Citizen-centric health data: "Getting people on board"

Making health data accessible and understandable for citizens in Denmark

2021 Thought Leader EHTEL Symposium

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medcom

Test & Certification

- Certification of all applications (incl. Apps) that use national standards
  - Standards for messaging - designed for health care professionals (HCPs) since 1994
  - Citizens were given access to the same data

- Semantic interoperability
  - Quality Management System (QMS) build upon European knowledge
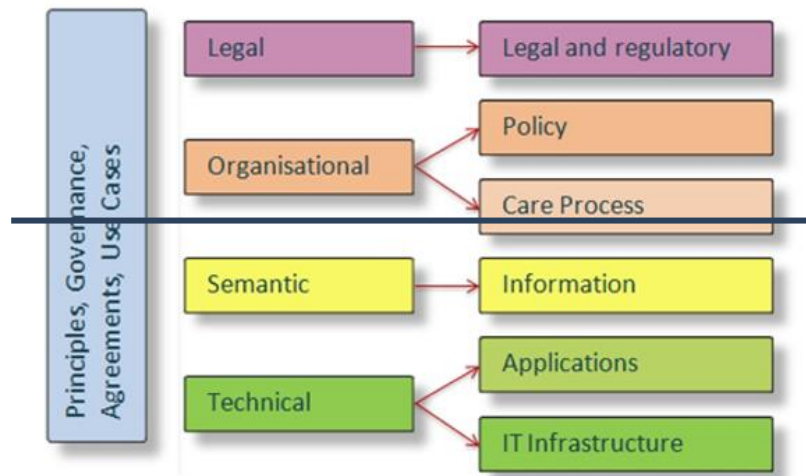 - **Sharing** and **understanding** are equally important

Figure 1: Refined eHealth European Interoperability Framework

Accessible

- Citizens' access to their health information through systems, portals and especially apps is growing. Having access to your own health information, however, does not automatically enable you to understand it and, hence, use it proactively.

- Citizens have different access points to the same health data, e.g laboratory report
  - National eHealth portal *sundhed.dk* (national repository for laboratory reports) for citizens and HCPs
    - *MyHealth* App
  - *MyGP* App to communicate with the family doctor/general practitioner (GP)
    (ordered by GP + analyzed by staff in primary care)
  - App access to hospitals healthrecord system (EHR)
    (ordered by hospital + analyzed at hospital laboratory)

- **Different terminology** and **design** confuse the citizens
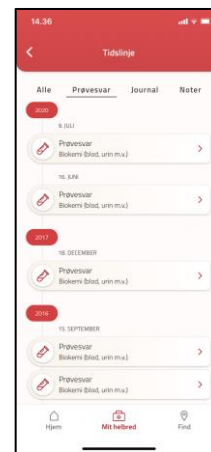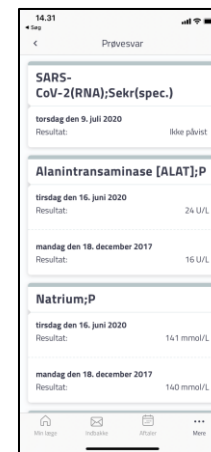
Understanding

- Health and care systems need to take responsibility for this and ensure that a truly citizen-centric approach is incorporated in the applications it offers as part of delivering health and care services.

- Covid-19 became an enabler during the analysis period
  - Extensive test strategy (with PCR-test results sent to GP, and rapid-tests uploaded to the national repository).
  - Citizens should **act upon** "positive" test results in the national health portal *sundhed.dk*
- Challenges
  - **Name** of analysis
  - Result text **content**
    - "Negative" is a good result, and "Positive" is a bad result
    - What is difference between "Not detected" and "Negative"?

Analysis 2020

- MedCom has, in respect to its test and certification processes of health data exchange, conducted a research and stakeholder-based analysis for how the same data, e.g., a laboratory result, should be displayed differently for the citizens than for HCPs but uniformly across the different public health applications citizens use.

- How to ensure that citizens **understand** health data made by HCPs – and at the same time maintain **consistency** in the dialog between HCP and citizen?

- How to **harmonize** multiple views for the citizen of the same data?

- Workgroup with all **stake-holders** (incl. patient associations)
  - International relevant research
    - More eyes on the same data identify errors
    - Choice between education to understand HCP terms or make different UI for citizens and HCPs

Analysis 2020 – Conclusions for citizens' view

- Reduced laboratory report, focus on avoiding misinterpretations
- Adaptive user interface (UI) allowed in Apps, with a fixed minimum content
  - Truncations allowed (but full text shall be accessible)
- Same **terminology** as for HCP
  - **Guide** to understanding the data (reference to medical handbook)
  - Medical handbook for HCP, for empowered patients, and for all citizens
- New indicators (arrow icons), since too high/low is misinterpreted as going up/down
  - Reference range for test result have different colors (red color trigger concern)
  - Same **color** is recommended
  - Better icons or other kinds of indicators
- Different design acceptable, but recommended initial **overview** more similar (sort by sampling date, not analysis code)

Actions 2021

- The work has resulted in a truly citizen-centric 'design' of laboratory results, incl. Covid-19 test, which is being implemented in e.g., the MyGP app but also in other digital services.

- Changes to MyGP App (based on recommendations)
  - Development in progress
  - Evaluation in early 2022
  - Implementation in other applications/Apps

- Future perspectives
  - **Personalised** reference ranges for laboratory analysis
  - Chatbot assistance, e.g. with use of artificial intelligence (AI), to substitute general guides
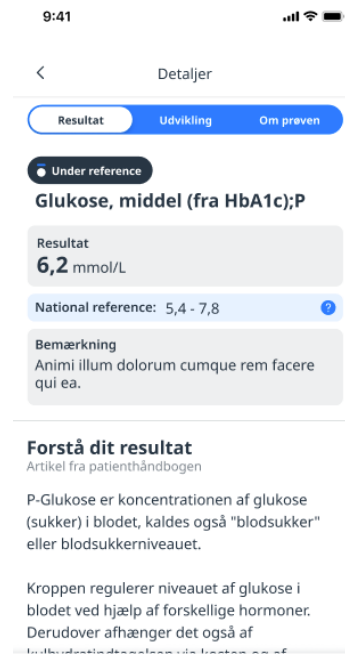
Main points

- Need for further work with the citizens' needs

- Changes to the procedure in MedCom, how to make standards

- Broad stakeholder involvement

- Look ahead for new technology, but await the relevant usecase before implementation