

Development of a National Distributed Research Network Data Infrastructure: Design of the PCORnet Common Data Model

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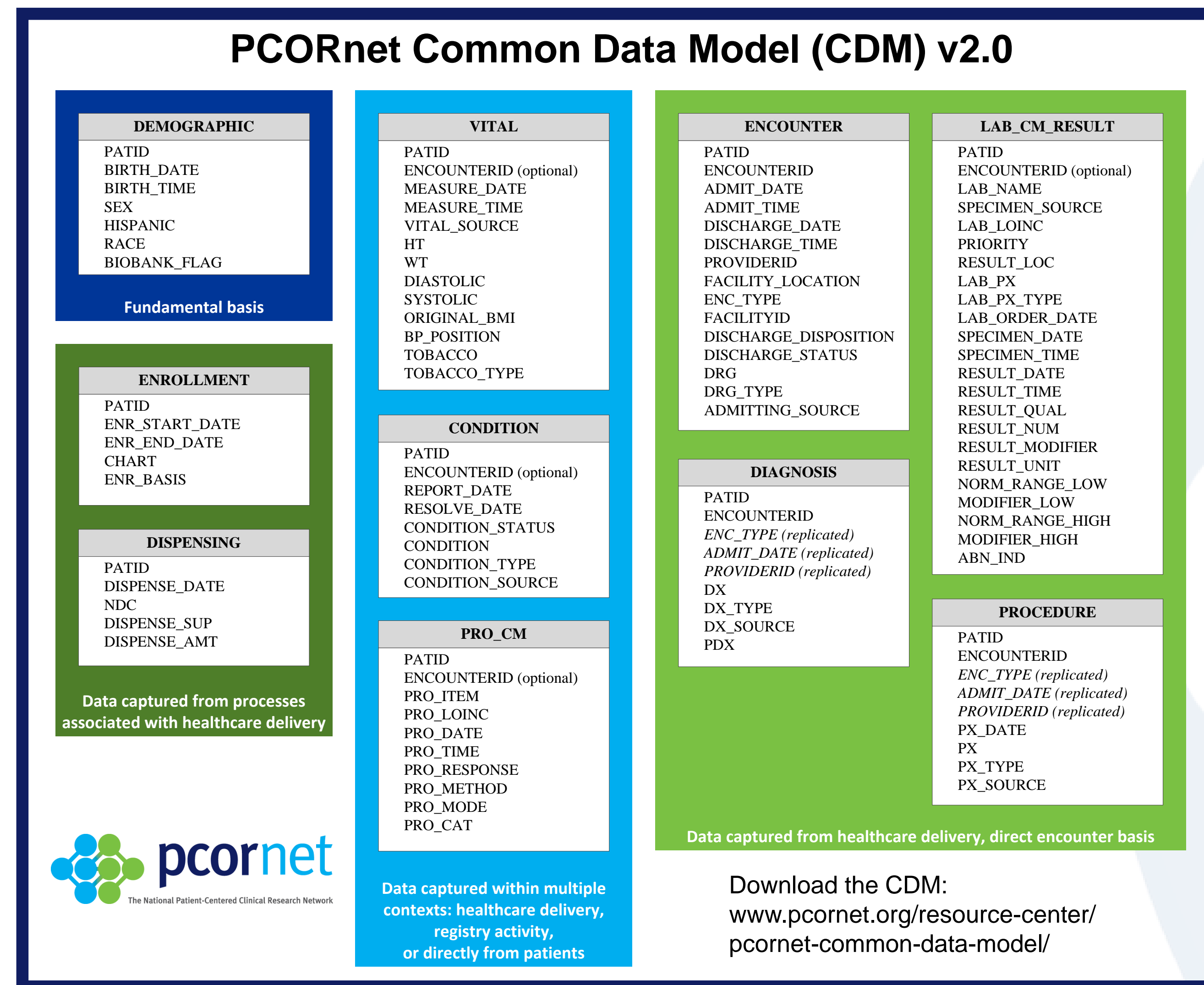
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Introduction

- PCORnet is a national Distributed Research Network (DRN) sponsored by the **Patient-Centered Outcomes Research Institute (PCORI)**
- Formed in late 2013 with 29 networks located across the United States
- Objective is to create a “network of networks” to form a **highly representative national infrastructure for research**
- Uses the **PopMedNet™** software infrastructure
- Architecture will allow queries and analytic programs to be **disseminated to individual data stores**
- The PCORnet Common Data Model (CDM) has been developed to provide a **standard organization and representation**

Methods

- Development began with the **Guiding Principles**, drafted as part of the charter of the PCORnet Data Standards, Security, and Network Infrastructure (DSSNI) Task Force
- The PCORnet CDM is a **stand-alone model** as a result of the **strategic direction** laid out in the Guiding Principles
- Heavily derived from the **Mini-Sentinel** Common Data Model and informed by other initiatives
- Developed in incremental phases**, allowing agility in deployment, and new data domains to be incorporated
- Modeling is **optimized for analytic functionality** and to be **intuitive to investigators**



Results

PCORnet CDM v1.0

- Released on **May 30, 2014**
- 276 discrete comments** received and incorporated

PCORnet CDM v2.0

- Released on **February 27, 2015**
- 265 discrete comments** received and incorporated in 2 feedback cycles
- Two stakeholder sessions with **79 and 60 attendees**, respectively
- Unanimous vote for adoption** by the Steering Committee

PCORnet CDM v3.0

- Currently in development

Discussion

- The CDM uses a strong basis of **secondary data** generated by **healthcare delivery processes**
- Development takes a **pragmatic approach**, supporting the **current state** of these data
- Area of future development is for data domains that **support multiple contexts**: healthcare delivery, registries and clinical studies, and data generated and received directly from patients
- Participation** in review cycles, comment submission, and attendance demonstrates **high engagement within the PCORnet community**

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