“ONLY ONCE” BEST PRACTICE USE CASE: DENMARK

XShare WP4

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History of the standardisation landscape in the public health domain in the country

After some initial pilot projects with ePrescriptions and laboratory reports in the early 1990'ies, the need for standardisation became obvious. The health authorities and MedCom have since the mid 1990'ies developed interoperability standards, at first for messaging, later expanded for service-based upload to national repositories and last extended for document sharing.

After evaluation, it was soon realised the need for a national roadmap, since the interoperability standards were not sufficiently harmonised.

National Roadmap

Denmark is one of the EU countries to have considered eHealth as a political priority and to have designed national health digital strategies. The last version of this strategy identifies five focus areas to achieve the two main goals of putting patient needs first and making daily workflows easier for healthcare professionals. These focus areas are: the patient as an active partner, knowledge on time, prevention, trustworthy and secure data and progress and common building blocks. The approved Digital Health Strategy 2018-2022 has been extended to 2024.

The Danish Roadmap does not include a specific action point related to the implementation of an "only once" strategy which would better connect primary and secondary use of data. However, the roadmap is flexible and can easily accommodate new initiatives if they are supported by the actors of the value chain. The DK Digital Health Roadmap is thus mainly incremental with however a recent willingness to anticipate most important evolutions such as the EHDS. The institutional landscape is however complex as agreements- involving financial flows- need to be made with all levels (national, regional and local). As a result the country is confronted with several legacy and redundancy issues which are not easy to solve. The initiative described below can thus be considered as being largely a bottom-up one.

Central inventory of registries and metadata used to categorise them

As other EU countries, DK has created its Health Data Authority which has as one of its core tasks to organise access to existing registers. Denmark has a long tradition of collecting and

using healthcare data for treatment and research. The long-established agreed use of personal identifiers makes also possible to link data across the national health registers.

The National Patient Register is the largest register and contains information about all examinations and treatments in Danish hospitals in the last 40 years. Currently 28 national registers are officially referenced.

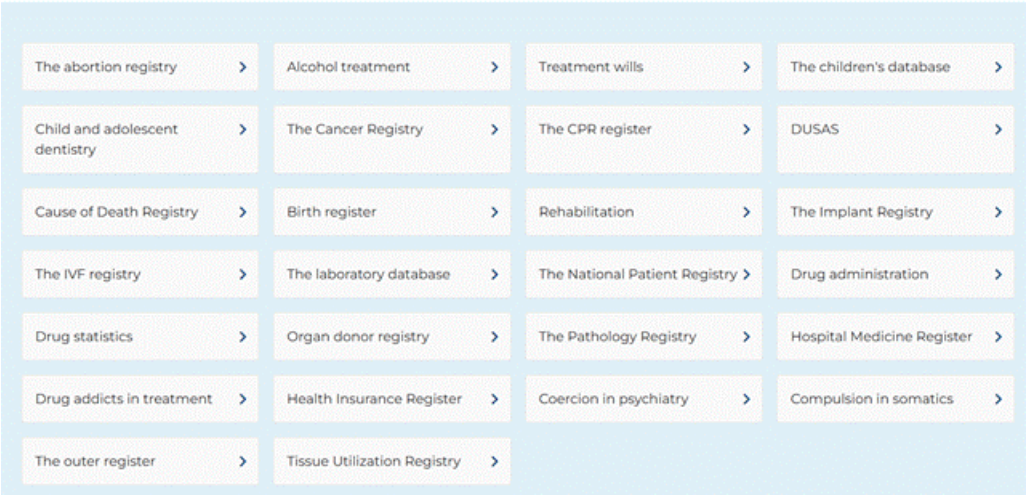


Figure 1: The 28 DK National Registers

The National Patient Register (DNPR) is the largest and oldest register: The DNPR provides nationwide longitudinal registration of detailed administrative and clinical data. It has recorded information on all patients discharged from Danish nonpsychiatric hospitals since 1977 and on psychiatric inpatients and emergency department and outpatient specialty clinic contacts since 1995.

The clinical quality databases, another group of medical databases, have also evolved in Denmark. Many of these databases had been founded and initially operated by enthusiastic clinicians. These databases typically cover all patients with a specific disease (eg, colorectal cancer) or those undergoing a specific surgical procedure (eg, hip replacement). In 2001, Danish Regions (formerly counties) established an administrative infrastructure for approval and support of the clinical quality databases with the aim of meeting the need for monitoring the clinical quality and patient safety. Since 2006, there has been a specific procedure in place to improve and operate the clinical quality databases, and since 2011 they have been organised in an administrative structure, the Danish Clinical Registers.

To obtain approval and public funding, the program requires that a database cover **at least 90% of the patients** with a disease in the Danish hospital system. The National Clinical Registries (RKKP) constitutes the infrastructure of the Danish clinical quality registries and the Danish Multidisciplinary Cancer Groups (DMCG). RKKP manages **about 85 clinical registries**, containing information about individual patients and is exempt from patient consent to data-collection. In most cases, the information collected leads to the publication os a specific (annual) report.

Figure 2: Sample of Clinical Registies

RKKP was constituted in September 2010 by a fusion of 4 existing support organisations. It has a yearly budget of app. 8 million Euro.

RKKP consists of:

- *a center responsible for analytical methods* including defining relevant register population, indicator algorithms, risk adjustment, relevant interpretation of results in the yearly reports, online feedback and communication with and support to the regions and clinical departments with regard to use of data for quality improvement.
- *professional boards* appointed by professional medical and nursing societies for each clinical registry, representing the main clinical stakeholders.

Strategy established to map semantic resources and avoid unnecessary misalignment

There has not yet been a documented initiative to describe those registers with common metadata and discuss possible evolutions in relationship to core data models and shared semantic resources. However there seems to have been an agreement to make use of the WHO International Classification of Diseases for coding diagnostics (ICD-10) in most registries with national extensions, and classifications of treatments. Further the Nomenclature, Properties and Units terminology (NPU) is used in laboratory medicine. Denmark is also a member of SNOMED International, but the actual use of SNOMED terminology is still embryonary.

Initiatives launched to avoid duplication of data and collect data from primary systems

SENTINEL

Brief history

Sentinel was created in 2006 to address the need **to incorporate quality of care knowledge** regarding patients seen in GP practices into the overall knowledge of treatment quality in the healthcare system; later that was extended to the private specialist practices. Access to data is necessary to guarantee the visibility of this care segment in clinical quality databases and ensure knowledge consolidation to support the design of clinical guidelines, etc.

Ophthalmologists and dermatologists were the first private practice specialties to start using Sentinel, **around 2013.**

Today, all specialists in Denmark may use and can benefit from Sentinel.

There are 15 practice-relevant specialties in Denmark, and it is the goal that all practice-relevant specialties will use Sentinel as an **active quality assurance tool** in everyday life and general quality development.

eKVIS (the public unit created to support specialist medical practice) **was established in 2011** by the parties through a collective agreement regarding the need of better coordinating the work around quality of care. Specialties medical practices agreed on implementing the quality themes and tools laid down in the collective agreement. **Professional development** was also identified as a secondary objective. eKVIS works closely with the representative specialties medical organisations and develops its work programme in close dialogue with many collaboration partners with different interests and competences in the area of quality, including the Danish Regions, the Regions' Clinical Quality Development Program- RKKP (which will become in 2025 the Danish Healthcare Quality Institute), the Patient Reported Outcome (PRO) secretariat, sundhed.dk and others.

As this is also relevant for xShare, it is worth mentioning here specifically the PRO initiative. It has the aim of standardising PRO instruments within specific clinical areas is supplemented by an aim to standardise across clinical areas – when feasible. The national work on PRO includes work to identify and share instruments that can be used generically across clinical areas, e.g. lifestyle habits. To enable and assure standardised use, both within and across sectors, the PRO instruments are published as 'PRO Packages' in a national repository from where they can be retrieved by registered users and implemented in local IT systems. Each package contains the questionnaire, algorithms to interpret and provide an overview of each patient's answers and recommendations for use.

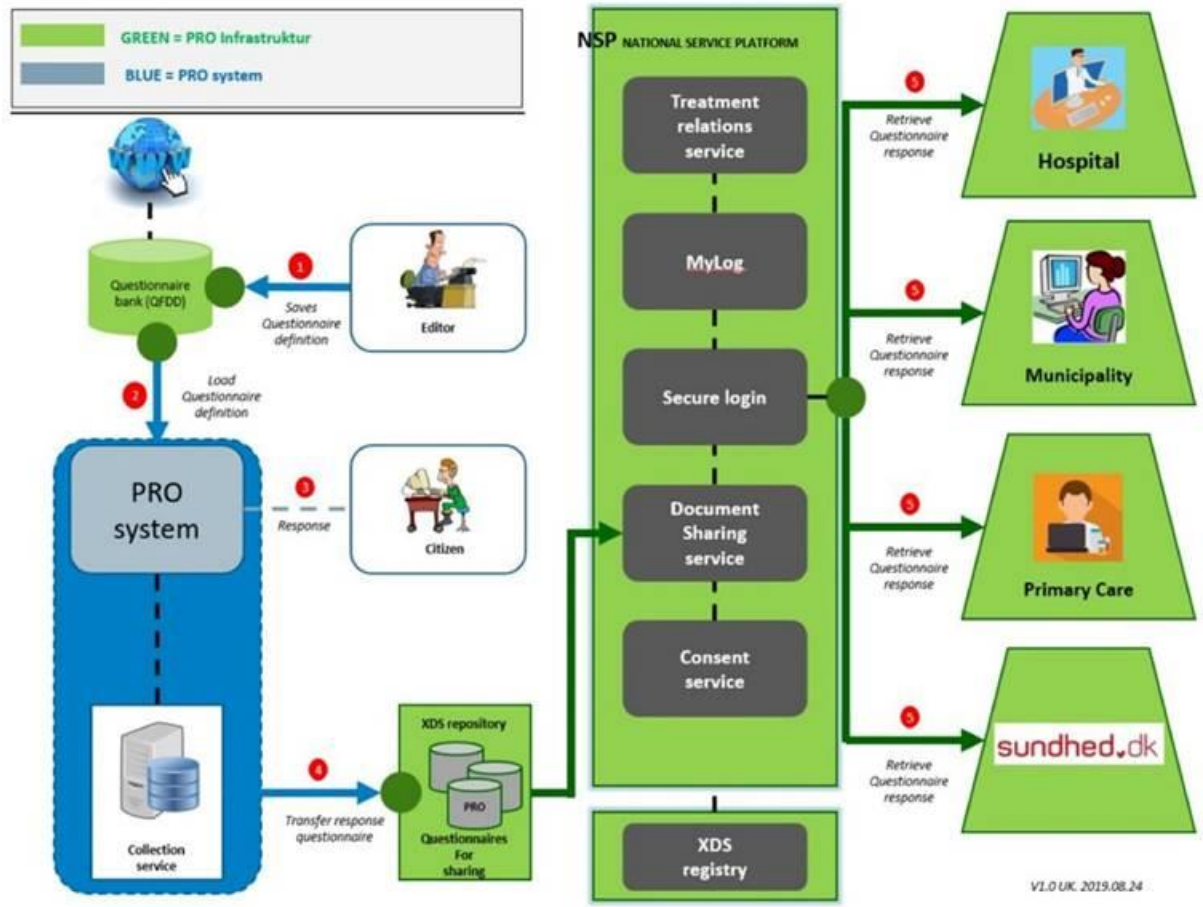


Figure 3: National IT infrastructure for the sharing of health data. XDS=Cross-Enterprise Document Sharing

The common public health portal sundhed.dk **was established in 2003**. Behind sundhed.dk are **Danish Regions, the Ministry of Health and the National Association of Municipalities.** Via Sundhed.dk, each citizen may see the health data that the government has registered about him/her.

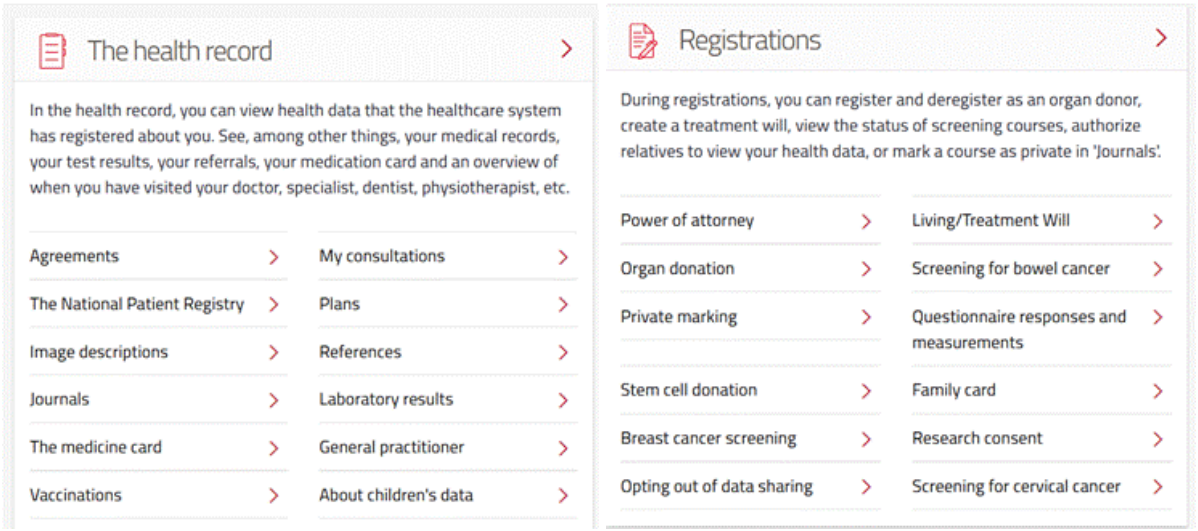


Figure 4: Overview of health data available through the portal of Sundhed.dk

The unit must further develop tools for data-driven quality work, so **that the practicing specialists can target and continuously ensure high quality in the treatment of patients.**

The SENTINEL application is however not used anymore by the GPs. Historically the GPs also used Sentinel as a pop-up application guiding the doctor, but due to several issues (read the interview in annex 1) the GPs stop using Sentinel, and now use another system, called "Health Hub", developed by PLSP (company created by the association of the six vendors of EHR for general practitioners).

The current situation is thus that there is a competition between the applications developed by Sundhed.dk and PLSP where the PLSP is now trying to attract other clinics than only GPs, betting on the better quality of the system proposed.

The Sentinel unit must develop tools to work with data-driven quality, so that the practicing specialists can purposefully and continuously ensure high quality in the treatment of patients.

Funding

eKVIS is financed by the **Foundation for the Professional Development** of Specialist Medical Practice, which also provides financial compensation for further education activities as well as a pool of research in specialist medical practice.

Today, Sentinel is **run by a sunded.dk unit** and is financed by the parties to the agreement: FAPS and Danish Regions- via this Foundation for Professional Development in Specialist Medical Practice.

Governance

Development and implementation of projects in Sentinel takes place between eKVIS, sundhed.dk's Sentinel unit and the specialist organisations.

All quality projects are run by eKVIS and are decided by **eKVIS's steering group** with representatives from the FAPS board (Association of Practicing Specialists) and Danish Regions.

The legal basis for all use of data is based on the fact that a data processing agreement has been signed between the practicing specialist and sundhed.dk's Sentinel unit.

Other Initiatives to support the only once strategy

The Health Hub

Already mentioned above, the Health Hub has been developed by the association of the four (ex six) EHR developers operating in Denmark used in General Practice as an alternative to the SENTINEL system. The system was developed collaboratively by the industry with a view to improve usability and security; it offers roughly the same functionalities than the SENTINEL system with however of course a different interface. More details can be found on the Health Hub history and development in the summary of the interview of one the original developers in annex 1. One of the reasons which convinced the industry to invest in this system was linked to the decision in 2018 to introduce a new bundled payment scheme for patients with type 2 diabetes and/or COPD. GPs now have population and treatment responsibilities for these patients (not requiring specialist services) and options for referrals are limited. GPs are paid, in addition to the capitation payment, a monthly fixed fee per registered patient with type 2 diabetes, COPD or both; GP practices need to synchronise their data with external registers such as the regional quality development program (RKKP) or the care plans made by GP together with patient.
The Health Hub supports a range of Extract, Transform, Load (ETL) processes that are vital for seamless data exchange across the healthcare system, including e.g. Standardized Electronic Messaging, cross-mappings or real time data monitoring.

The KL gateway

The 98 municipalities in Denmark have developed a "KL gateway", a FHIR® server where the municipalities can upload data, and the purpose is to allow a fluent upload of the data to numerous national databases.
The association of municipalities (KL) have defined a logical model for the municipality specific domain (FKI), which the EHR used in in the municipality can use or map into, so that the same data can be used for multiple purposes.
The first purpose is the common management information system (FLIS) for the whole municipality sector. The next projects in line are data for prevention and health promotion, and data for rehabilitation which are uploaded to the Health Data Authorities.

Present development is extending the healthcare dataset with information about child healthcare and are planned for upload to the National Clinical Registries (RKKP) late 2024.

CAPRI

CAPRI stands for "Clinical Adaptive Platform for Research and Implementation". It aims at a faster, better, more efficient and cheaper **comparison of interventions across a population** by re-using data through **automatic data collection** and standardising trial infrastructure, and framework.

The CAPRI system, or Clinical Adaptive Platform for Research and Implementation, is an advanced framework implemented in Denmark aimed at enhancing clinical research efficiency

and effectiveness, **particularly in critical care and intensive care settings**. This approach uses adaptive platform trial designs, which allow for real-time adjustments to trial protocols based on accumulating data. These adaptations include changing study arms, adding new treatments, or focusing on more promising interventions, all without restarting the trial process.

The key aspects of the CAPRI system include:

Efficient Trial Designs: By integrating adaptive methodologies, trials under CAPRI can assess multiple treatments simultaneously and refine their focus dynamically, which reduces costs and timelines while maintaining rigorous standards.

Integration with Clinical Practice: CAPRI is built to incorporate findings directly into clinical workflows, ensuring that evidence-based interventions are rapidly implemented in patient care.

Collaboration and Sustainability: The system emphasizes a long-term, collaborative research model that involves clinicians, researchers, and patients to develop and evaluate interventions continuously.

Together with INCEPT (the Intensive Care Platform Trial research programme), CAPRI is part of a broader movement, including initiatives such as REMAP-CAP (Randomized, Embedded, Multifactorial Adaptive Platform trial for Community-Acquired Pneumonia) at the European level, which aim to optimize critical care strategies using adaptive trial designs and data-enabled platforms. These initiatives leverage electronic patient records and Bayesian frameworks for precision medicine in areas such as sepsis, respiratory failure, and acute illnesses.

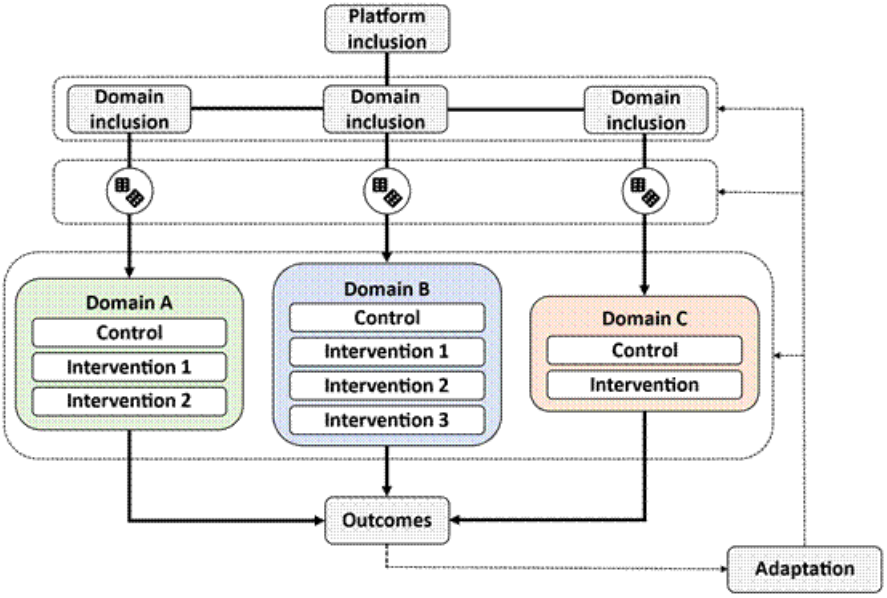


Figure 5: CAPRI simplified architecture

Detailed description of the Sentinel application

Application objectives:

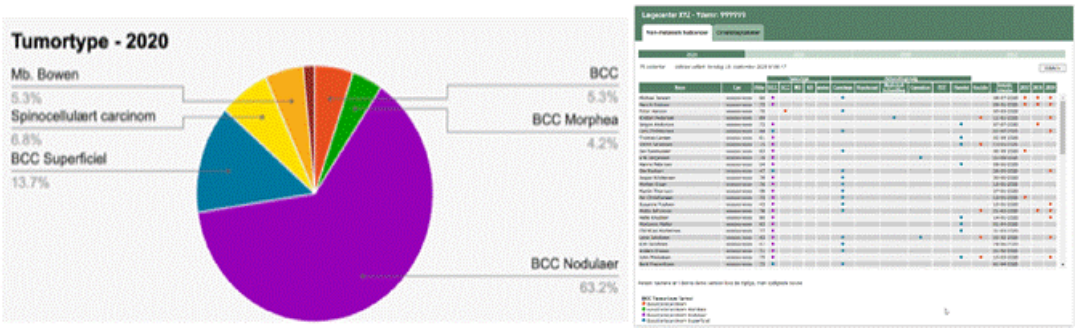
Sentinel is an IT application that is interfaced with the medical practice system, so that clinical data can be reused for the quality projects that are worked on in specialist medical practices. Sentinel is used for **reporting to clinical quality databases**, **to support quality development in clusters and the work with diagnosis coding**. The quality work is linked to projects, which are defined by each individual specialty.
The project determines **which clinical goals** are pursued on and which data are needed to monitor each of those set goals.

Sentinel is interfaced and integrated with the HCP patient record. Sentinel can thus be seen as an extension of the specialist's own EHR system: the specialist is responsible for the data stored in the patient record and also for information collected via Sentinel. Sentinel is thus creating a **direct connection between primary and secondary use of data**. Sentinel automatically **copies all structured data from the HCP journal**: it collects data from the patient record and returns it to the data producer in a structured and personally identifiable form. Copied data are stored in a **local Sentinel database** that is part of the HCP journal system. Data are then also kept separate for each clinic in the sundhed.dk databank in exactly the same way as an account in an ordinary bank.

Depending on requirements of each quality project, **information that is not already structured in the EHR may be needed**. This could, for example, be about assessing how a clinical guideline has been implemented.
In such cases, a pop up is displayed if, for example, the HCP enters a specific diagnostic code. Because Sentinel copies structured data from the journal, fields appearing in the pop-up are always available and pre-filled with the copied data from the local Sentinel database.

The same information is thus only introduced once. Tis way one can avoid having to enter the same information several times. The pop-up can function both as reminder and decision support in the patient treatment.

Quality reports
Data in local EHRs are linked to specific patients. To improve quality of care, it makes sense to provide the HCP with **different visualisation patterns**. The Sentinel system can provide, for example, a **global overview of the HCP patient population**, **list patients with a specific diagnosis**, or it may also be possible eventually **to use quality reports to see development over time for selected parameters**.
The choices made by the HCP in relation to the exchange of data during project registration determine which quality reports can be accessed, as **only data for which you have given permission are exchanged**.

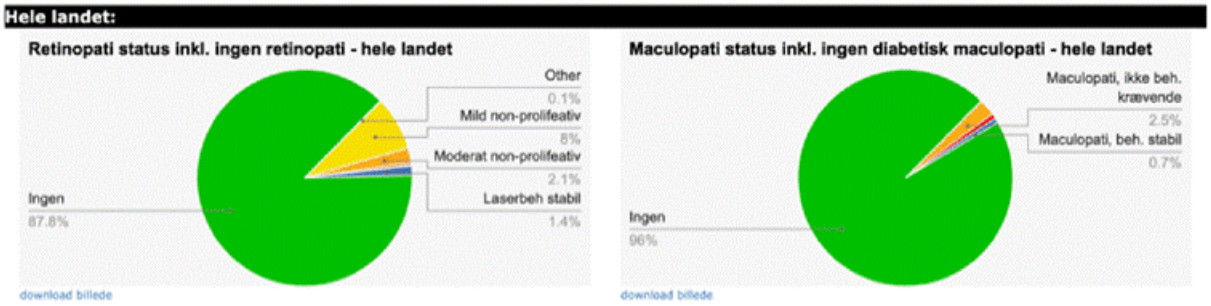


Examples of visualisation patterns offered by SENTINEL for a practice

Benchmark data

As part of the provided overview, data are anonymized in the sundhed.dk database and are transferred to a statistics database.

Anonymized data can be shown for a specialty or a relevant group of specialists. In addition to benchmark data at the clinics, information in the statistics databases is used for disclosure, e.g. when, according to the agreement, the regions must receive information about diagnosis codes from the individual clinic. **Data must not contain personal data that can be traced back to a specific patient, but data is linked to a specific clinic**.



Examples of benchmark for retinopathy and diabetic maculopathy

Agreed data processing finalities:

- Use by the specialist himself
- Individual and practice benchmarking
- Reporting to national approved clinical quality databases
- Passing on diagnosis codes to the regions
- Quality improvement in treatments
- Sentinel quality check and diagnostic codes

Who else than the HCPs can access the Sentinel data?

The regions

The regions have access to **diagnosis codes** from the individual specialist clinic.

The Ministry of Health has established an Executive Order on the reporting of information from specialist medical practices to the Danish Health Data Agency, which came into force on 1 January 2024. Access is given to the most frequently used diagnosis codes at clinic level, municipal level, regional level and national level. The diagnosis codes are anonymised so that the individual patients or their social security numbers cannot be identified.

These are diagnosis codes where a service code has been set on the same day. Sentinel checks whether a service code has been set, but not which one, and thus there is no linking of the diagnosis code with a specific service code. The solution ensures that diagnosis codes are not passed on to patients who are treated privately or under a health insurance for the regions. Diagnostic codes registered from 1 August 2023 onwards are displayed.

The health journal

In the Health Record, diagnosis codes and epicrisis (critical or analytical summing up of a medical case history) are shared with the patient himself and other practitioners who treat the patient. The obligation has been agreed upon in the collective agreement with took effect effect on 01.11.24. Data are shared with patients from the specialist registers for the "Health record" project in the Sentinel administration module. This is thus personally identifiable information.

Region Nordjylland is the operating supplier of "Sundhedsjournalen". A sub-data processor agreement has been signed between Sundhed.dk and Region Nordjylland whereby Region Nordjylland is imposed the same data protection obligations as those set out in the data processing agreement between the specialist and Sundhed.dk.

A function has been developed that gives a specialist the possibility – by agreement with a patient – to block the uploading of data to the Health Record for the patient in question.

Clinical quality databases

The Ministry of Health has established an Executive Order on the reporting of information from specialist medical practices to the Danish Health Data Agency, which came into force on 1 January 2024.

The registers include data from local health services together with data from General Practice and the municipalities.

The following information is provided:

- Diagnoses (type: action diagnosis or by-diagnosis and date)
- Date of referrals to and from specialist medical practice
- Date of dispatch of epicrisis.

Concerned Data

The structured data that are currently captured are:

- Diagnostic codes
- Laboratory results/values
- Medication information
- Patient ID
- Practice information

But also:

- Electronic communication, referrals, prescriptions, discharges letters etc.
- Clinical procedures
- Payment information (only for chiropractors and physiotherapists)

The data captured depends on each specific approved project.

For the Coding of diagnostics, **ICD-10 is used**. Diagnostic coding is not currently mandatory for radiologists and anaesthesiologists who only anaesthetize.

Architecture

The following two figures provide an overview of the SENTINEL system architecture which summarises the description made above.

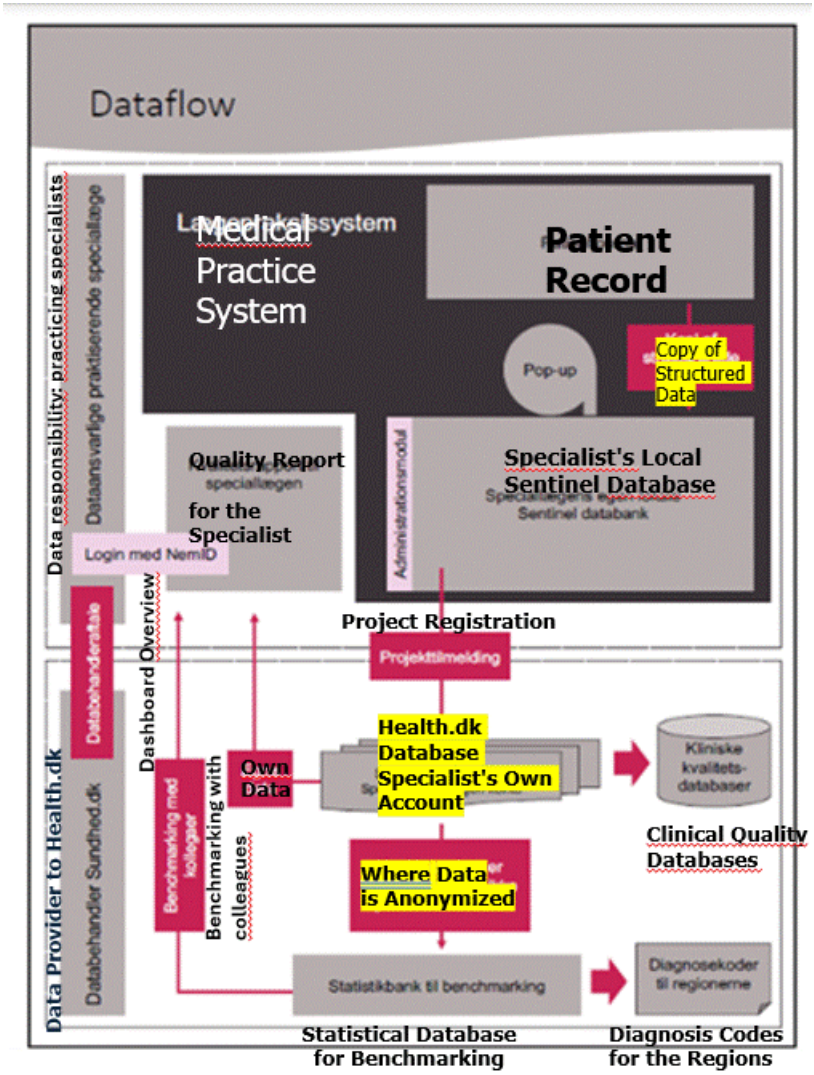


Figure 6: SENTINEL data flow

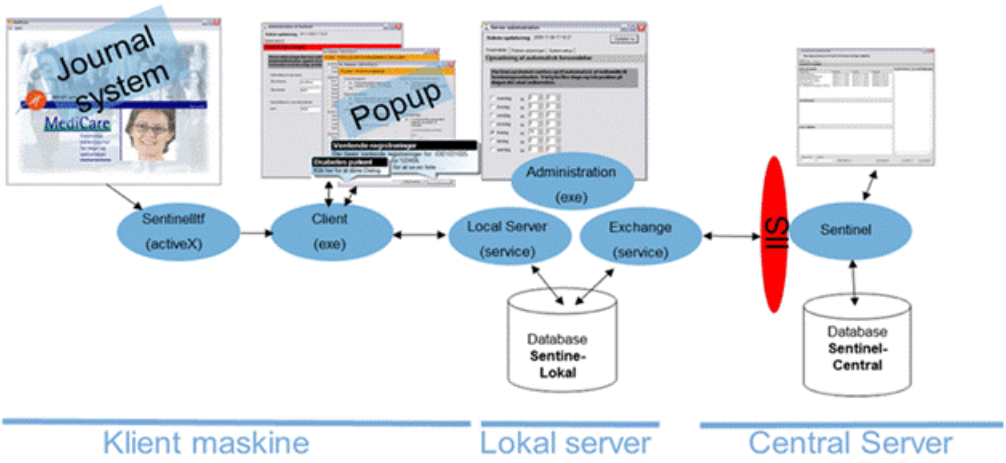


Figure 7: SENTINEL Simplified Diagram

To provide a comparison, we also reproduce here below an overall vision of the interactions of the solution developed by the collaborative company PLSP used by General Practitioners. As one can notice, the industry has clearly understood the strategic business importance of

positioning itself as a champion in its capacity to connect the EHR systems with external databases and third-party applications. To make this happen, all GPs EHR are sharing the same basic data model.

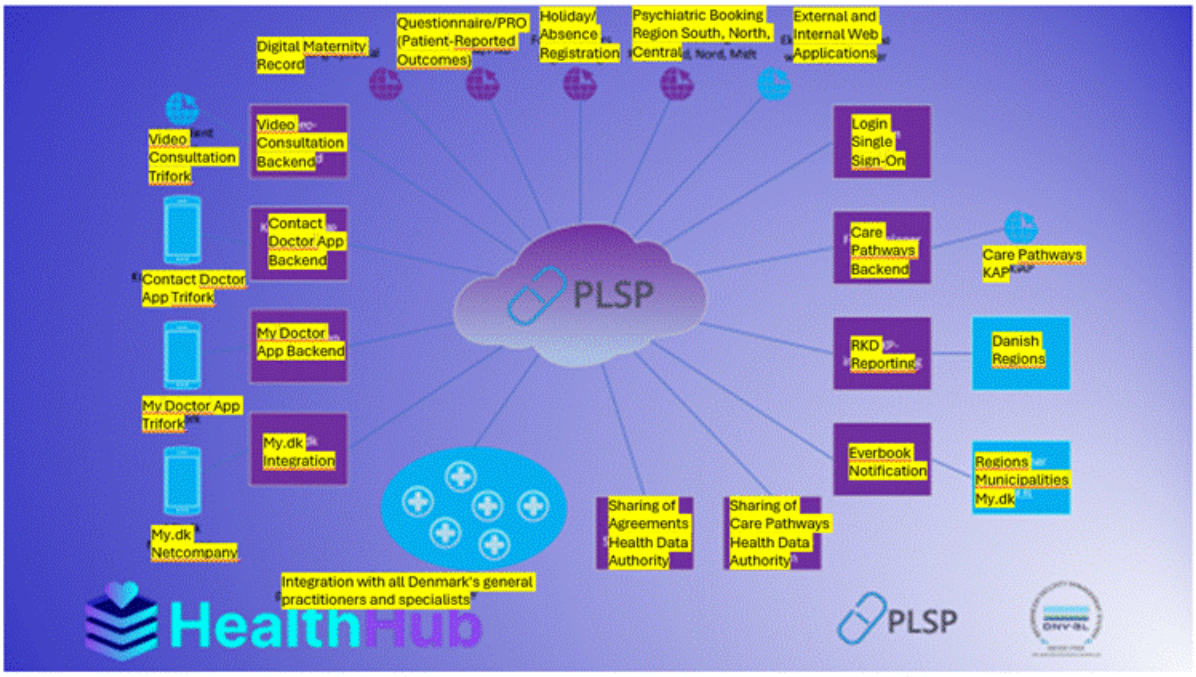


Figure 8: Representation of connectors with external sources of the Health Hub

Evolution of the application since its creation

The creation of the Health Hub has convinced Sudhed.Dk to improve both the look and feel and security of the SENTINEL application. However, SENTINEL remains mainly focused on its key mandates: benchmarking, knowledge management and provision of data to regions.

Expected impact of the EHDS implementation

The SENTINEL and Health Hub initiatives have proven their added value both for primary and secondary use of data: They have been largely adopted and implemented. However Denmark has been slow in reflecting on the conversion of national legacy standards towards internationally recognised standards such as FHIR®, CDISC® or OMOP®. Denmark is also member of SNOMED-CT international but has not yet made a real extended use of this important resource. The Industry via the Health Hub seems to have understood the need make very quick progress and is expecting that official DK choices will be closely correlated to the upcoming EEHRxF specifications. The EHDS implementation has also begun to have a major impact on the governance and infrastructure for the secondary use of data with the merge of several organisations and the creation of the National Health Data Agency. EHDS will

have a deep impact on secondary use of data as many of the supported use cases are cross-border by nature. As all secondary data with EHDS is expected to be for further European use by default, the task of mapping existing registries with the European EHR exchange format will become critical.

Conclusions

For the sake of concision, we do not reproduce the conclusions already mentioned in section 8.1 of this deliverable.

The SENTINEL and Health Hub initiatives have succeeded to create a direct connexion between primary and secondary use and have bought the users in thanks to an adapted mix of drivers, providing thus one of the very first European examples of “only once” best practices. Furthermore, the solution deployed has a very wide spectrum as it covers all medical specialties. This is thus an impressive achievement and an excellent preparation for the upcoming EHDS. However Denmark needs to urgently appropriate international standards and initiate urgently conversion of legacies. Only at this very condition, will the country be in the best position to make the best of this best practice in the context of the EHDS.

Annex 1: Interview with Michael Michael Frank Christensen (ex. EG Healthcare), representing the GPs EHR industry

This interview was conducted in October 2024. Michael Frank Christiansen is the Vice-President of EG A/S which is major software developer in Denmark active in multiple domains, including health and social care.

The interview is focusing on the rationale behind the creation of the Health Hub, in parallel to SENTINEL

INITIATION of the Health Hub

Initially, the initiative was not driven at all by Industry. It started in a relatively small circle of healthcare professionals who wanted to have more information (knowledge) on certain clinical conditions and focusing on specific patients. The initiative was received positively and developed quickly. However, concerns quickly emerged – especially among GPs – related to privacy and data protection issues on one side and transparency on the use of the data on the other side. Data were gathered centrally but there was no clear view on what the data would be used for and by whom. The initiative experienced then a kind a standstill.

MOTIVATION FOR INDUSTRY

The EHR producers have then decided to relaunch the initiative but to develop their own system. They had been listening to their customers and were in close contact with PLO – the DK GPs association. The demands coming from individual GPs related to specific feed-back and research related to specific diseases. The producers also understood that the appetite for data was becoming much bigger and the number of external parties in demand for data was also quickly expanding.

They believed that taking the initiative would allow them to remain partially in control and be in a better situation, to negotiate with external parties. They wanted also to prevent a situation where they would have to comply with multiple requirements and connectors from external parties while ensuring a better buy-in by the GPs by focusing on improved usability, privacy and security and transparency on data collection finalities.

The GPs EHR producers took then the initiative to meet with MEDCOM, PLO – The DK GPs association- and the people in charge of initial system within SUNDED.DK; the discussion focused on how to ensure a generic transmission of data without having to develop new connectors for each new data receiver. It also became clear that the EHRs industry was best positioned to find the right compromise between the point of view of GPs and existing and future external parties. Access to data of the GPs segment by external parties had to become easy but had to remain under the control of the GPs providing all necessary credentials in term of privacy and security.

This Industry initiative is also seen as having an impact on the SENTINEL system developed by SUNDED DK as it probably also contributed to its adaptation: the system also became more transparent with a capacity for the specialists to see and choose what their data are used for and no more centralisation a priori of the data.

It should be noticed that – contrary to the situation in many other EU countries- the huge majority of consultations by specialists do not take place in hospital setting but in private practice. Specialists are thus using roughly the same EHR software's than GPs. The patient journals are thus roughly the same for GPs and Specialists, but they use different interfaces to share data with external parties (SENTINEL for specialists and Health Hub for GPs).

The legal incentive (data sharing has become compulsory only since 2024) has to be seen as the final stage of the process but actually it Is not a revolution as it only adds the legal lawyer to a process which was already largely implemented and supported both by Industry and users

HOW DID YOU GET ORGANISED?

Cooperation between Industry and official public body such as MEDCOM has already a long history in Denmark. In particular there was a wide consensus that interoperability needed a strong cooperation between all actors involved and that competition on this aspect between Industry actors should not take place. Competitors came also to see each other as colleagues who needed to reach agreements, especially on interoperability issues. As a patient, you should be sure that all systems operating In Denmark can deliver the same minimum level of quality. Competition takes place between solutions mainly when considering usability, flows and of course prices.

In 2018, the 4 EHRs producers have decided to create a for profit **dedicated company called 'PLSP A/S"** to ensure the development and maintenance of the GPs data sharing application

called "**Health Hub**". The company is thus working with an independent staffing. Each company has an equal share (not representing thus each company share of the market). The consolidation of the market in the last 20 years: from 13 actors 20 years ago to 4 6 systems) today has of course greatly facilitated this process.

There have been a number of problems to be solved but without major crisis. The initially approved development timeline was globally respected, and the first version of the application was made available within one year. The decision to have an independent company proved efficient in achieving the set goal as individual companies need to constantly integrate new priorities which can thus have an important impact on development.

The new company is responsible to negotiate with all third parties – including thus contracting will all data receivers.

Although the initiative launched by Industry was necessarily praised by Public Agencies such as SUNDED.DK and MEDCOM, there has been an active collaboration to ensure it success. Both MEDCOM and PLO have been actively involved in the development phase. The company also **received public financial subsidies** to support the initial development phase. The work necessary to interface the application with the EHR individual systems was however supported by each individual system.

The users club of each company/product has been used to test and validate the application. Each company was also responsible to ensure all needed training and support activities. A lot of work with PLO GP organisation and MEDOM is part of the group. Involving different GPs. But training and support was organised by EHR vendors themselves.

A **common data model has been adopted and implemented by all EHRs systems**. The central data element is today the diagnostic which is coded with ICD-10, Lab national codes and a limited number of procedures coded with the local classification DKS. All systems are using the same standardised web services.

All data collected from GPs are stored on a cloud under the control of the company.

Data could also potentially be sold to third parties provided that companies and PLO are in agreement with the terms. This has however not happened until today.

Although no formal specifications compliance testing has been performed, thanks to its intensive collaboration with the company, MEDCOM can be considered as the certification entity which validated the application.

WHAT HAVE BEEN THE MAIN DRIVERS TO SUPPORT ADOPTION AND USE BY CLINICIANS ?

The Danish health system is a decentralised one but is funded by the state. There are thus no financial transactions between the patients and the HCPs. Healthcare professionals are thus directly contracted as employees by the State. As employees, they need to demonstrate that their level of activity is sufficient but in the absence of financial transactions this is difficult to demonstrate. The first driver supporting adoption has been the capacity to demonstrate its level of activity and compare it with his pairs. It was seen also as a good system to demonstrate their compliance with a number of compulsory care pathways for specific diseases (e.g. diabetes) or problems (smoking).

The second driver for HCPs is related to the capacity to be provided with a global analysis of their patients portfolio which can be visualised according to a number of criteria and be compared with average local, regional or national portfolios.

The now compulsory sharing of essential data with central and regional authorities is not requiring additional work from HCPs as it refers to the same dataset than the one required for practice analysis. It is of course not true for non-official additional requests which then require specific developments and/or efforts of developers and users.

There have been intensive discussions about the possibility to share the patients journal but without reaching a consensus for now. However in 2023, an agreement has been reached over the "patient cockpit" which can be seen as the Danish equivalent of a Patient Summary with an implementation foreseen from the end of 2025 on. This should provide the opportunity to develop additional data sharing use cases.

The company is thus now the key node to develop additional features, focusing on exchange of more standardised medical procedures and laboratory results. The company is also aware of the need to rely more on international standards and make use of an extended set of terminologies.

WHICH POSSIBLE EVOLUTIONS?

The company is very much aware of the need to rely more on international standards and make use of an extended set of terminologies as the appetite data will keep on increasing.

There is thus a stated willingness to evolve and rely increasingly on the FHIR standard. However, dealing with legacies remains complex and getting rid of the old DK standard EDIFACT might take as long as a 10 years. Demark was often seen as a e-Health front runner in Europe but alignment with EU specifications and use cases was up to now not a priority even when the global infrastructure began to become more mature Thanks to the Danish regions, priorities are now been adapted and the question of alignment with EU standards is now much higher on the agenda. This must remain a point of attention as there is a national tendency to privilege national solutions and the EHR market remains largely a national market.

Annex 2: Interview with Dr Hanne Roed, Ophthalmologist and user of the SENTINEL system

The Interview took place on October 10, 2024 and focused mainly on the natural incentives for the actual use of the SENTINEL system.

MOTIVATION

We are paid by the state, and we are paid a pretty small amount per patient. So we need to have a very big patient turnover to make a good living. We're thus pretty busy. So an average day would be 40 patients. For specialties such as ophthalmology and ENT (ear, nose and throat), there is no referral requirement, and people may request a consultation anytime. There is also no "out of pocket" contribution from the patients and hence no financial or

administrative flows with the patient or the State. For other specialties a referral is required and hence there is a capacity to monitor the flows.

And this means that the time per patient is limited. So the main thing for us in private practise is to reduce the time we spend on registering things. And since we don't have a benefit from it on a direct basis, then we need and we need to have processes to help us do that as fast as possible.

We have a union for private practitioners and our scope is also to get political attention and to get the politicians to see how much we actually produce and also to get some science out of this.

Because if we can contribute to science and knowledge management, we have more value as partners from the State point of view.

EXPECTATION

What I expect from this system is to be able, for all the codes of diagnosis I entered, to verify how many patients I actually see and how often I see them in order for me to produce statistics.

And then there are some specific requirements. We have a diabetes database which locks into my system and every time I enter a diabetes related code, every -all patients need to have a diagnostic code-then there will be a pop up and I will have to provide a number of complementary information. But pop ups only work if they are in line with the doctor needs and workflow. They thus need to be carefully selected by the doctor, otherwise the doctors will just skip over it. For Diabetes, everybody reckons it is useful.

This gives us also access to statistical material from a very large population and specifically, part of that population, the diabetic population.

As we are using the CPR – an official personal registration number- we can actually follow the same patient throughout the system. And we can see who will become worse, who will become better, who does not progress. And this provides us with the needed data for evaluating how often we need to see these patients. How often do we need to to do fundoscopy, how often we need to look in the eyes to see if they have retinopathy etc..

And actually we are able to reduce the number of visits per patient because we have very good data and we can thus "profile" our patients, and especially the most complex ones, like the ones with diabetes for example.

The knowledge is improving year after year as we now have a database covering many years.

WHAT IS MANDATORY?

The only mandatory thing is to enter a diagnosis and then – for the agreed diagnosis codes- requested information can be pulled out from the system. But of course, we cannot have a pop up for all patients and for all diagnostics because that would be much too time consuming. However- even if it is used not to be compulsory -it is still important for me to have diagnostics encoded for each patient as I am then in a position to have a more evidence based discussion with the policy-makers and of course because it can contribute to knowledge management and hence better health policies.

Since this year, the transmission of the ICD-10 diagnostic codes are compulsory but I am not sure it is already widely implemented. Furthermore, I do not think the authorities are making use of it yet. This is pity. I'm affiliated with the Big Eye Fund where we give money for research and one of the applications was to find out how much diabetes medicines can have an impact on problems in the eyes. They plan to analyse the national Database but as for now it excludes 95% of the patients who consult in private practice.

We need all specialists and healthcare professionals to collaborate and thus the system needs to focus on the most acute needs in order to guarantee both a wide coverage and a good data quality. Other important needs will probably emerge and will be discussed, and then additional pop-ups could be added.

In summary, the participation of clinicians is first of all motivated by the need to demonstrate your level of activity to the employer (the State) but given important workload, the data sharing also allows you to have evidence to support the practice and make concrete decisions on patient follow-up which helps you to "rationalize" your work.

A CONTRIBUTION TO POLICY

This is thus also an important "political" tool: we need to have the evidence to tell the politicians how many patients we actually see because we need them to be aware that we need more manpower. 95% of the ophthalmology patients are consulting in private practise. In Hospitals, everything is recorded, and the State has access to the needed information to plan resources allocation. This is not the case for private practice. This is essential as we play a major role in the Danish Health system, and we want to be part of the discussion on its evolution and future planning.

DECISION SUPPORT AND USABILITY

The SENTINEL system can also be used to provide some kind of decision support: comparing patient with similar clinical patterns, similar history or similar interventions or procedures. But currently it is not very detailed, so it is not very much used.

We actually use the data collected to compare our practice pattern to national and regional pattern and they are also used for quality control, for education and to optimize our clinical decisions.

Using ICD-10 to code diagnostics is not time consuming for me: My system allows me to register with my own words all the main diagnoses I am using and they are mapped to the right ICD and other needed codes. I still have to look sometimes for additional codes but this is the exception not the rule. We are only coding a very limited number of procedures, mainly for billing purpose.

Denmark is a member of SNOMED International but in practice SNOMED-CT is not used in Denmark, only ICD-10 is.

CO-CREATION

Looking back at the initiative and how it has been developed, we cannot say that we have really been involved. Only a few people and mainly unions were. And our main motto was: " we want to reduce at the very minimum the number of clicks we need to do". All healthcare professionals have been correctly informed about the application. However, I am not sure if

they are aware of all the added value it can bring. We are trying to trigger more discussion, and interest is raising now that we have good statistics to show, such as for example the diabetes screening. But not everybody is interested to take part in this as they have other priorities. However, I believe the initiative is now widely supported and everybody accepts to provide the required info.

The system is pretty straightforward- kind of "plug and play": So there was no need for a lot of training as there was also a support service available both from SENTINEL and the EHR producer.

Altogether the system is made in such a way that I do not need to bother about external interfaces when I am sharing my data, so there is zero duplication.

COCKPIT IMPLEMENTATION:

Specialists do not seem to have been involved in discussions around the "cockpit" aimed to provide a global overview of a patient situation at a certain point of time. But from a specialist point of view this might not be seen as a priority. It is more a tool for GPs while my role is making available to them information under my direct responsibility (i.e. ophthalmology).

DATA PORTABILITY:

Specialists are quite reluctant to change their EHR systems and are not thus not seeing data portability as a major incentive to boost interoperability further.

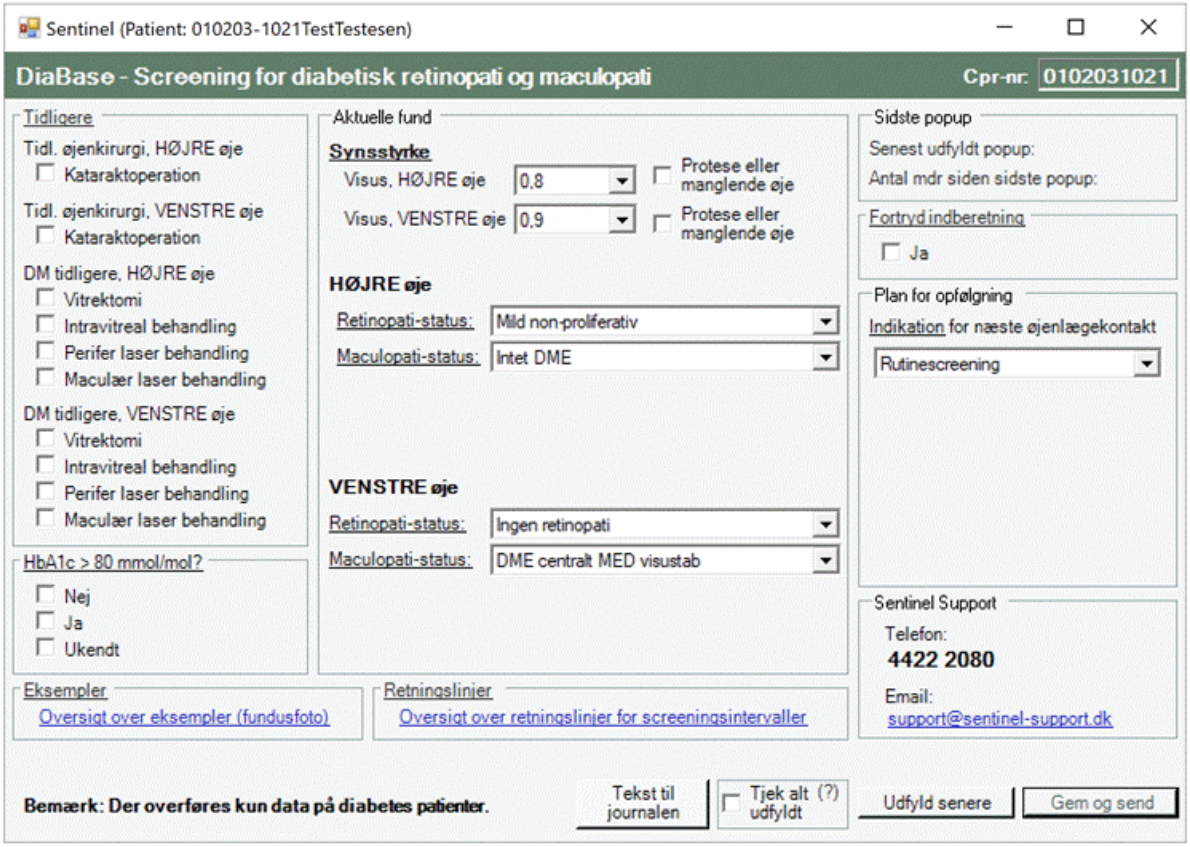
WHAT DO YOU THINK IS STIL MISSING TODAY ?

In my specialty having access to all relevant pictures produced in the country and in particular in hospital setting would be a big plus, bring more efficiency in our work and support collaboration with colleagues.

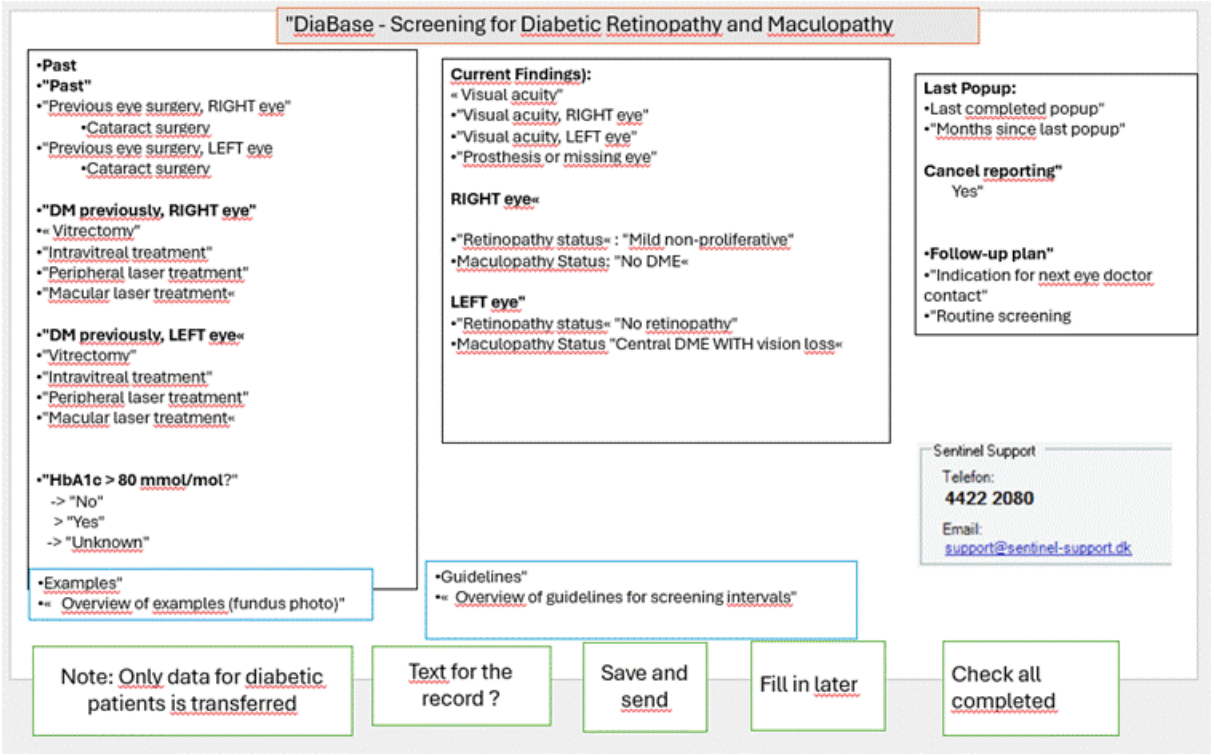
PARTICIPATION TO RESEARCH:

If my system could connect to ongoing research and support the selection of patients and allow the pre-testing of basic research, I would be very happy to contribute. But actively participating in research is more time consuming.

Annex 3: Free Translation of the Diabetes popup Dataset related to diabetes



Free translation:


"DiaBase - Screening for Diabetic Retinopathy and Maculopathy
•Past
•"Past"
•"Previous eye surgery, RIGHT eye"
•Cataract surgery
•"Previous eye surgery, LEFT eye
•Cataract surgery
•"DM previously, RIGHT eye"
•« Vitrectomy"
•"Intravitreal treatment"
•"Peripheral laser treatment"
•"Macular laser treatment«
•"DM previously, LEFT eye«
•"Vitrectomy"
•"Intravitreal treatment"
•"Peripheral laser treatment"
•"Macular laser treatment«
•"HbA1c > 80 mmol/mol?"
-> "No"
> "Yes"
-> "Unknown"
•Examples"
•« Overview of examples (fundus photo)"
Current Findings):
« Visual acuity"
•"Visual acuity, RIGHT eye"
•"Visual acuity, LEFT eye"
•"Prosthesis or missing eye"
RIGHT eye«
•"Retinopathy status« : "Mild non-proliferative"
•Maculopathy Status: "No DME«
LEFT eye"
•"Retinopathy status« "No retinopathy"
•Maculopathy Status "Central DME WITH vision loss«
•Guidelines"
•« Overview of guidelines for screening intervals"
Last Popup:
•Last completed popup"
•"Months since last popup"
Cancel reporting"
Yes"
•Follow-up plan"
•"Indication for next eye doctor contact"
•"Routine screening
Sentinel Support
Telefon:
4422 2080
Email:
support@sentinel-support.dk
Note: Only data for diabetic patients is transferred
Text for the record ?
Save and send
Fill in later
Check all completed