“ONLY ONCE” BEST PRACTICE USE CASE: FINLAND

XShare WP4

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Standardisation landscape in the public health domain in the country

National Roadmap

Finland has long been at the forefront of digital health innovation. Since the 1960s, the nation has maintained national health registries in databases, and today, the entire Finnish population is represented in electronic health records.

In 2021, Finnish municipalities were grouped into 21 welfare counties, responsible for managing social and health services. Additionally, the City of Helsinki and the autonomous Region of Åland, although not counties themselves, exercise similar competences.

Healthcare services in Finland are provided by both public and private organisations. Public services are mainly financed by the state and private services by customer fees. All data collected by public health care and social welfare service providers must be connected to the national data archives. Also private health and social service providers using an information system for the purpose of processing of client and patient data need to share their data with the central archive.

Over the past 20 years, Finnish legislation has actively supported the digitalization of health data through various laws. Notably, in 2007, the framework for a centralized patient data archive was established, and in 2019, the Secondary Use Act was introduced to enable the effective and secure processing of personal social and health data for secondary purposes, in alignment with the EHDS legislation.

National Agencies in Finland related to health information management

- Ministry of Finance is the national body assigning resources
- Ministry of Social Affair and Health legislation is responsible for strategic and steering decisions
- Finnish Institute for Health and Welfare (THL) includes both the National research institute for health and welfare and the Statistics and data authority in health and social services. Besides conducting steering tasks for information management, it also proposes rules, specifications, code systems, information models, etc.
- The Social Insurance Institution of Finland (Kela) is an independent social security institution supervised by the Finnish Parliament, with its own administration and finances. Kela manages national funds and is responsible for the development and maintenance of national health and social services IT infrastructure (Kanta services)
- National Supervisory Authority for Welfare and Health (Valvira) is the central agency operating in the administrative sector of the Ministry of Social Affairs supervising the appropriateness of social and health care.

Other agencies related to information management are:

- Finnish Medicine Agency (Fimea)
- Digital and population data services (DVV)
- Finnish transport and communications agency (Traficom)

Finnish milestones on patient data management

In 2007, the Act on the Processing of Client Data in Healthcare and Social Welfare laid the foundation for central archive services. That same year, the Act on Electronic Prescriptions was enacted, with the deployment of these functionalities rolled out in stages.

The creation of the Kanta Services, a centralized national archive of patient information, was a collaborative effort involving Kela, the Association of Finnish Municipalities, the Ministry of Social Affairs and Health, THL, and Valvira responsible for registering information systems and supervising compliance.

On 20 May 2010, the first electronic prescription was issued during a live broadcast in Turku, with all pharmacies enabled to process electronic prescriptions. To allow users to access their prescriptions, the private patient portal, MyKanta, was introduced.

In 2014, healthcare patient data began to be stored in the Kanta Services alongside prescriptions, and in parallel this data also became accessible through MyKanta. By 2015, the entire public healthcare sector was using the Kanta Services, with private healthcare following in 2016.

In 2017, electronic prescriptions became mandatory, with paper prescriptions permitted only in exceptional circumstances. By January 2018, over one billion healthcare documents had been stored in the Patient Data Archive (now the Patient Data Repository).

In 2018, social welfare services began storing client data in the Client Data Archive for Social Welfare Services (now the Client Data Repository for Social Welfare Services). That year also saw the introduction of the Archive of Imaging Data (now the Imaging Data Repository) and the archiving of historical patient data.

Additionally, in 2018, the first version of the Kanta Personal Health Record (PHR) was launched. This national repository allows citizens to enter their own wellbeing data. Information system providers can develop applications using the Kanta PHR, enabling users to store personal data and measurements in the system.

In 2019, the Act on the Secondary Use of Health and Social Data was passed, establishing Findata as the centralized data permit authority. Findata grants permits for secondary uses, such as research and policymaking. Public healthcare entities, such as university hospitals, retained the authority to grant data permits for single-registry studies. By 2020, Kanta Services data could be forwarded for secondary use, such as research or regulatory purposes, with authorization from Findata.

During the COVID-19 pandemic, Kanta Services played a critical role in delivering laboratory test results.

Year	Act	Focus
2007	Electronic Prescriptions Act (61/2007) and updates	electronic format for prescriptions
2007	Processing of Client Data in Healthcare and Social Welfare 159/2007	framework for the establishment of the

		centralised archive (Kanta Services)
2019	Act on the Secondary Use of Health and Social Data (Secondary Use Act, 552/2019)	Establishment of Findata for secondary use of data
2023	Processing of Client Data in Healthcare and Social Welfare Act (Client Data Act, 703/2023)	Harmonization of format

Table 1: summary of most relevant Acts concerning health data management in Finland

Data catalogue

Finland promotes transparency and accessibility by maintaining a national health metadata catalogue, known as Aineistokatalogi or the Data Resources Catalogue. As mandated by Findata’s Regulation on data descriptions, all data governed by the Secondary Use Act must be documented in this catalogue. This ensures researchers and stakeholders have access to detailed metadata about available health data resources.

Kanta and the National Patient Data Repository

Kanta services

Kanta is a nationwide information system maintained by Kela for managing patient, client, and welfare data. Its use is mandatory for private health and social service providers that process client and patient data through an information system.

Kanta Services are jointly developed by Kela and THL, with THL responsible for strategic guidance. A key component of Kanta is the Patient Data Repository, where patient data is securely stored and easily accessed by healthcare professionals.

When a healthcare provider uses an electronic patient information system, it must be integrated with the Patient Data Repository. Kanta publishes the specifications for each individual service outlining the requirements that systems must meet to obtain certification and be authorized to send data to Kanta. A testing environment is provided by Kanta for this purpose. This centralization allows healthcare data from both public and private providers to be collected in one place, ensuring up-to-date and easily accessible information. Patient information is entered into the provider's system and automatically stored in Kanta. Patients can access their health information via the MyKanta portal or app, and healthcare professionals benefit from continuity of care, even when patients change providers. The archiving of imaging documents is also a feature of the Patient Data Repository, where care documents such as requests, study records, and reports are stored within the Kanta Services. These imaging care documents are connected to the images saved in the Imaging Data Repository, enabling healthcare professionals to access both the imaging results and their associated care documents in one centralized location.

In addition to patient records, and diagnostic images, prescriptions, and pharmaceutical product data. Recent updates in 2024 added appointment information and wellbeing data to Kanta, further expanding its scope.

My Kanta

MyKanta is a nationwide online platform that provides citizens with centralized access to their public and private social welfare and healthcare data. Data is automatically accessible in MyKanta as soon as healthcare providers upload it to the Kanta services. This ensures timely and seamless access for users. The information available in MyKanta includes:

- Visits to health care services and diagnoses
- Test results
- Prescriptions, dispensation and prescription renewals
- Vaccination records
- Living wills and organ donation testaments
- Wellbeing data and measurement results
- Social services client data
- Medical certificates and statements
- Consents and denials of consent
- Appointments

Discharge reports are available in Kanta as part of general health record entries, but not as separate documents in a fixed structured format.

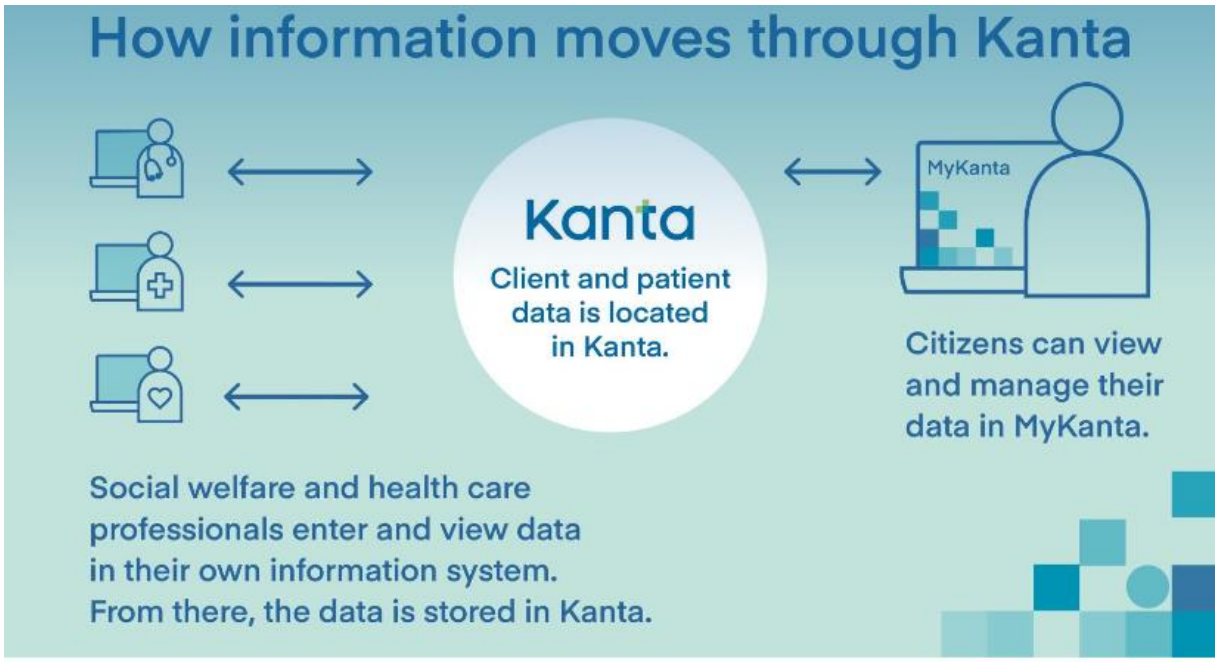

Fig 1: The architecture of the Kanta services (Source: https://www.kanta.fi/en/data-in-kanta)

Citizens have the ability to control the sharing of their data by setting up denials of consent. These denials restrict the exchange of data between wellbeing services counties as well as between public and private health and social welfare services.

Through MyKanta, citizens can also provide consent for transferring their Finnish patient data abroad if required. The Patient Summary can be shared with another European country for medical care only if the patient has explicitly agreed to the transfer.

Additionally, citizens can restrict or object to the use of their Kanta-provided data for research purposes via Findata.

Kanta PHR

Wellbeing data and measurement results can be entered and edited directly by citizens and constitute the Kanta Personal Health Record (PHR) national data repository. Applications can integrate with the Kanta PHR, which provides interfaces and standardized national data content based on the HL7 FHIR standard. The FHIR Rest API interfaces are detailed in the Capability Statement description.

Applications that include a back-end service operating in a trusted environment can be integrated with the Kanta PHR. The back-end service is responsible for managing communication with the Kanta PHR. Currently, applications installed directly by end users that do not connect to a back-end service are not supported.

Connection models

Public-sector social welfare and health care service providers plus pharmacists join the Kanta Services via a direct connection. Private-sector social welfare and health care providers can choose a joint connection model where a main joining party submits an application to join Kanta and administrative burdens are shared.

In certain cases, private-sector social welfare service providers can access the Client Data Repository for Social Welfare Services through a parallel connection model. This is allowed if a public-sector service organizer, such as a wellbeing services county, grants the provider access to its client information system. This way, private providers do not need to apply to join Kanta Services if all stored client data belongs to the wellbeing services county's client register.

Each service enabler utilizing Kanta Services operates through at least one Kanta access point. An access point serves as a communication hub, connecting the service enabler's information system to the Kanta Services.

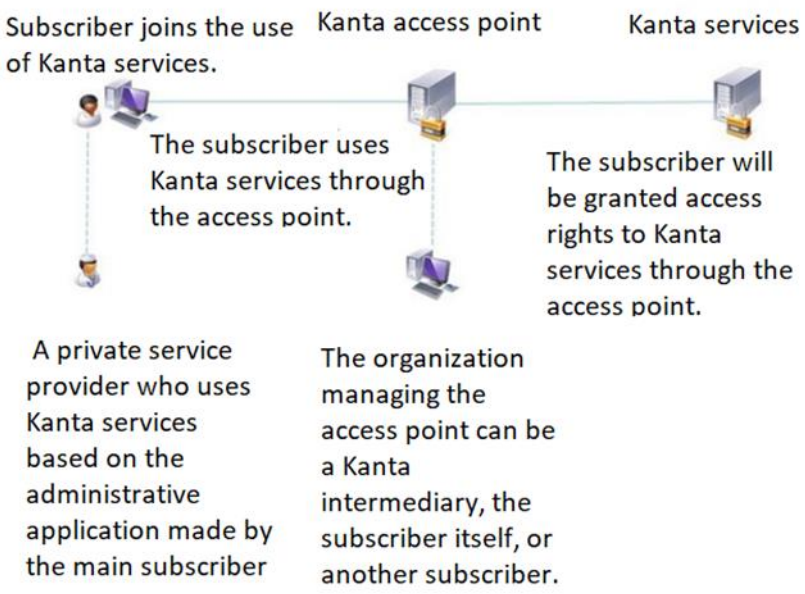

Fig.XX Image from the technical document on the connection model
https://www.kanta.fi/documents/d/guest/kanta-tekniset-liittymismallit-3_16

The entity responsible for implementing a Kanta access point is known as a Kanta provider. Service enablers rely on Kanta providers to establish connections between their information systems and the Kanta Services.

Kanta providers are listed in the Provider Register maintained by the Finnish Institute for Health and Welfare. This register includes intermediaries authorized to function as Kanta providers when connecting to the Kanta Services, excluding pharmacies or health and social service organizations.

Incentivisation to engage stakeholders

Finland's healthcare system is constitutionally mandated and is based on the social welfare and healthcare services offered by the 21 wellbeing services counties.

Healthcare providers must enter the required mandatory data in the information systems and developers of patient data systems must comply to the necessary specifications to connect their applications to the Kanta services.

Support information is offered on the Kanta website for citizens, professionals and system developers. Kanta offers testing possibilities for information system providers before migrating to the production environment. Two sandbox environments have been established and are available for developers for testing new PHR applications.

Data security

Using the Kanta Services requires healthcare and social welfare information systems to be integrated with Kanta. All social and health care providers, pharmacies, and data intermediary organizations that electronically process client and patient data must comply with Kanta's data security requirements.

Information systems, wellbeing applications, intermediary services, and other systems connecting to Kanta must undergo a data security assessment conducted by an approved information security inspection body, as stipulated by the Client Data Act.

A data security certificate, valid for up to three years, is issued upon successful completion of the assessment. The costs of the data security assessment are borne by the respective manufacturers or providers of the information system, wellbeing application, or technical intermediary service.

Software Developers

System providers are responsible for classifying their information systems correctly in accordance to the THL Regulation 4/2024, as the classification determines how key requirements are verified. Compliance with interoperability, data security, data protection, and functionality standards is essential, and compatibility with Kanta Services is ensured through joint testing.

Providers must notify Valvira to register their systems meeting the Client Data Act requirements, and deployment is contingent on inclusion in Valvira's information system database. Additionally, systems connected to Kanta Services must have an approved data security assessment, which the provider coordinates with an inspection body.

If multiple parties are involved, they must mutually agree on certification responsibilities, including for system entities and subsystems.

Specifications

The specifications that apply to several Kanta Services are available on the Kanta website and include information on:

- Connection models and message exchange
- Health Level Seven Version 3 (HL7 V3) specifications
- Security
- Acting on behalf of someone else
- Version practices for the specifications
- Reports and policy documents
- National Code Service interfaces

The standard format for the Patient repository and ePrescriptions is HL7 Version3 CDA. HL7 FHIR has been implemented in the latest developments of Kanta: the personal health record, medication list, social services disclosures, appointments and new implementation guides.

Finland has a national terminology server (https://koodistopalvelu.kanta.fi/codeserver/pages/classification-list-page.xhtml?clearUserCachedLists=true) with glossaries and vocabularies for the health services. International codes such as ICD are used mainly for diagnoses. LOINC is not used to exchange laboratory information and proprietary coding are used instead.

Although Finland is a member of SNOMED, the adoption of SNOMED CT is presently limited to the domain of Pathology and Problem list, it is however increasingly being adopted in other domains.

The standards ICD-10 & ICF, LOINC, ATC, ICPC-2,NCSP, MeSH, UCUM, CCC and various ISO classifications are used for nursing classification.

Services with the EHDS Regulation

Currently, Finland offers two European electronic health services:

- Cross-Border Prescription: Allows the use of Finnish prescriptions abroad and foreign prescriptions in Finland.
- Patient Summary: Enables the transfer of patient information between European countries.

The specifications for these services are available in Finnish on their respective subpages:

Specifications for Cross-Border Prescription

Specifications for Patient Summary

With the EHDS, new European health services will be gradually introduced in Finland. These upcoming services will enable the exchange of additional types of health data between European countries, including:

- Laboratory results and reports, expected around 2028.
- Medical images and related reports, expected around 2030.
- Patient discharge summaries, expected around 2032.

Strategies to avoid duplication of data and to collect data from primary systems

The Act on the Secondary Use of Health and Social Data

The Act on the Secondary Use of Health and Social Data aims to enable the effective and safe use of personal health and social data for purposes beyond its original collection. This includes activities like steering, supervision, research, statistics, and development within the health and social sectors.

The Act ensures individuals' rights and freedoms are protected while promoting efficient data utilization. It seeks to reduce administrative burdens, streamline permit processes, and improve the collation and use of data from various registers. Additionally, it enhances knowledge management by service providers and aligns data access rights and the Finnish Institute for Health and Welfare's registers with the General Data Protection Regulation (GDPR).

Secondary uses of data covered by the Act include:

- Scientific research
- Statistics
- Development and innovation activities
- Steering and supervision by authorities
- Planning and reporting by authorities

- Teaching
- Knowledge management

By facilitating these secondary uses, the Act supports clearer and more efficient use of valuable social and health data for a range of beneficial activities.

The Act on the Secondary Use of Health and Social Data outlines regulations regarding the data permit authority, its responsibilities, and the use of health and social data for secondary purposes. A data permit authority is responsible for granting permits when data is needed for secondary use and the data originates from numerous different public controllers, public service providers, the private sector and the Kanta Services.

As a result, all data stored in Kanta is automatically accessible for secondary use through Findata, aligning with the 'only once' strategy.

To enhance efficiency and security, a centralized system, Findata, was developed to manage data requests and permits. This system includes secure user environments and interfaces for data provision, ensuring strong privacy protection and safe data usage.

Data Permit Authority: Findata

Findata is the Finnish data permit authority for the social and health care data, and its activities are based on the Act on the Secondary Use of Health and Social Data.

Findata operates as an independent entity within THL, functioning separately from the Institute’s other activities. It is guided by the Ministry of Social Affairs and Health, which appoints its director and steering group. A management team, including leaders from key departments, oversees its operations.

The primary responsibility of Findata is to provide guidance and issue permits for the secondary use of social and health data, ensuring secure processing and handling. Permits are granted for:

- Data held by multiple public social and health sector controllers.
- Data from a single public controller that has delegated permitting authority to Findata.
- Register data from private social and health service providers.
- Information stored within the Kanta Services.

Findata also handles data processing tasks such as combining datasets, pseudonymizing, anonymizing, and producing statistical data outputs.

The issuance of permits is based on fees, which are determined by a decree from the Ministry of Social Affairs and Health on charges for the work carried out by the health and social data permit authority, Findata.

GDPR and Protection Act

Data processing in Finland is based on the EU’s GDPR. The Data Protection Act (1050/2018) specifies and supplements the EU's GDPR. Among other things, the Act provides for the appointment, organisation and powers of the supervisory authority on data protection matters.

In EHDS however citizens have a right to opt-out specifically from secondary use, in an easy and reversible way. However, for certain important public interests and under strict safeguards, including transparency requirements, data may still be used. Under Finnish law, there is no explicit right to opt out. Individuals can exercise their right to object under GDPR Article 21 by submitting their objection to Findata, the data permit authority, providing a personal justification. There are circumstances where an applicant for a data permit could override such objections. In cases where objections are overridden, individuals who opted out must be informed and given the opportunity to appeal the decision.

It is important to note that Findata is not the original controller of health and social data. Consequently, submitting an objection to Findata regarding the use of personal data does not prevent the data from being disclosed for secondary use by other controllers specified in Section 6 of the Act on the Secondary Use of Health and Social Data (Secondary Use Act).

Unfortunately, Finland lacks a centralized system that would allow individuals to universally and conclusively prohibit the secondary use of their data in a manner binding on all parties.

It should also be emphasized that Finland's national data protection law, which complements the GDPR, requires data controllers to assess on a case-by-case basis whether it is necessary to restrict the right to object or other rights under Article 89(2) of the GDPR for a specific research project.

Below, the most relevant articles concerning conditions for processing personal and sensitive data from EU´s GDPR and Finnish legislation are reported:

- **Article 6, (1)(e) of the EU’s GDPR:** processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller
- **Article 4(1)(2) of the Data Protection Act:** processing of data that is provided for by the law or that is directly attributable to the controller for the task prescribed by the law
- **Article 9(2)(g) of the EU GDPR:** processing is necessary for the performance of a task carried out in the public interest or the exercise of public authority
- **Section 6(1)(2) of the Data Protection Act**: processing is necessary and proportionate for the performance of a task carried out in the public interest by a public authority.

European Health Data Space

Role of Finland in EHDS

Finland has a long tradition and experience in national legislation and strategies concerning digital health. The Finnish system offers common specifications and interoperability standards for the centralisation of patient information. Additionally, with its Act on the Secondary Use of Health and Social Data, Finland shows to be fully aligned with the EHDS objectives. Through Sitra, the Finnish Innovation Fund, Finland is also playing a leading role in the first and second

Joint Action Towards the European Health Data Space (TEHDAS 1 and 2) for the definition of recommendation on EHDS sustainability, data quality and utility, and establishment of common guidelines and technical specifications for cross-border exchange of information.

European Health Services in Finland

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New Services with the EHDS Regulation

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Challenges and future developments

Challenges

Despite the advanced digital service infrastructure and health data legislation, stakeholders in Finland still face challenges that require careful consideration.

Currently, the increasing number of mandatory data fields required by Kanta specifications has added to the administrative burden on healthcare providers. Additionally, selecting appropriate codes from the structured information format further increases this burden. Moreover, information systems often lack adequate analysis and search capabilities to fully leverage structured data, leading physicians to perceive little immediate benefit from their additional work.

System developers, on the other hand, must contend with the economic burden of complying with the evolving Kanta specifications and bear the costs of obtaining compliance certifications.

For researchers, the cost of accessing data through Findata is sometimes too high, and the response time is too long to meet research needs. As a result, many researchers rely on their own data or make agreements with other institutions to bypass Findata.

Future developments

Findata is actively working to improve its service and functionalities. To this purpose, it has launched a four-year project, FinHITS, co-funded by the European Union that aims to strengthen Finnish health data ICT for secondary use and to enable Finland to integrate seamlessly into the EHDS. Its specific objectives are:

- Increasing the capabilities of data access applications management system
- Developing the national dataset catalogue for health data
- Strengthening Kapseli, the secure processing environment for health data
- Creating a cross-border gateway to connect with the HealthData@EU infrastructure
- Elevating the quality of health data

The Kanta Services are also undergoing a modernisation process shifting from document-based HL7 v3 CDA structures to an information model-based framework based on HL7 FHIR. The transition will occur gradually, but the newest contents already compliant with the FHIR standard: booking healthcare appointments, managing notifications of social welfare disclosures, and sharing wellbeing data stored in MyKanta with healthcare and social welfare professionals.

Conclusion

Finland boasts comprehensive, high-quality information resources and advanced digital service infrastructure, anchored by the extensive Kanta services system. The implementation of the Act on the Secondary Use of Health and Social Data in 2019, along with the establishment of Findata as a centralized access point for secondary use of health and social data, solidifies Finland's position as a global leader in health data management and accessibility.

Moreover, its robust health information system, combined with active participation in European initiatives, positions Finland as a key player in shaping and preparing for the European Health Data Space (EHDS).

Annex 1: Interview with Mikael Rinnetmäki, founder of Sensotrend

Mikael, the founder of SensoTrend, brings a unique perspective shaped by his roles as both as diabetes patient and a data activist working to influence policies. While his insights reflect his personal experiences and advocacy, this particular interview was conducted with a focus on his role within the industry and his view on the centralised Kanta services.

INITIATION of the centralized services

In Finland, there was a progressive centralization of services through the Kanta services over the last twenty years or so. Kanta acts as a centralized platform where medical data from both private and public healthcare providers is sent. Collected data are sent to Findata for secondary use.

MOTIVATION FOR INDUSTRY

In Finland it is mandatory for industry to comply to Kanta specifications. Anyone developing software that handles patient data needs to to be enabled at Kanta and undergo a certification procedure. The legislation mandates that Electronic Health Record (EHR) systems used by healthcare organizations comply with the requirements defined by Kanta.

HOW DID YOU GET ORGANISED?

The responsibility falls on healthcare organizations to ensure their EHR systems send the necessary data to Kanta.

Usually developers have a two- three year transition period. And that's the time that you need to have to adapt your technology to the new requirements.

Sensotrend is not an EHR system but is connected it to the Kanta PHR section which one of the newest sections and specifications recommend FHIR. Sensotrend develops innovative apps to support people living with diabetes. Their main app integrates data from various medical devices, such as continuous glucose monitors and insulin pumps, and wellness trackers, providing a unified view for patients. This helps users understand how factors like exercise, sleep, and nutrition impact glucose levels.

By combining medical and wellness data into a comprehensive dashboard, Sensotrend enables patients to see all relevant information in one place, even when the devices are from different manufacturers.

Sensotrend had to adhere to the existing PHR specifications to establish a connection with Kanta. A Sandbox environment is provided by Kanta to test the service. However, if certain specifications are lacking, there is a significant risk of prolonged delays due to insufficient investment in this area.

Kanta PHR

The Personal Health Record (PHR) platform has struggled to gain traction, with only few apps currently connected to Kanta's PHR. Additionally, there is no complete predefined format for integration. Software developers submit their proposed specifications to Kanta, which are reviewed internally, and data elements are enabled on Kanta one by one. This process is inefficient. Moreover, since the collected data currently lacks a clear use case, there has been little incentive to invest heavily in optimizing the platform for speed.

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

EHRs are legally required to comply with Kanta specifications, meaning that system providers must update their software to meet these standards. For doctors, the challenge lies more in the system's usability and the mandatory data requirements set by Kanta.

WHICH POSSIBLE EVOLUTIONS?

The format

The format for Kanta PHR is already FHIR but for clinical records it is all CDA. A big discussion about the shift to FHIR is ongoing. Developers would expect Kanta to take care of the conversion, but it is likely that until the new regulation imposes it there will be no change in the data format. With the legislation, it will probably be again on the develoeprs´side to take care of the transformation. Somebody needs to pay for the transition.

Terminology

Laboratories in Finland currently use proprietary codes (Kuntaliista koodisto), and LOINC is not yet adopted. A transition to FHIR is anticipated, potentially incorporating SNOMED CT and LOINC while maintaining mappings to existing national standard codes.

The current national terminology server predates FHIR and lacks FHIR capabilities. While it provides some APIs, it does not support functionalities like validating FHIR Implementation Guides. HL7 Finland plans to implement a new CSIRO terminology server, but this will require political decisions on who will manage the FHIR server and how to transition from the existing Finnish codes to the new system.

Reccomendations for improvements

Industry

Enhanced collaboration of the public world with the industry is essential. Infomration systems are often viewed more as an obstacle that adds additional burden rather than problem-solvers. In particular, prices for software and subsequent adaptations are perceived as too high in relation to the often offer limited usability.

Secondary use

Doctors are frustrated with Findata due to its high costs and excessive bureaucracy. Individual practitioners often find it unaffordable and resort to alternative methods to conduct research efficiently. The processes remain identical for both small and large research groups, highlighting the need for a thorough review of costs and timelines.

Medical devices

Accessing information from medical devices remains challenging. Integrating medical devices into the European Health Data Space (EHDS) would be a positive step, ideally through a standardized xShare button that allows patients to access their data in a unified format rather than across fragmented dashboards. This would enable better connectivity with other devices and systems. Patients should have access to their data regardless of which standard is used.

Key learnings

- The new centralisation of services has also introduced new rigidity
- System developers face significant financial burdens as they adapt to evolving specifications and undergo Kanta certifications with little to no economic incentives to support these efforts.
- While the transition to FHIR is both promising and necessary, it raises numerous questions about the implementation process and who will bear the associated costs.
- National coding systems continue to dominate national specifications. To align with the EHDS, international terminologies should be adopted more consistently.
- More attention on Medical devices should be placed by EHDS to enable patients to see and analyse their own data.

Annex 2: Interview with Dr Emil Heinäaho, Chief Physician within the Western Uusimaa Wellbeing Area in Helsinki, Finland.

Dr. Emil Heinäaho, specializing in primary healthcare, medical leadership, and training works primarily in the public healthcare sector in the Western Uusimaa Wellbeing Area, and is involved in a significant shift in the country's healthcare system. They are helping to build a new model where individuals will have personal doctors, which is currently not the case in Finland. In Finland, doctors are randomly centrally assigned to patients. Dr Emil Heinäaho is working to improve information systems to allow doctors to manage their own patient lists Dr Emil Heinäaho and support continuity of care.

CHALLENGES WITH ELECTRONIC HEALTH SYSTEMS

Dr. Emil Heinäaho highlights significant issues with Finland's electronic health systems. Clinicians frequently complain about the inefficiency of the systems, citing problems such as difficulty in finding information, excessive clicking, and the lack of meaningful use of the data entered. The administrative burden is compounded by legislation that mandates data entry, but the data is not effectively used. This has led to frustration among healthcare professionals, as they are often uncertain about the value of entering detailed information if it does not seem to serve any practical purpose.

KANTA SYSTEM: BENEFITS AND LIMITATIONS

While Kanta has eliminated the need for paper-based communication between healthcare providers, it is difficult for clinicians to navigate the data due to poor software design and unintuitive user interfaces. Although legislation mandates structured data entry, the system's design does not make it easy to access or use the data efficiently, leading to a significant impact on clinicians' daily work and increasing their administrative burden.

MOTIVATION

AI could be used to streamline data entry by converting spoken language into structured data, allowing clinicians to focus more on patient care. Better integration of AI and more user-friendly software could reduce the time spent on data entry and provide valuable feedback to clinicians, making the data more useful and motivating them to engage with it.

DATA PROTECTION AND ETHICAL CONCERNS

Finland's strict data security measures are a major concern, and there is tension between protecting patient privacy and using health data to improve care. There are challenges in balancing the need for privacy and the need to use data for preventive care, such as reaching out to patients at risk of deteriorating health. Ethical concerns arise, especially regarding the proactive use of health data, as there are legal questions about whether healthcare providers should contact patients without their explicit request.

SUGGESTIONS FOR PUBLIC HEALTH

Finland´s public health would benefit from more national quality registries. It would be very important to visualise data to see where healthcare was successful and were problems persist. Showing recovery rates and costs in relation to continuity of care would be a very interesting index for public health.

Key learnings

- Information systems often lack usability and sufficient analysis and search capabilities to fully leverage structured data, which diminishes physicians' motivation in providing the information.
- While a significant amount of data is being collected, the focus should now shift to making effective use of it, in particular through efficient and user-friendly information systems.
- In Finland, general practitioners are assigned randomly, which often hinders continuity of care. Integrating information systems with patient lists could help doctors maintain their own list of patients, thereby improving continuity.

Annex 3: Interview with Pirkko Kortekangas, Medical Doctor Turku, Southwest Finland, Finland

Dr. Pirkko Kortekangas isChief Specialist at UNA Oy which operates as a non-profit development company within the social and healthcare sector, specialising in streamlined information flow.

EXPERIENCE IN MANAGING DATA

Data is recorded using software-specific templates, allowing for tailored default templates to be created for different services (e.g., maternity and child health clinics, specialized care sectors) and their corresponding care situations (e.g., income estimates, procedures, final statements). These templates, used within specific applications, include headers containing predefined data structures that guide how information should be recorded.

The effectiveness of this approach depends on the usability of the application and the commitment of those responsible for designing appropriate recording platforms. However, a significant limitation of current templates is their inability to display previous entries in a sufficiently user-friendly manner. Furthermore, clinical work often lacks accessible aggregate views, making it difficult to obtain a comprehensive understanding of a patient’s overall condition.

At a high level, legislation outlines requirements such as providing sufficient justification for care decisions and specifying the information that must be recorded for a treatment. When it comes to individual data, specific orders are issued by the relevant authority. For instance, additional requirements may include documenting the cause of treatment specifying the diagnosis, the relative code and information on whether the diagnosis is temporary or permanent, and noting the degree of certainty.

A unique aspect of our system is that each entry must be linked to a "service event." This concept refers to an individual therapeutic situation, such as a visit or a ward period, along with related activities like laboratory tests. While the concept has been in use for years, it occasionally presents challenges for registrars. On one hand, it provides a structured framework; on the other hand, its implementation has not been entirely successful. In many cases, the appropriate service event can be determined automatically, minimizing disruption to the documentation process. However, this is not universally the case.

WHAT IS THE TERMINOLOGY USED?

In Finland, the reason for medical treatment must be reported using ICD-10 codes. These codes are mandatory in summary-level documents created by doctors, such as visit and department period records. Despite being a decades-long routine in specialized medical care, the use of ICD-10 codes remains a persistent frustration for doctors. In primary care, the challenge is exacerbated by the need to address multiple issues simultaneously, leaving little enthusiasm or time to record repetitive codes—especially as current systems lack support for sensible automatic copying. The anticipated transition to ICD-11 is expected to provide more

sophisticated tools for identifying the correct codes based on terms used by physicians in free text.

For reporting the reason for seeking treatment, ICPC-2 codes are widely used, particularly in services provided by nurses and emergency care. Physiotherapy has increasingly adopted the ICF framework.

Physiological measurements utilize FinnLOINC, a localized version of LOINC. However, LOINC poses challenges, as it uses the same code to represent multiple details (e.g., blood pressure measurement, including the patient's position and device used) without capturing all available metadata. A more comprehensive data model capable of storing this metadata would be a better solution.

SNOMED is not directly used in data entries but is mapped in the background within some systems. Finland also has a significant number of country-specific code sets, which often overlap and are inconsistent. Efforts to clean and streamline Finnish code sets have aimed to align them with SNOMED, which is already used routinely in pathology.

Finland employs the Nordic Classification of Procedures, for which a local version has been developed. While many therapeutic actions are categorized within this framework, the classification of non-surgical operations remains vague. A coded value can efficiently represent many actions, but defining and maintaining precise meanings for codes requires significant effort to keep pace with evolving procedures. This issue also arises in specialized quality systems used in certain fields, such as orthopedics, which often result in double data entry.

The Finnish Nursing Code Set is commonly used but not mandatory. While full adoption of such codes could enable data reuse, many organizations view the additional documentation workload as outweighing the potential benefits. Furthermore, most nursing documents are not currently transmitted to Kanta, the national health information archive.

EXPERIENCE WITH KANTA

Some types of documents are sent to Kanta automatically, while others remain stored locally and are not transmitted. In Kanta's early years, archiving was often delayed, but now the process typically takes only seconds. Everything in Kanta is visible to the patient unless a professional has specifically delayed its visibility.

Today, the benefits of sending data to Kanta outweigh the challenges experienced during its early implementation. One key advantage is that many people now know how to access and review their information through MyKanta.

Looking forward, it should be possible to store data more easily and include more extensive metadata—achieving this without increasing the burden of manual or structured documentation on professionals.

The problem is not the transmission of information, but the utilisation of information in real treatment situations. The support of current patient information systems for viewing Kanta data is very poor. But it's clear that a radical change could only be coming when the EHDS details become clear.

Currently, utilizing Kanta in basic systems is too challenging, and professionals lack the time and energy to fully engage with it. Thus far, the primary beneficiaries have been citizens and

providers, the latter of whom have managed to reduce administrative staff. However, Kanta’s implementation has introduced a host of complexities in documentation, leading to unnecessary work without delivering meaningful improvements to patient care or other tangible benefits.

Too much planning has focused on governance and too little on practical processes.

Kanta was a significant achievement in its time, but it cannot remain effective without further advancements. While there were several suboptimal decisions in the past, these can potentially be rectified in the future through AI and the adoption of robust data-level models.

WHAT ABOUT SECONDARY USE OF DATA?

The only realistic path forward is to support storing data in a common, open, and sufficiently rich data model. Repeated integration projects involving semantically non-interoperable data are neither sustainable nor affordable.

Policymakers must ensure that services operate effectively and deliver added value to overall welfare. Achieving this requires access to certain business data from service providers.

At the population level, policymakers should monitor changes in welfare and health. Aggregating the necessary data should occur within secure, decentralized environments, avoiding the consolidation of all personal data in a single storage location.

Citizens’ data should be accessible as a reference for professionals making care decisions, but only within highly secure environments where no human can access individual-level data. All other uses of personal data must remain under the control of the citizen.

Key findings

- More focus on practical processes is needed to support clinicians
- Information systems often fail to provide a user-friendly view of previous entries and aggregate data
- Current patient information systems do not support efficient utilization of Kanta data

Annex 4: Interview with Prof. Kristiina Patja, Professor at University of Helsinki

Dr. Kristiina Patja is a professor of healthcare science with a background in medicine and public health. She has conducted research on various public health topics, including diabetes and tobacco use, and has experience in economic analysis.

DATA UTILIZATION CHALLENGES IN FINLAND

Finland has long been a pioneer in data integration, leveraging unique social security numbers to link diverse datasets, including healthcare, social security, and occupational data. Its high quality registries and have been pivotal in epidemiological research since the 1970s. This tradition has supported comprehensive research and public health analysis. However, the introduction of GDPR and new legislation has introduced significant challenges. While intended to safeguard privacy, these changes have made accessing and linking datasets increasingly complex, slow, and costly, presenting a significant obstacle for researchers and analysts.

A key challenge lies in balancing efforts between capturing reliable, relevant data and avoiding an overwhelming amount of mandatory documentation that can hinder productivity. For instance, while hospital data quality is generally strong, there is a noticeable discrepancy between recorded obesity rates in clinical records and actual population health surveys, such as FINRISK. This highlights the need for a more participatory approach to data collection that empowers citizens to contribute their health information, particularly through emerging technologies.

DATA INTEGRATION

Integrating data from various digital devices with existing health records is still challenging, there is need for standardized data collection methods. It would be important to have quality measures for digital health interventions and a better understanding of the relationship between different data sets.

Meaningful public health metrics would help address socioeconomic differences and target specific health outcomes. Health behavior data should be integrated into performance indicators. By focusing on prevention and early intervention, healthcare systems can become more sustainable and effective, ultimately leading to better population health outcomes.

SUSTAINABILITY

There is a tendency to prioritize specialist care and costly treatments over preventive measures, which are crucial for long-term sustainability. For example, Kaiser Permanente in the U.S. integrates behavioural health outcomes into performance metrics to track preventive actions.

It is important to align healthcare reforms with broader societal goals, such as sustainability and equity. The planetary health approach emphasizes the need for hospitals to adopt sustainable practices in care delivery. It highlights the potential for healthcare systems to

leverage data for achieving environmental, social, and governance (ESG) objectives, such as reducing emissions, improving care coordination, and fostering staff well-being.

LEGISLATIVE IMPACT ON RESEARCH

There are struggles due to new legislation affecting the secondary use of health data. While the intentions behind the legislation were good, it has resulted in a slow and cumbersome process for obtaining necessary data for research. Hospitals and healthcare districts are now relying more on their data pools, limiting collaboration and data sharing opportunities, which could otherwise enhance research and public health outcomes.

FUTURE DIRECTIONS AND RECOMMENDATIONS

Health policies should prioritize citizens' well-being over political agendas and stress the importance of realistic goals that can yield meaningful outcomes. Instead of striving for perfection in data systems, healthcare stakeholders should focus on implementing practical projects and gradually refining processes, as evidenced by the evolution of evidence-based medicine.

Key learnings:

- Need to reform legislation for faster and more cost-effective data access while balancing patient data protection.
- Need for integration of information from citizen and inclusion of behavioural information in performance indicators
- Focus should shift toward inclusivity, sustainability, and prevention rather than reacting to health issues after they arise