



# Patient Generated Data National PRO (Patient Reported Outcome) in Denmark

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**DANISH HEALTH  
DATA AUTHORITY**

# The Danish Healthcare System

**Universal  
Coverage**

**Free & Equal  
Access**

**Financed by  
general taxes**

**A high degree of  
decentralization**

# Organization of the Healthcare System

> App 5.5. mill inhabitants

## National Level



Ministry of Health

## Regional Level



5 Regions

## Local Level



98 Municipalities

App 3500 GPs

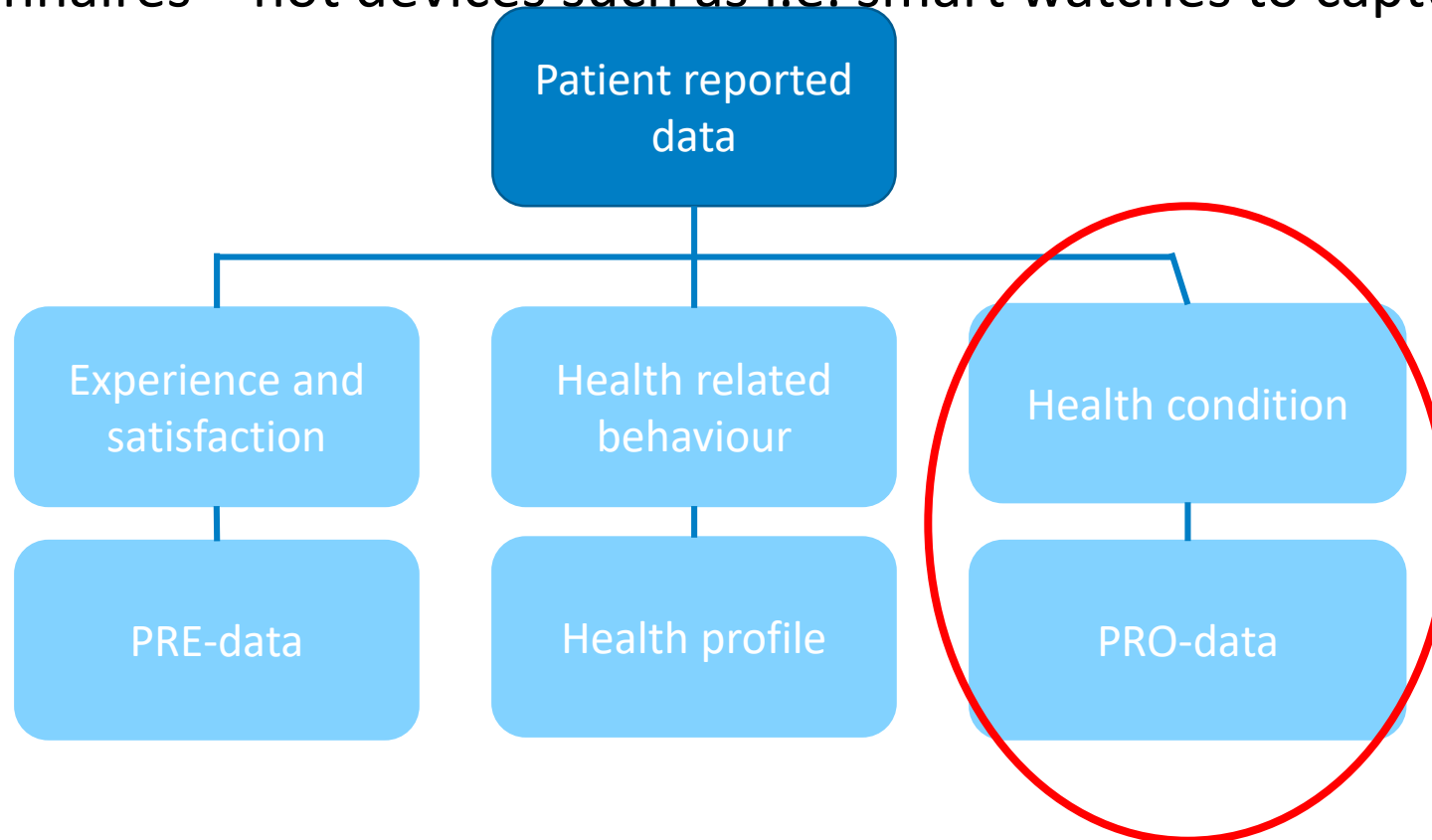




# Conceptual frame for PRO in Denmark

”Patient reported data, are data – reported by the patient - regarding the patients health condition including physical and mental health, symptoms, health related quality of life and functional abilities”

We use questionnaires – not devices such as i.e. smart watches to capture data.



# National PRO in Denmark

## Background

- Decided as part of an economic agreement for 2017 between the Danish State, the Danish Municipalities and the Danish Regions:
- *The Danish steering group for PRO shall establish a framing supporting **use of PRO in daily clinical practice and quality development in health care in all sectors and across sectors - where it may be relevant***
- **Purpose:**
  1. **Standardization**
  2. **Guidelines for standardization**
  3. **Knowledge sharing**



## The steering group of national PRO

- The Danish Health Ministry
- Organization of Danish patients
- The Danish Regions
- The Danish Municipalities (KL)
- The Danish Health Data Authority
- The Danish Health Authority
- The Danish Digitalization Authority

# The aim and framing of PRO in Denmark

- PRO-data are to be used actively in the patient-healthcare professional encounter
  - Supporting efficiency of care
  - Empowering the patient
  - Part of preparation for the clinical encounter
  - Part of decision support
  - Individualised patient care
- PRO-data is a part of the patient record
  - Covered by the same legal demands
  - Can be accessed by all health professionals that have a treatment relation with the patient
- It shall be possible to use PRO-data cross-sectorial when relevant
  - Presupposes a shared semantic infrastructure
- It shall be possible to use PRO-data for quality improvement and research

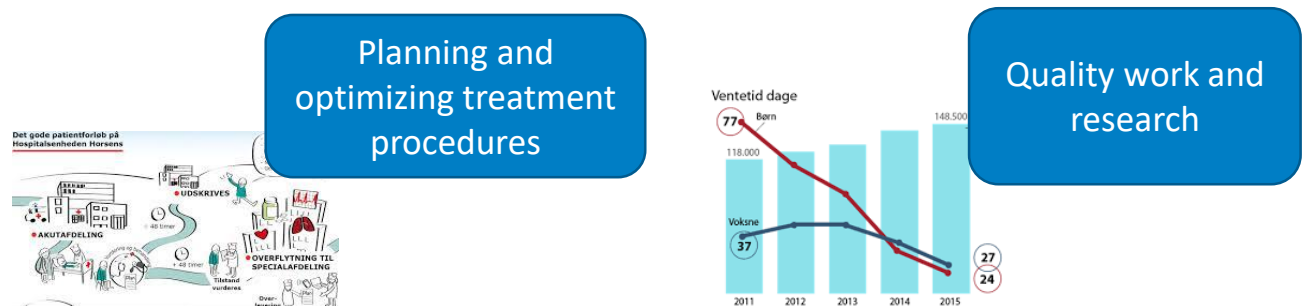
# Conceptual frame - Danish PRO

'Structured report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else'

➤ **Active use of PRO:** when the patient experiences that his or hers answers are used actively in the clinical encounter by the health professional. It may be as dialogue support or as pre-encounter assessment leading to decision on whether a contact is relevant or can be postponed



➤ **Passive use of PRO:** when the patient does not experiences that the questionnaire is used actively by a healthcare professional. This may be as part of research or quality development



# Developing areas for PRO in the national program

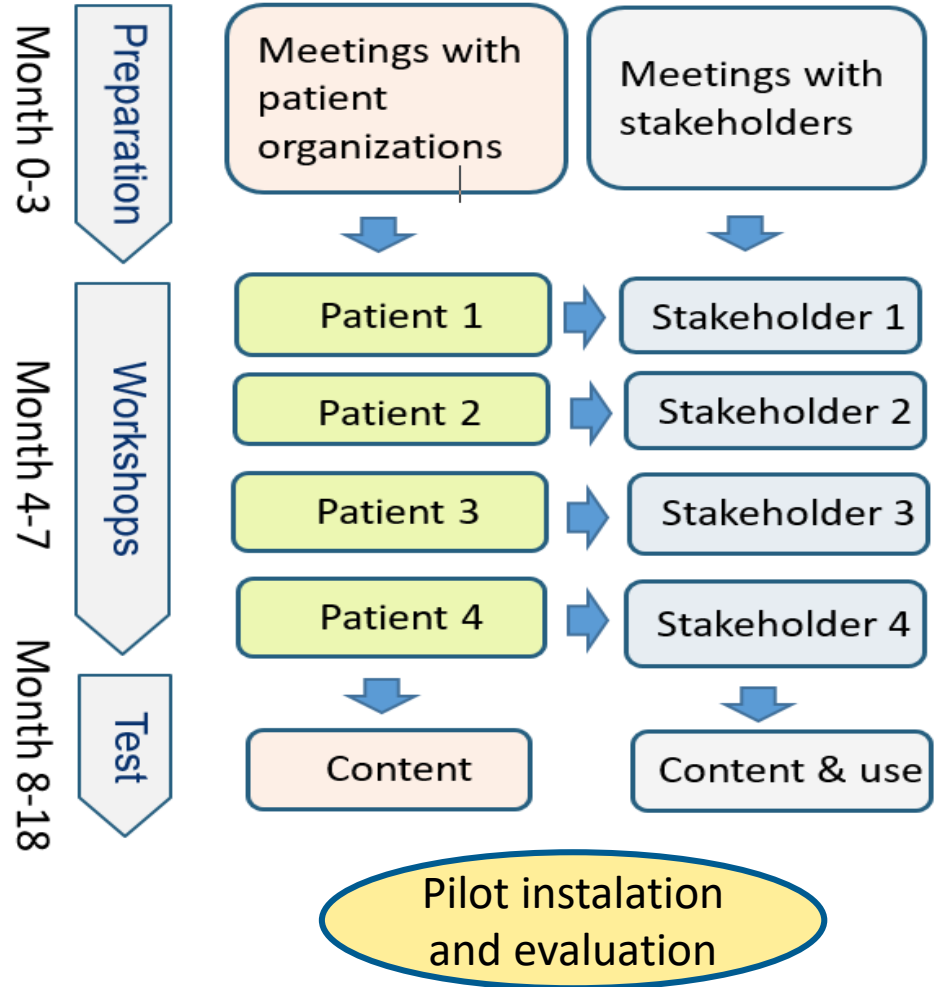
Area	Status
Apoplexy	Pilot testing almost completed
Arthrosis (knee and hip)	Pilot testing almost completed
Screening for depression in somatic patients	Pilot testing almost completed
Pregnancy and childbirth	Pilot testing starts December 2019
Heart rehabilitation	Pilot testing starts December 2019
Diabetes	Pilot testing starts December 2019
Psoriasis	Development at the moment
Paliative care	Development from start 2020

+ appr 30 pilot installations and 4 PhD projects

Furthermore there are appr 170 local projects



# Development methodology for concerted national questionnaires



# Co-creation with patients

Describes patient journey and discusses purpose, questionnaires and use

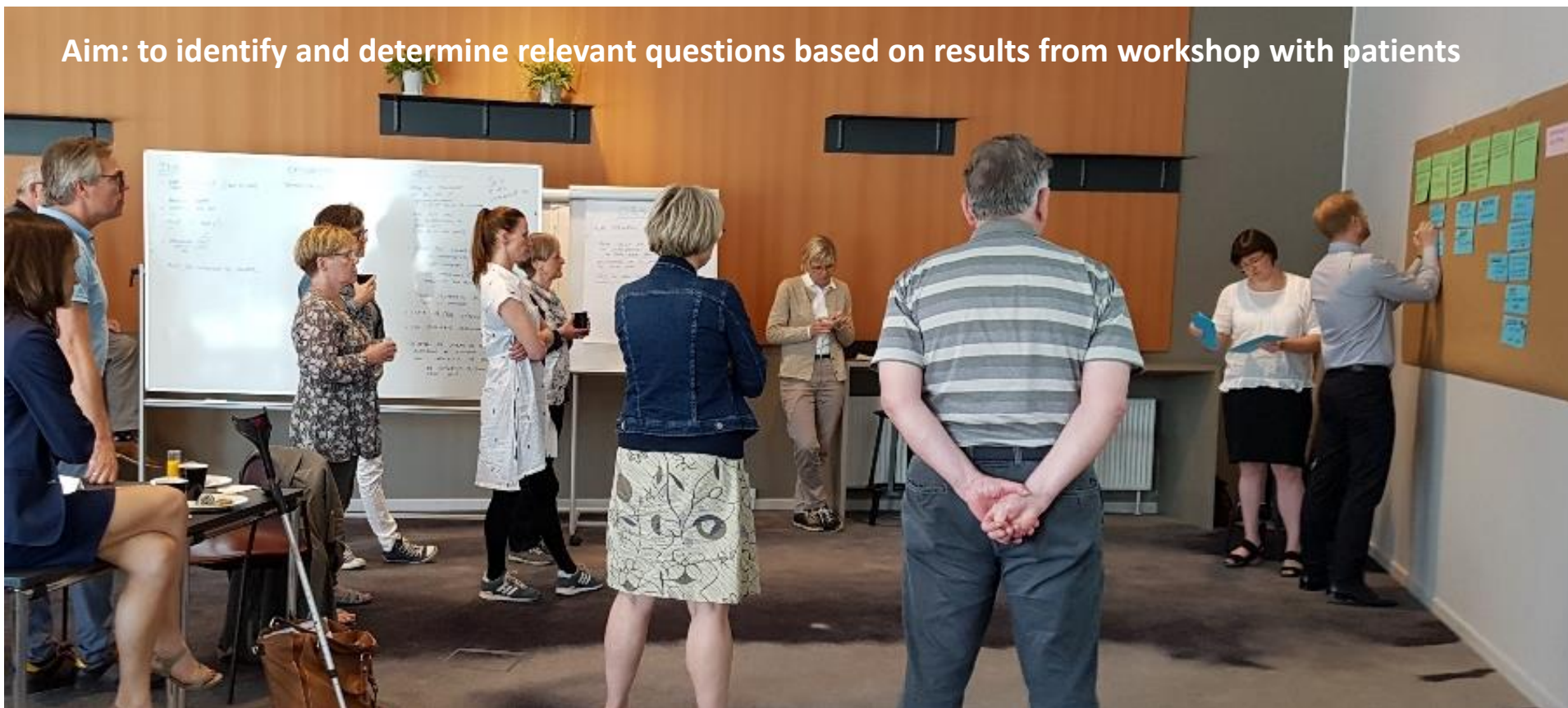


**Aim: to ensure relevance and understanding of questions and possible answers. Results from workshops are used in workshops with other stakeholder**

# Co-creation with stakeholders

Decides purpose and use as well as content of questionnaires

Aim: to identify and determine relevant questions based on results from workshop with patients



Participants: Health care professionals from all sectors patients, patient organizations, health care scientific organization, quality managers

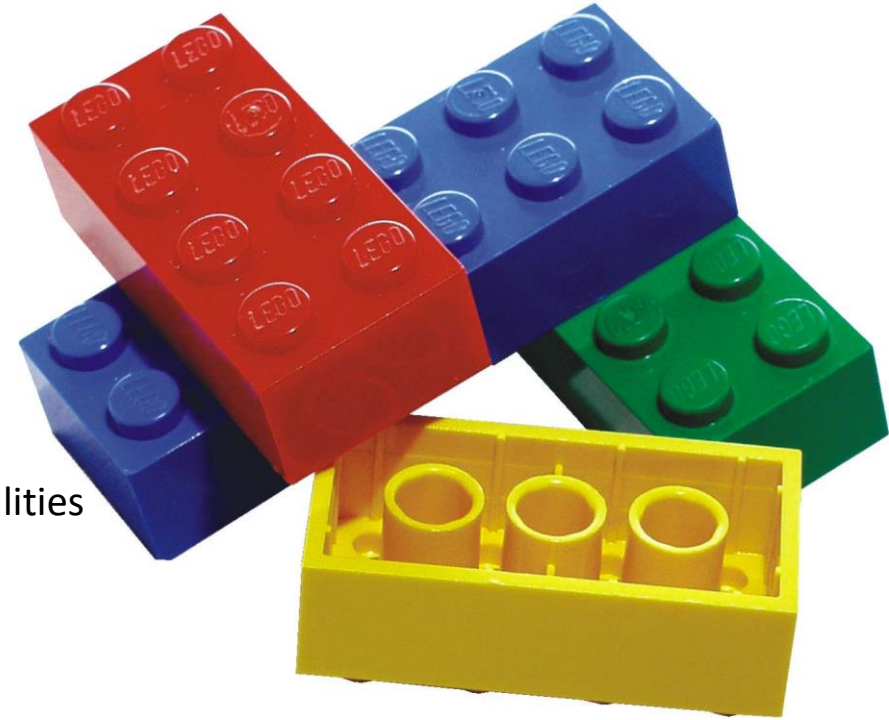


# PRO-packages

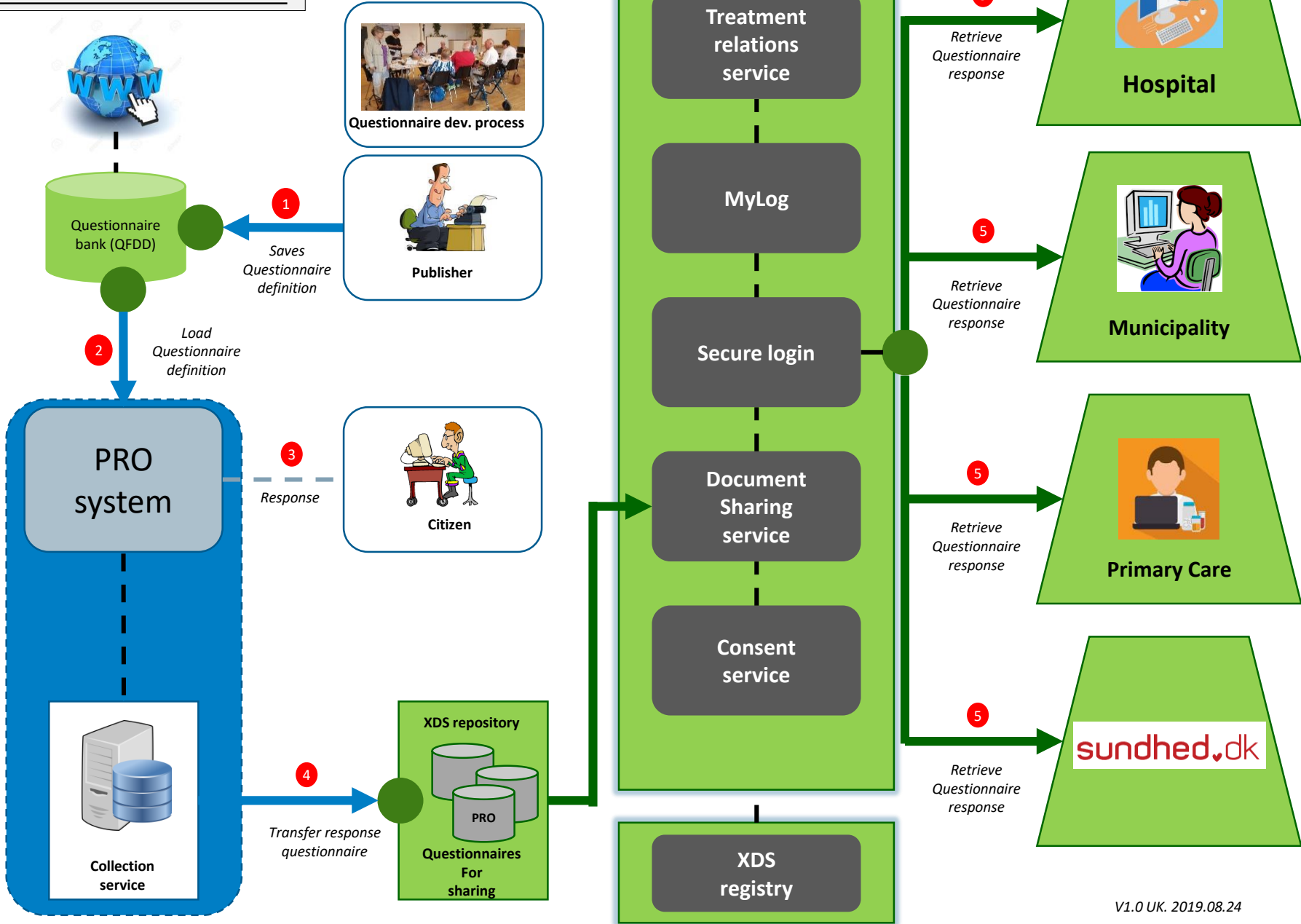
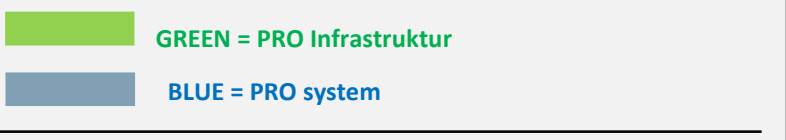
PRO-package	Content	Description: Questionnaire & development
		Recommended use & target group
		Questionnaire definition (QFDD)
		Clinical decision algorithms
	Meta data	ID, name, version etc.
		Recommendation level
		Search parameters
	Other info	CE preparation, (evaluation reports etc)
		Other relevant material

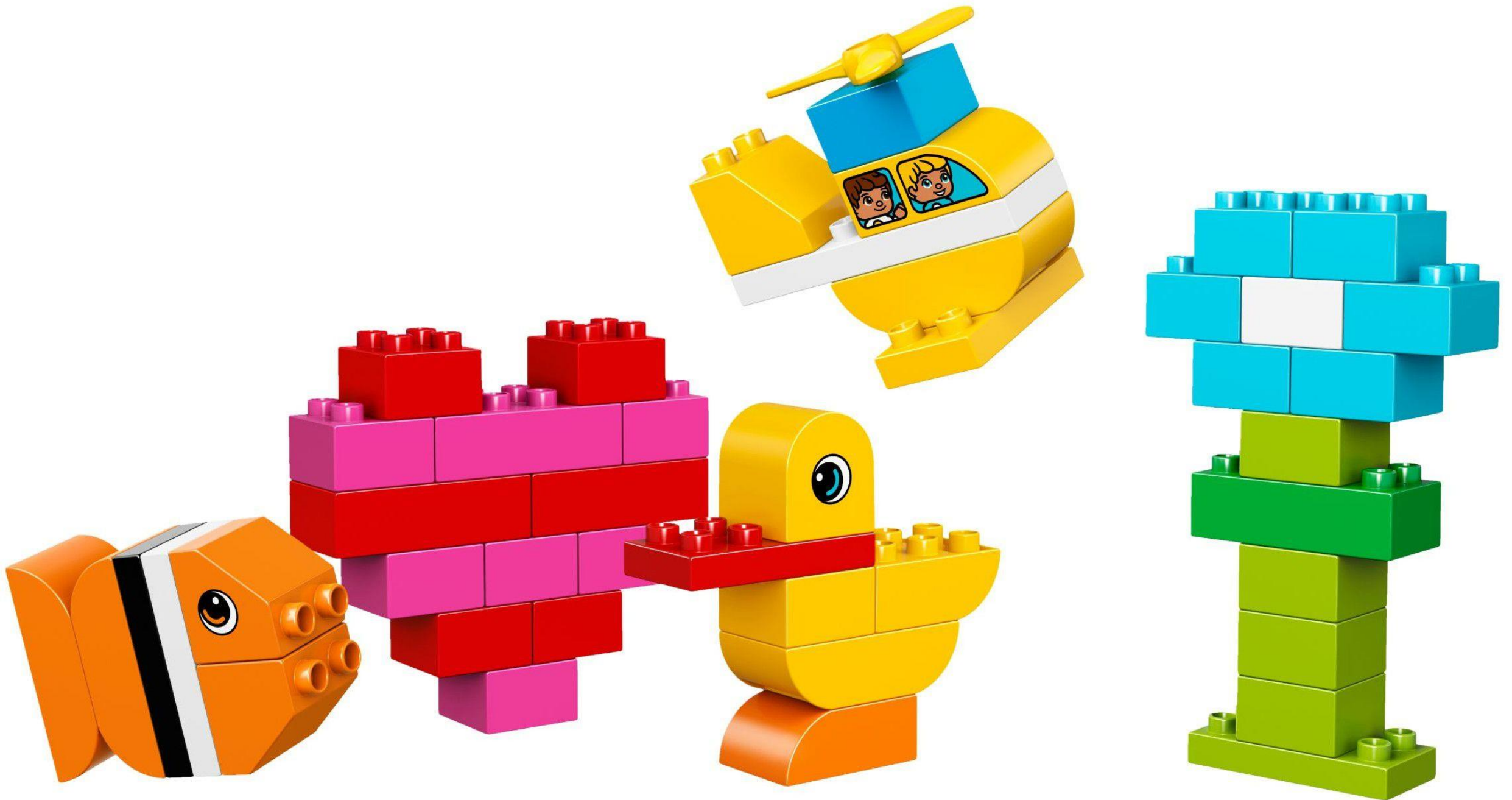
# Existing National (health) IT infrastructure

- Safe health data net
  - Covering all healthcare institutions
  - Standardized messages (MedCom)
- Unique identifiers for all:
  - Citizens
  - Authorized health professionals
  - Care providing organizations
- Digital signature
- Limited number of classifications systems
  - Healthcare classification system (SKS) based on ICD ++, ICF, NPU in hospitals
  - ICPC, ICF, NPU in primary care
  - 'Shared language' (Fællessprog III) based on a SNOMED CT subset in the municipalities
- National patient databases
  - National patient registry
  - Shared medication portal (FMK)
- National health portal
- Mandatory technical standards
  - HL7 – CDA, QFDD....., APIs
- Governing bodies

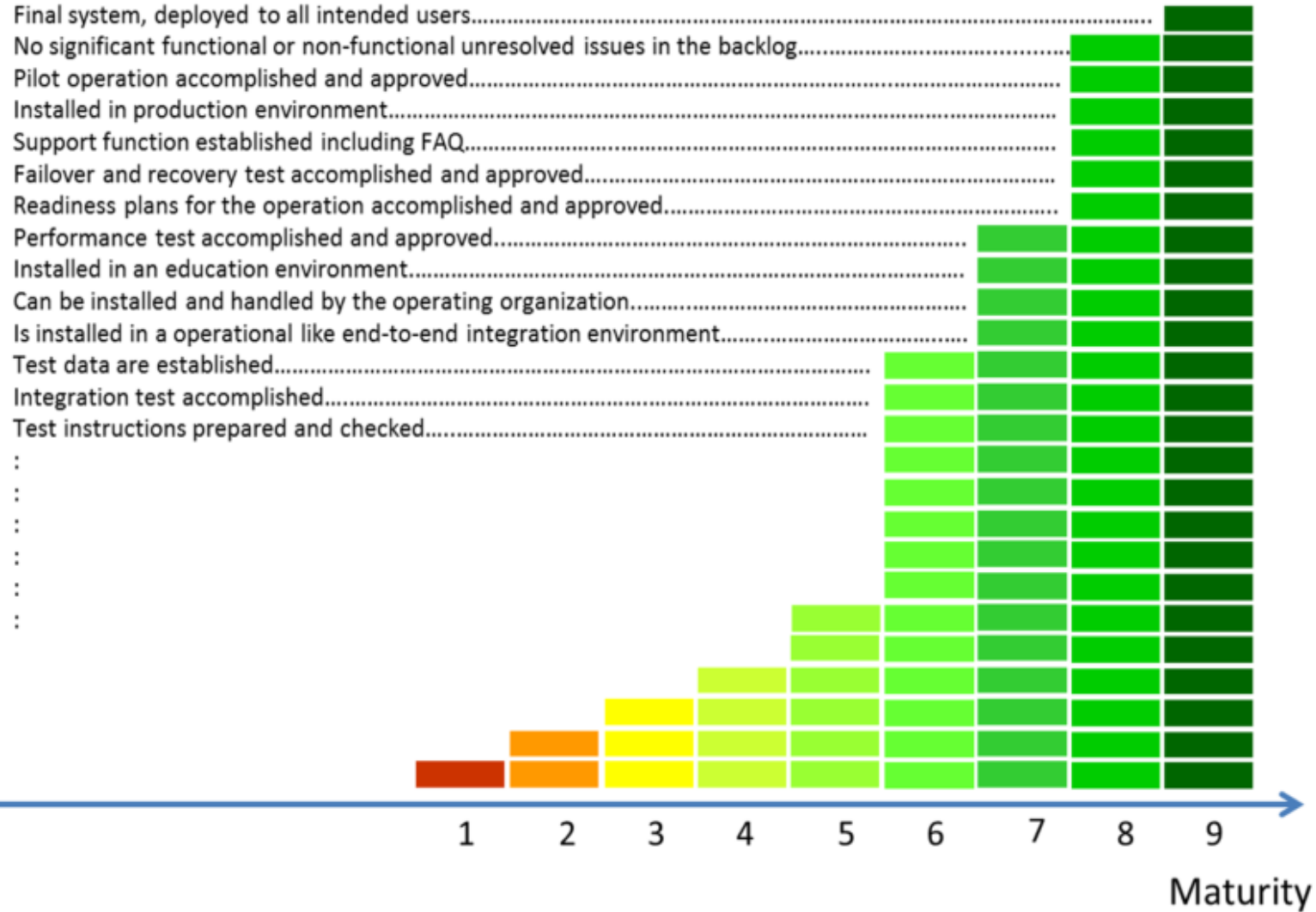








# TRL scale to access the maturity



# Status on national PRO in Denmark

- Methodology for development of questionnaires are developed/established
- Patient involvement
  - In cooperation with Danish Patient Organization
  - Cooperation and involvement of relevant patient organizations
- IT infrastructure are established
- Classification and terminology work have started
- Patient workshops have been conducted Stakeholder and patient workshops conducted in six focus areas
  - Apoplexy, Knee/hip arthrosis, Screening for depression
  - Diabetes, Heart rehabilitation, pregnancy/maternity
- Two new focus areas
  - Psoriasis, Palliation
- Sharing of knowledge
  - Homepage
  - PRO seminars and conferences every half year
  - Pamphlets and video

# BATON

Transferred care





# Take home messages

- Even relatively simple tasks put high demands on infrastructure
- Take the time and resources to do things right and include all relevant actors
- Governance is important

