

DATABASES FOR CLINICAL RESEARCH – THE NEXT QUANTUM LEAP

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1. The new organization for health documentation – a solid foundation for better and more accurate data for clinical research
2. The pathway to transparent, valid and adequate clinical research data – a new method for data collection and dissemination





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March 1st 2012 all health documentation at state level was reorganized and became a part of Statens Serum Institut in the National Health Surveillance

- Health documentation units from the National Board of Health
- DRG from the Ministry
- Medication register from The Danish Medical Agency





New tasks at Statens Serum Institut

Collects, describes and analyzes data on population health status and data on activity, economy and quality in health care.

Responsible for development and implementation of tools and data to be used in financial models and economic incentives in the health care sector

Provides health data to relevant users and research.

Together with former:

Responsible for monitoring tasks, counseling and dissemination and outbreak investigations of infectious diseases

Danish National Biobank.

The basic idea behind the organization is

“value chain” for changing data into information



Health
documentation

Health
analysis

Data Delivery and
Medicinal Product
Statistics



Purpose

Responsible for the collection, preparation and processing of all relevant information on health and related sectors.

Describes the activity, the economy and the results of the healthcare system.

Responsibility for basic statistical reports, development and maintenance of the data bases.





Purpose

Responsible for the development of health analysis in health, including inequality in health, prevention, patient care, episodes of care, quality and efficiency in health care etc.

Assist and coordinate analyzes for the Ministry for budget agreements with the regions and municipalities, the state budget and supporting the National Health Board with data to do their business, etc..





Purpose

Researcher support

Own IT for researchers for those that can handle data themselves

Less than 30 days for handling researcher orders

Broader data foundation

etc.

To ensure stable and timely data delivery to relevant stakeholders (eSundhed)

Responsible for the operation of Medicinal Product Statistics register and the related statistical and analytical tasks

Responsible for distribution of information regarding the financing models

International obligations.



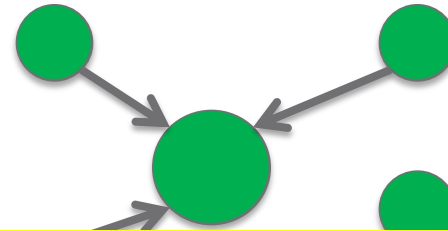
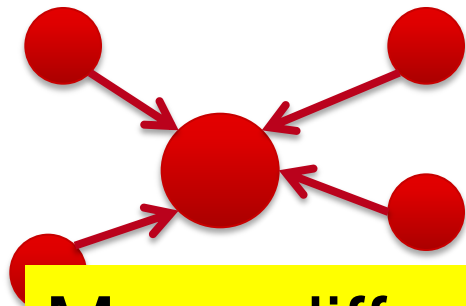
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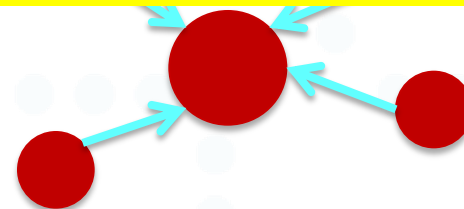
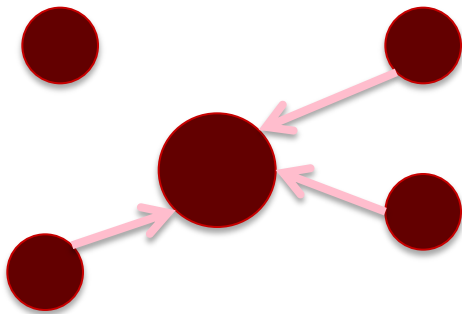


1. Comprehensive and reliable description of all events in the health care sector - and related sectors
2. Quality assurance of data when recorded
3. "On demand" access to data for researchers





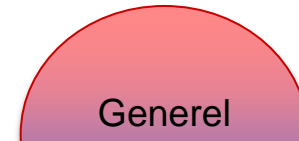
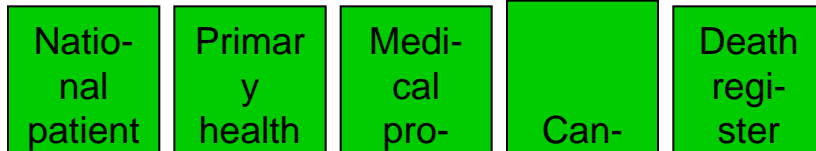
Many different registers formed independently and with different purposes and quality



THE CURRENT RESULT

National Health Surveillance

Statistics Denmark



The registers are not primarily constructed to support research



Center for Psychiatric Research



DAK-E

DAMD



Special characteristics of the current model:
Very high level of commitment and professionalism

Problems

Data collection is not always systematic and above all not always with the best possible quality.

Data that exists cannot be easily retrieved and combined from different data sources.

A number of valuable information and other data sources are not saved



The target:

Easy and equal access to all data recorded in the Danish health sector (including written medical records, etc.).

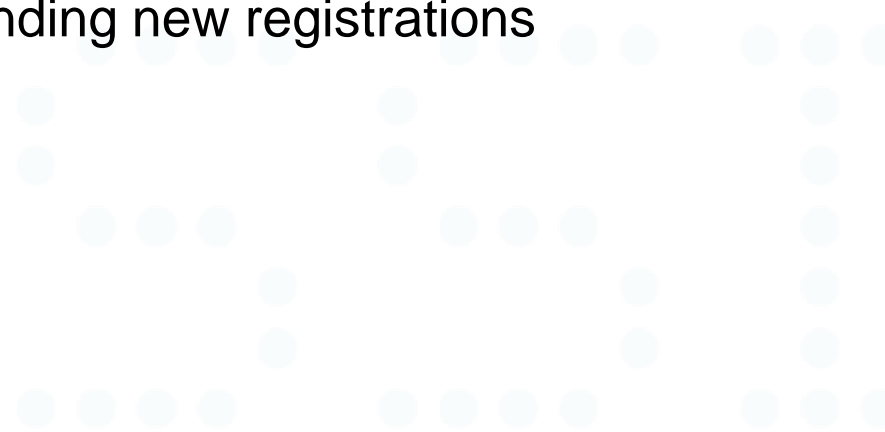
The general principles:

Use everything that already exists

Do not put stress on clinicians demanding new registrations

Do not wait for the perfect, but

Use the perfect when it is in place



Exploits pointer function

1. The current system already contains a pointer to all clinical services (eg. a cholesterol measurement) - but not RESULTS

The result of all benefits obtained.

2. Data collection expanded to include RESULTS of the clinical services

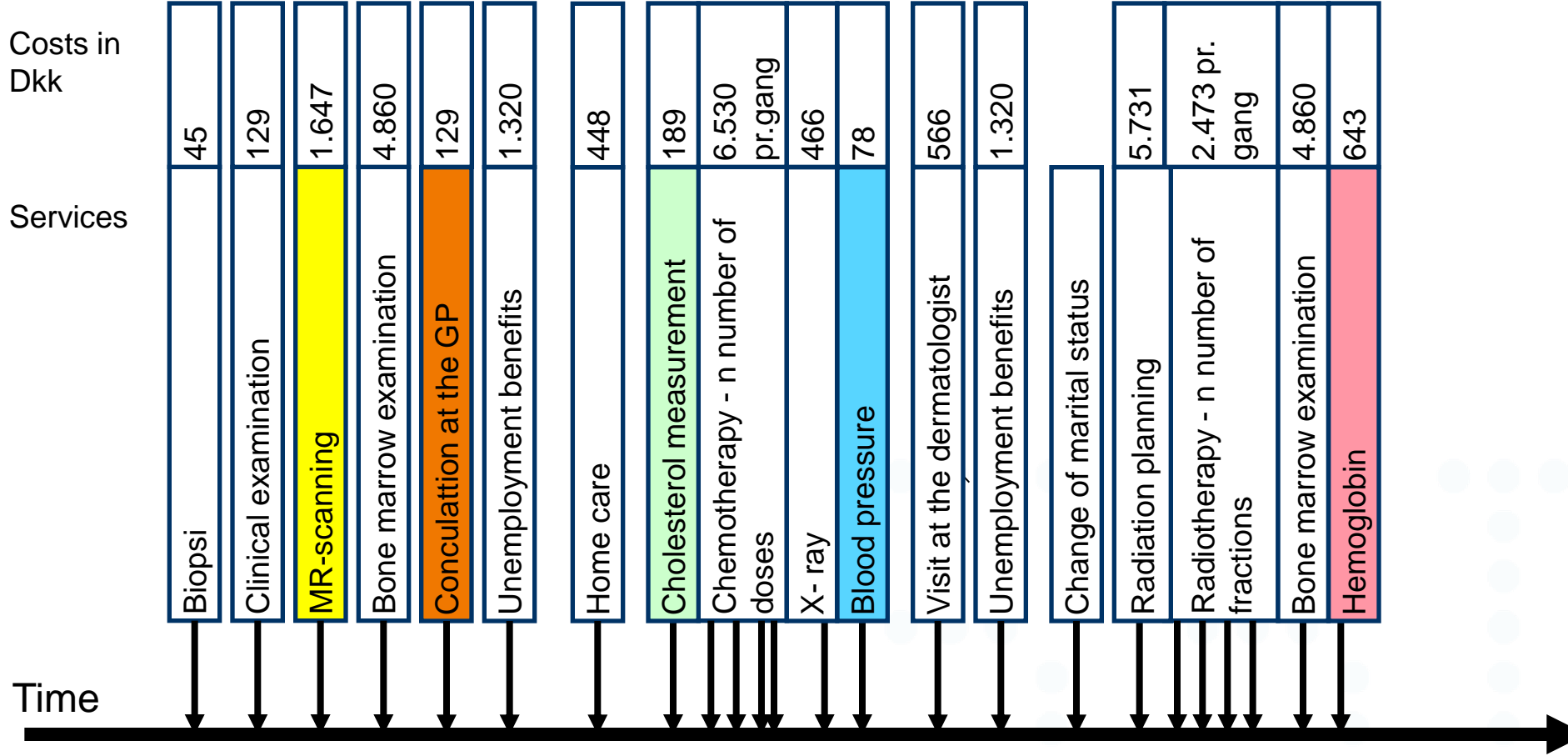
Updating

3. The update will be changed from daily / monthly to "near real time" data and "swung" back to the controller for quality assurance of correct registration

Dissemination

4. Data made available immediately upon demand (online access)

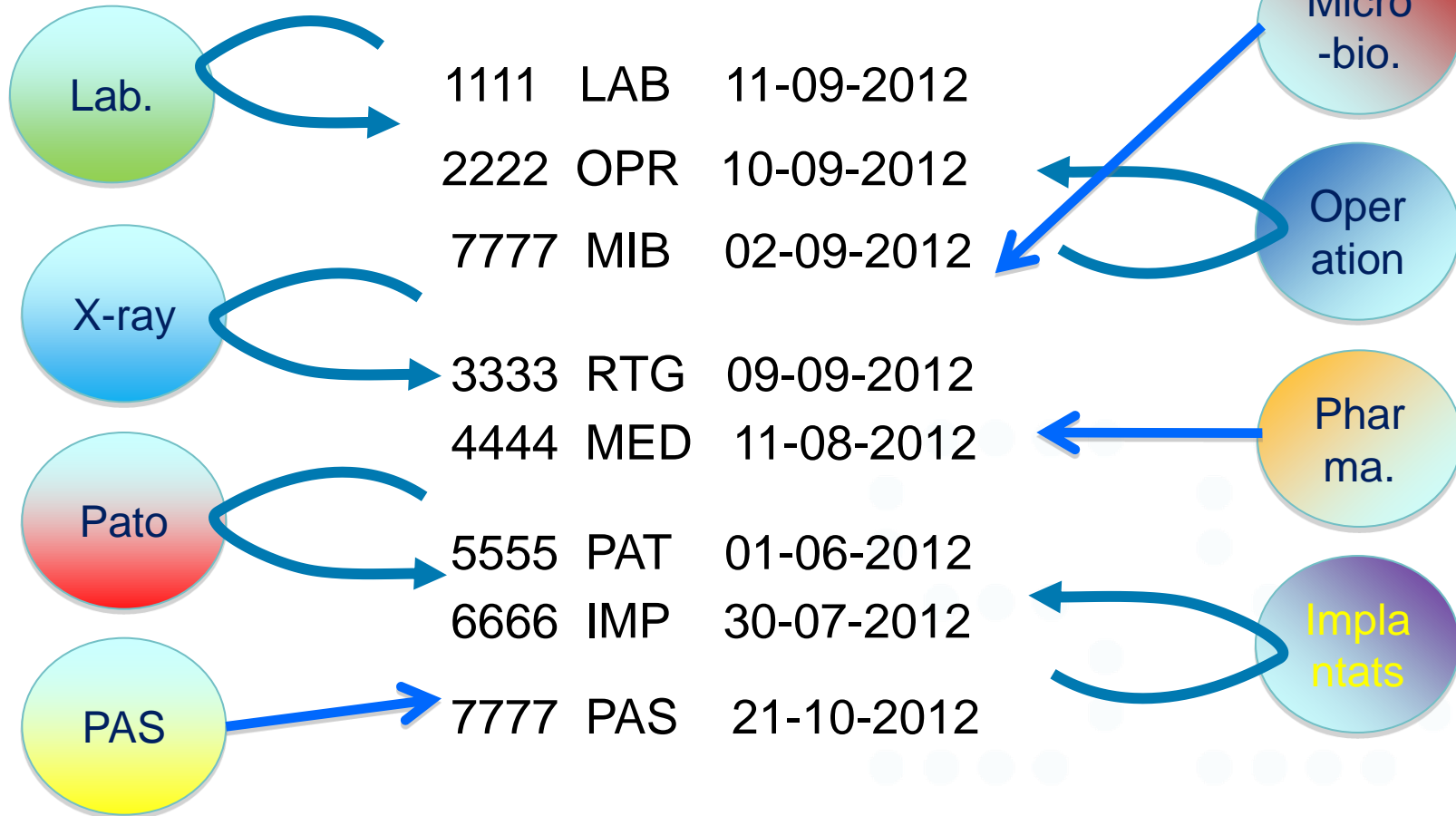
THE FUTURE-PROOF MODEL



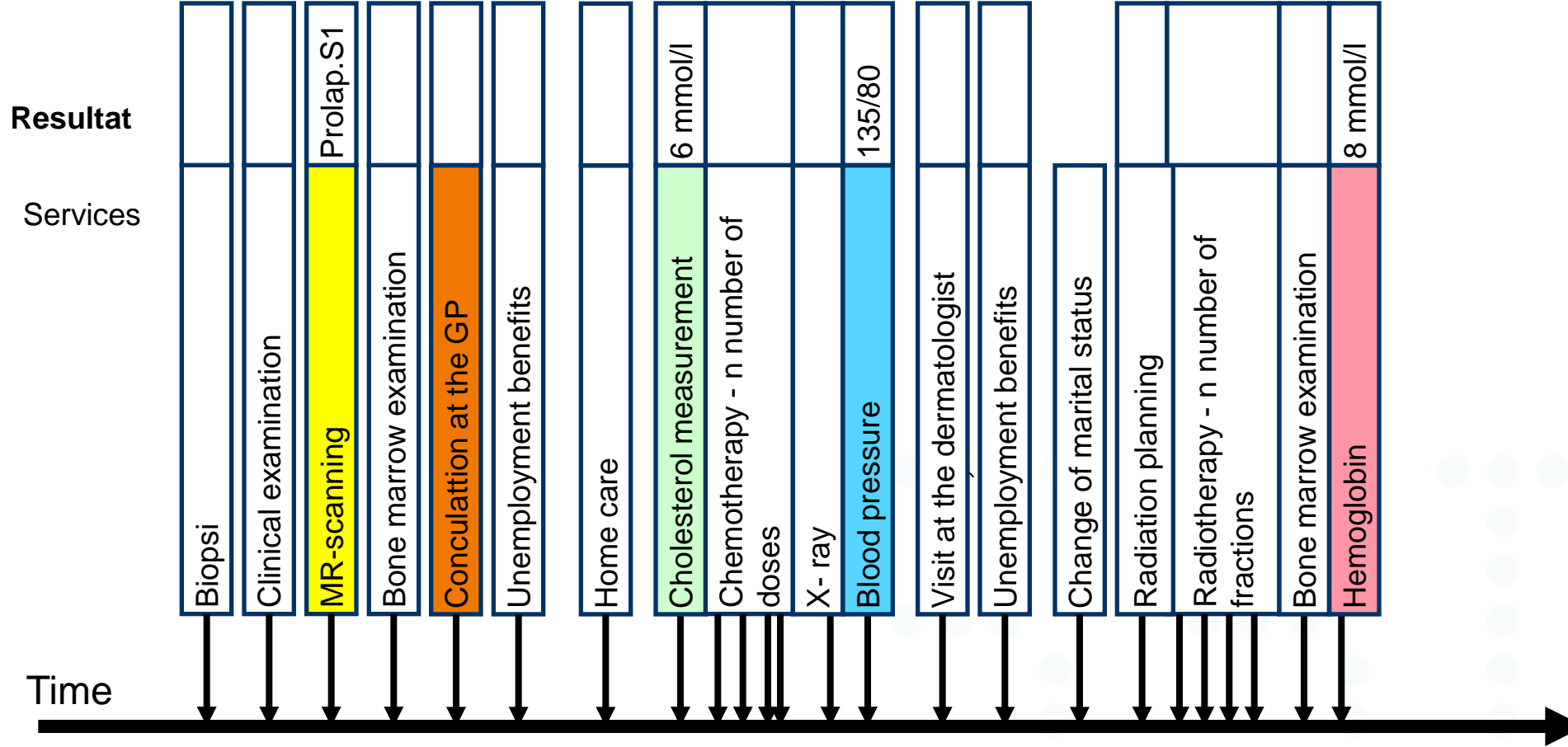
THE FUTURE-PROOF DATACOLLECTION

**Collect everything
that is registered**

Who Where When
CPRnr System Timestamp



THE FUTURE-PROOF MODEL



The building blocks of the outlined model

Basic services

PAS-data

Other services

**Biochemistry
Clinical Physiology and nuclear medicine
Immunology
Microbiology
Neurophysiology
Pathologic anatomy
Diagnostic radiology
Genetics**

Other information

**Operations
Anesthesia
Intensive treatment
Pharmaceuticals
Dialysis
Radiotherapy
Physical and occupational therapy in hosp.**

Municipal health information

Labor marked

Rehabilitation

Dreamdata

Electronic care systems

Agreements:

Contact to KL on municipal health information - first area is home nursing
Cooperation on data exchange with other ministries (Labor, Social Services and Education)



Research on ALL levels:

Illness (all registered diseases)

Patient (complete patient / cohorts)

Analysis (effect/ significance of analysis results (eg. Cholesterol measurement) across disease categories)

