the Netherlands in the field of health-ICT [3].



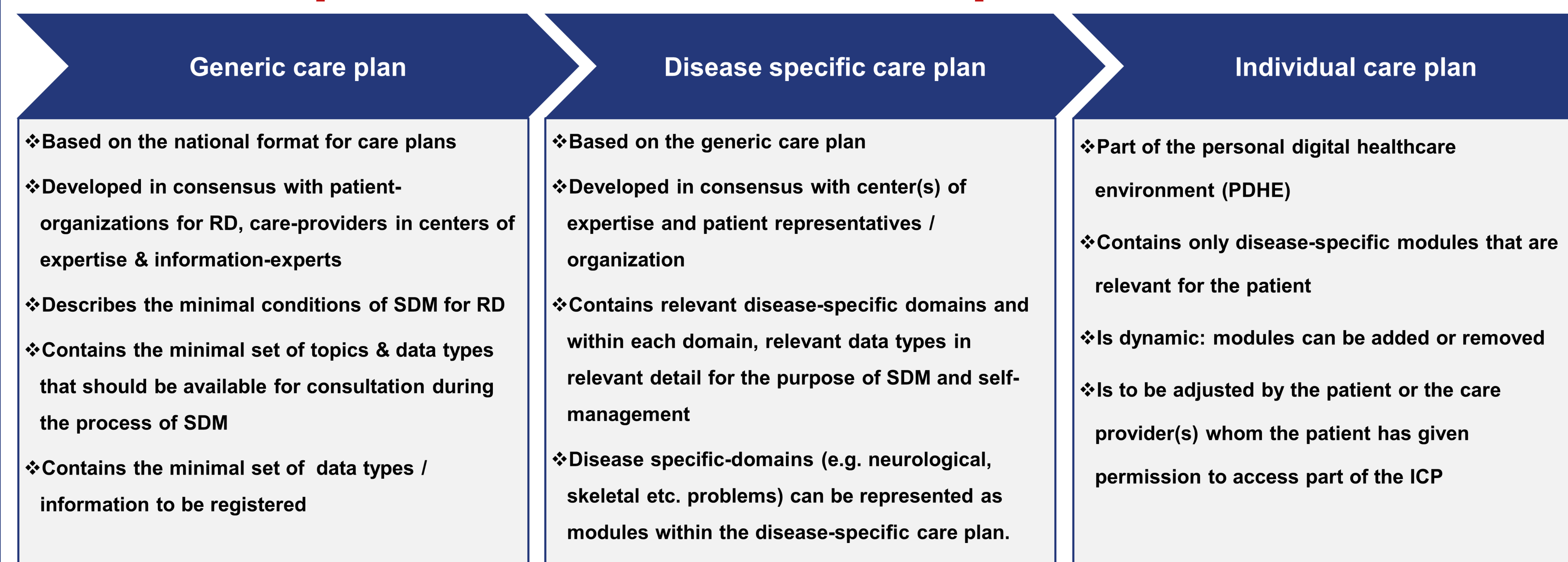
A DCM is a relatively small, standalone information model designed to express / describe a precise clinical concept in a standardized and reusable manner. It documents clinical information as a discrete set of precise clinical knowledge for that concept. A DCM provides the data elements and attributes needed to convey the clinical reality in a fashion that is understandable to both clinical domain experts and modelers [4].

More than 40 DCM concepts are currently available in The Netherlands to be used for various purposes [5]. To the left, the concept "Problem" is depicted with its relevant data elements. The code lists "behind" the majority of the data elements are showing the terminology systems, concept names and the concept codes within the terminology.

For example the concept Diagnosis in our generic care plan (see table 1) is represented by the root concept "Problem", type "diagnosis" and can take on names available from ICD-10 or other relevant terminology systems.

Within the current project we are synergizing our minimally required concepts of a generic care plan with the already developed and available DCMs: this means that we will match our (sub)topics with the DCMs and when possible, will adopt the DCM or part of a DCM available. If a (sub)topic in the generic care plan is not matching any available (part of) an existing DCM, the project group will submit an official request to either adjust a DCM or to develop a new DCM for the (sub)topic in question.

From blueprint to individual care plan



Where are we now?

