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Finnish national patient data repository as data source for FINRISK risk calculator

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Abstract

The FINRISK risk calculator is a tool for the evaluation of the 10-year risk of cardiovascular diseases (CVDs). It is based on a Finnish population survey and is frequently used in Finnish healthcare. Currently, risks are calculated manually by inputting the required values. An alternative source of input values could be the Finnish Kanta Patient Data Repository (PDR). Risk calculation based on the Kanta PDR could enable monitoring of predicted CVD risks at the level of the Finnish population and targeting of preventive healthcare to high-risk individuals.

The goal of this study is to assess if the FINRISK risk calculator can be made to work effectively using only structured data available in the Kanta PDR. We approach the issue from two perspectives. The first is the availability of individual inputs, and the second is the ability to categorize people to risk categories used in healthcare.

The study was based on patient histories of roughly 60 000 persons who met the inclusion and exclusion criteria of the FINRISK risk calculator. The data had been recorded into the Kanta PDR between January 2014 and June 2022. To enable risk calculation even when individual input values are missing, we calculated a minimum and maximum risk for each person based on data that was available at a prediction time point. Risks were predicted at seven different time points between the years 2016 and 2022 to analyse the development of categorization performance over the years.

The highest categorization performance was achieved for the year 2022, where we were able to identify the FINRISK risk category of 1.69% of persons. With additional categories for low or moderate and moderate or high risk, 4.15% of persons could be categorized. The risk level of the remaining 95.85% of individuals could not be specified. The reason behind the poor performance was the inadequacy of input values. Namely, family history of CVDs was not available in structured format and smoking information was rarely found. Information about blood pressure, blood cholesterol, and diabetes were more frequent.

We conclude that population level risk assessment is not viable based on only the structured data in the Kanta PDR. Extracting inputs like smoking status from text data could improve the situation. As the FINRISK

risk calculator is often used by inputting structured data into an electronic form, the lack of same inputs in the Kanta PDR highlights incomplete flow of data in the Finnish health data infrastructure.

Keywords: health data, health and wellness sector, risk groups, risk assessment, cardiovascular diseases

Introduction

The FINRISK risk calculator is a tool for the evaluation of the 10-year risk of cardiovascular diseases (CVDs) [1]. Automated risk calculation based on the Finnish Kanta Patient Data Repository (PDR) could enable monitoring of predicted CVD risks at the level of the Finnish population and targeting of preventive healthcare to high-risk individuals. In addition to population-level monitoring, individuals and healthcare professionals benefit from automated risk calculation. Individuals could use the automatically calculated risk scores to monitor their risk level and make lifestyle choices to lower their actual risk. Healthcare professionals could utilize risk evaluation during the patient visit to plan tests for the patient regarding the disease if the risk is high or guide the person to lower the risk. Information about the risk and its development over time would also improve the general overview of the patient health status obtained by the healthcare professional. [2]

The purpose of this study is to assess if the FINRISK risk calculator can be made to work effectively when using only structured Real-World Data (RWD) available in the Kanta PDR. We approach the issue from two points of views. The first is the availability of individual inputs, and the second is the ability to categorize people to risk categories used in healthcare. We present results from an evaluation of the FINRISK calculator on roughly 60 000 randomly selected persons' patient histories that had been recorded into the Kanta PDR and matched the FINRISK inclusion and exclusion criteria. The next sections of the paper introduce Kanta PDR and the FINRISK calculator, followed by details of the methods, results, and discussion.

Kanta PDR

The Kanta PDR is part of the Finnish National Electronic Health Record (NEHR) archive that is collectively known as the Kanta Services. The Kanta Services are a collection of services for storing and exchange of healthcare and social welfare data and prescription information. [3] Based on the Finnish Act on Secondary Use of Health and Social Data [4], each public healthcare service provider must record patient data to the Kanta PDR. The act also states that private social and healthcare providers must record data to the Kanta PDR if they utilize information systems that handle patient data. In 2023, over 70% of all private healthcare service providers recorded data to the Kanta PDR [5]. This means that records from almost every healthcare visit in Finland should be available in the Kanta PDR.

The first patient health records were stored into the Kanta PDR in 2014 [6]. Different health data types have been added to the Kanta PDR in phases, which means that variables have different lengths of history, and the availability of variables should be considered case by case. A general overview of the availability of data types in the Kanta PDR is provided in a previous study [7]. The study concluded that after 2019, laboratory results, physiological measurements, and diagnosis information have been widely recorded into the Kanta PDR. From a risk prediction point of view, the Kanta PDR is a source of RWD, as the data is recorded by healthcare professionals as part of current healthcare processes. The data is also continuously recorded, which opens possibilities for analysing changes in risk level over time.

Cardiovascular disease risk prediction

Cardiovascular diseases (CVDs) are a global health problem and various risk calculators have been developed to help in the prevention and early diagnosis of CVDs. CVDs are still the leading cause of death globally. [8, 9] In this study, we considered three CVD risk calculators with links to Finland. The FINRISK risk calculator is a risk prediction model for assessment of a 10-year risk of coronary heart disease and stroke [10]. A digital version of the FINRISK calculator is freely available [11]. Two internationally developed CVD risk calculators, Framingham [12] and SCORE [13], have been previously tested on the Finnish population [14].

CVD cases have been decreasing in the Finnish population for several years but just lately the rate of decrease has slowed significantly or even stopped. [15, 16] There are signs that CVD risk is going to increase in the population. [16, 17] Smoking generally has decreased in the population but the reason why the CVD risk has increased is the general increase in overweight, which leads to diabetes and increased blood pressure levels. [17]

The Framingham, SCORE, and FINRISK risk calculators share several input variables which can be seen as known CVD risk factors. As can be observed from Table 1, only the FINRISK risk calculator considers the family history of CVDs.

In this study, we decided to concentrate on the FINRISK risk calculator as it has been developed based on data from the Finnish population [10]. Also, due to shared inputs, the compatibility of the FINRISK calculator with Kanta PDR can be expected to be on a similar level as the Framingham and SCORE calculators. The first version of the FINRISK risk calculator was published in 2007 [10] and an updated version in 2020 [1].

Table 1. Input variables of the FINRISK, SCORE and Framingham CVD risk calculators.

Risk calculator(s)	Input variable
All	Gender
All	Age
All	Total cholesterol level
All	HDL cholesterol level
All	Smoking habits (yes/no)
All	Systolic blood pressure
Framingham	Treated for high blood pressure (yes/no)
Framingham, FINRISK	Diagnosed with diabetes (yes/no)
FINRISK	A parent has had an acute myocardial infarction before the age of 60 (yes/no)
FINRISK	A parent has had a stroke before the age of 75 (yes/no)

The FINRISK risk calculator is intended for persons who are 30–74 years of age and have not previously experienced a myocardial or cerebral infarction. A FINRISK risk score of 10% or higher is considered high risk in the Finnish healthcare guidelines [10]. Low risk is defined as a risk score <5% and a moderate risk as a risk score in the range of 5–9% [1,10].

Research questions

This study aims to evaluate the possibilities of predicting risks of CVDs with the FINRISK risk calculator using Kanta PDR data as input. The analysis is done in two steps. First, we analyse the availability of the inputs of the FINRISK risk calculator in the Kanta PDR. In the second step, we implement the FINRISK risk calculator and evaluate the predicted risk scores and whether they enable categorization of persons according to their risk levels. The research questions we aim to answer are the following:

RQ1: Which input variables of the FINRISK risk calculator can be found from the Kanta PDR?

RQ2: Does the structured data in the Kanta PDR enable categorization of people based on risk levels?

Methods and materials

Research data description

The study was based on roughly 60 000 randomly selected persons' patient histories that had been recorded into the Kanta PDR and matched the FINRISK inclusion and exclusion criteria. The first data entries were from January 2014 and the last entries were from June 2022. The same dataset was also used in a previous study presenting a wider overview of the available data [7]. The data that was used in this study were used under the legislation of secondary use of social and healthcare data. This legislation defines the secure use of personal healthcare data. Data was pseudonymized by the Finnish authority Findata who also confirmed that the results of the study are anonymized. The pseudonymized data was delivered and stored in the secure operating environment Kapseli which had limited access. All the results produced in the secure environment had to be taken out through the anonymization validation by Findata. The data was delivered in the original CDA R2 XML format, and thus required additional processing. We extracted all information required by the FINRISK risk calculator from the documents.

FINRISK risk calculator

Input values

The input variables of the FINRISK risk calculator are listed in Table 2. The table also presents the range of values that were found from the dataset for each variable.

The diagnosis codes that were utilized as exclusion criteria are for myocardial infarction: ICD-10: I20.0, I21, I22; ICPC-2: K75 and for cerebral infarction: ICD-10: I61, I63, I64; ICPC-2: K90. The full list of diagnosis codes is available in the FINRISK article [1].

Table 2. Input variables of the FINRISK risk calculator and the range of values that were found from the dataset after applying inclusion and exclusion criteria.

Input variable	Category	Value range
Gender	Basic information	Male/Female
Age	Basic information	30–74
Smoker	Basic information	No/Yes
Cholesterol	Laboratory	2–20 (mmol/l)
HDL cholesterol	Laboratory	0.3–5 (mmol/l)
Systolic blood pressure (SBP)	Measurement	80–240 (mmHg)
Diabetes	Diagnosis	No/Yes
Myocardial infarction (Parents)	Diagnosis	No/Yes
Cerebral infarction (Parents)	Diagnosis	No/Yes

Output

The FINRISK risk calculator can be used to estimate the overall risk of CVDs or solely the risk of either coronary heart disease or stroke. In each case, the risk calculator produces a risk score that is a percentage estimate of the level of risk. To enable calculation of risk scores in the case of missing input variables, we calculated the minimum and maximum risk scores for each person instead of absolute risk scores. The difference between the minimum and the maximum risk levels allows quantifying the additional uncertainty caused by missing input values. The goal is to organize persons into risk categories so that we can say that a person's risk is in that category despite of the missing input data. To achieve this classification, the risk value range defined by the difference between maximum risk and minimum risk needs to be small enough to fit inside the defined categories. The uncertainty of the risk increases when the risk value range increases. In the case where all the input variables are available for risk assessment, the risk value range is zero as the minimum and maximum risk gives the same result.

In practice, if an input variable was missing, the minimum and maximum values for that input variable (Table 1) were used in the risk calculation. This can be done when the risk calculator is defined with a linear mathematical formula. The same method would not work for non-linear prediction methods such as neural networks.

In addition to the risk level categories presented in the FINRISK article [1], we introduce three new categories: The first one is called 'moderate or high risk' and it is for persons who have an increased risk that cannot be determined precisely. The second one called 'low or moderate risk' is for persons with a lower but imprecise risk. The third one that we refer to as "Gray area" is for combinations of minimum and maximum risk scores that do not allow an individual to be categorized under any of the other risk categories. The category for moderate or high risk may be too vague to allow decisions on medical treatments but would identify patients from whom additional inputs could reveal a high risk of CVDs. Similarly, the category of low or moderate risk would indicate persons that do not belong to the high-risk group. All the risk categories are listed in Table 3.

Table 3. Risk categories.

Risk category	Cut-off values
Low risk	Min risk < 5%, max risk < 5%
Low or moderate risk	Min risk < 5%, max risk >= 5% and <= 10%
Moderate risk	Min risk >= 5%, max risk <= 10%
Moderate or high risk	Min risk >= 5% and <= 10%, max risk >= 5%
High risk	Min risk > 10%
Gray area / imprecise risk	Min risk < 5%, max risk > 5%

Implementation of the FINRISK risk calculator on a real-world dataset

The FINRISK calculator was implemented according to the published formula [1]. While the formula was well-defined, the mapping of RWD data into the defined inputs leaves room for interpretation. Laboratory test results are stored into the Kanta PDR under various code systems [7], which complicates the use of laboratory data for medical risk prediction. Using all the laboratory test code system for risk prediction would need manual work to identify all possible codes for cholesterol measurements. This requires detailed knowledge on laboratory code namings as the codes are recoded in various forms. In this study, to simplify the data utilization in the first iteration we utilized only laboratory test results that had been recorded using the Finnish laboratory test naming system Kuntaliitto, as it is the single most frequently used laboratory test code system [7]. We would achieve higher occurrences for needed laboratory measurements by including also other code systems from Kanta. Smoking and SBP information were searched from entries under code system "FinLOINC - The Physiological Measurements" that is based on the international LOINC nomenclature [18]. Diagnosis information was extracted from entries under Finnish versions of the international code systems ICD-10 [19] and ICPC-2 [20].

Results

RQ1: Which input variables of the FINRISK risk calculator can be found from the Kanta PDR?

The availability of the input values of the FINRISK risk calculator was analysed over the entire time span of the dataset. Age and gender information were found for all persons. In our implementation, the input variable for diabetes is based purely on recorded diagnosis codes (ICD-10: E10–E14), and thus also that variable was defined for all persons. Table 4 shows statistics of the availability of other input values. SBP measurements were the most frequently available input value after age and gender information. Cholesterol values were found for approximately 7% of persons. Smoking information was very rarely recorded in structured format.

Table 4. Availability of the FINRISK risk calculator's input values in structured entries of the Kanta PDR dataset (N = 60 700).

Input variable	Number of persons in the dataset with at least one value available
Systolic blood pressure (SBP)	12 656 (20.85%)
Total cholesterol	4 243 (6.99%)
Diabetes diagnosis	4 112 (6.77%)
HDL cholesterol	4 081 (6.72%)
Smoking information	913 (1.50%)
Family history of CVDs	0

Family history-related information does not have a defined structured format in Kanta PDR currently. There could be some information in the patient's ongoing treatment report as a free text regarding family incidents if the healthcare professional has written some extra information to the report. In this study, we did not analyse the free texts. For research purposes, it is possible to combine Kanta PDR data and Finnish Digital and Population Data Services Agency (DVV) family relationship data to obtain this information but that could not be implemented in the actual automated risk assessment because regulations do not allow the utilization of health information from other persons.

RQ2: Does the structured data in the Kanta PDR enable categorization of people based on risk levels?

Table 5 presents the number of persons in each risk category. Most persons fall into the category of imprecise risk. However, every year an increasing number of individuals can be classified into the other categories.

Table 5. Distribution of persons over risk categories for the years for which risks were calculated with the FINRISK risk calculator.

	2016	2017	2018	2019	2020	2021	2022
Low risk	0.00%	0.03%	0.13%	0.23%	0.32%	0.61%	0.71%
Low or moderate risk	0.00%	0.05%	0.15%	0.27%	0.36%	0.72%	0.72%
Moderate risk	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%
Moderate or high risk	0.00%	0.15%	0.53%	0.66%	0.72%	1.67%	1.74%
High risk	0.00%	0.06%	0.20%	0.43%	0.57%	0.93%	0.98%
Imprecise risk	99.98%	99.70%	98.99%	98.41%	98.03%	96.08%	95.85%
Total	63 828	63 210	62 792	62 381	61 864	61 019	60 700

We were not able to classify any persons into "Moderate risk" category. This is because we couldn't get a risk value interval of less than 5% for many people due to missing input values. The goal would be to categorize the person to either "Low risk", "Moderate risk" or "High risk" category that are accurate enough to allow making practical decisions. Despite the inability to categorize numerous people into precise risk categories, the current study demonstrates that health risks can be effectively categorized using the FINRISK model and Kanta PDR even though with RWD some input data is always missing from patient medical history. By improving the availability of input variables and the quality of laboratory test data through a uniform coding system we would achieve significant in the accuracy and coverage of the FINRISK model. By making these improvements the size of the imprecise risk category will decrease, and the size of the other categories will increase. The size of the imprecise risk category reflects the availability of input values of the FINRISK calculator and thus, it can be considered an indicator of Kanta data quality. As we can see from the results, the imprecise risk category has decreased already 4% over the 6-year time span of our dataset but with the improvements mentioned earlier we can expect bigger decreases.

Discussion

Automated risk assessment opens new possibilities in preventative healthcare and treatment at the patient level but also at the wider population level. By utilizing the NEHR system as a source of risk assessment we can analyse risk development at the population level and use that information in healthcare resourcing, preventative healthcare, and in analysis of current health status development of certain groups. Automated risk assessment also helps individuals to understand their current health status to guide them to better choices in everyday life but also healthcare professionals to have an overview of certain risk developments. In this case, FINRISK would give valuable information about the risk of CVD and results would guide the professional to make correct tests for a person to verify the current risk level.

The main result of this paper is that the structured data in the Kanta PDR allowed the identification of the FINRISK risk category for less than 5% of the sample. Based on these results we would need to both improve data in Kanta but also identify all information in Kanta that could be used as input for FINRISK as the 5% categorization would not enable any identified use cases. The most beneficial use case would be achieved when individuals could be categorized into the three specified categories where we know the exact risk value (Low risk, Moderate risk, and High risk). However, three new categories both help to understand the current situation of the data in Kanta and show the development of the data but also give valuable information to identified use cases. In the "Low or moderate risk" category we can say that a person does not have a high risk, yet which is a good thing but what we don't know is if a person has a moderate risk. Similarly, in the "Moderate or high risk" category, we know that the person has an increased risk, but we don't know how high the risk actually is. In this category the healthcare professional or the person can take action to figure out the real risk status by collecting new data. The Gray area on the other hand tells straight that there is not enough data for a person but what is more valuable is that it indicates at the national level how the quality of input variables in the Kanta PDR has developed.

To understand the reasons behind the lack of structured data in the Kanta PDR, we can consider the case of smoking data. In the FINRISK population

survey of the year 2012 [21], 17.8% of respondents were identified as regular smokers and 8.8% of respondents smoked occasionally. Based on THL statistics from 2014, 17.0% of Finnish persons aged 20-64 years smoked daily and 7.1% of over 65-year-old persons smoked daily. From that year to 2022 the general smoking prevalence has decreased over the years and in 2022 only 11.3% of persons aged 20-64 years and 6.2% of over 65-year-old persons have reported to smoke daily. [22] We found smoking information only from 1.5% of persons from our study cohort which by default does not cover all smokers based on the smoking prevalence statistics. The general decrease in smoking might affect Kanta PDR recordings regarding smoking information because it might be so that healthcare professionals are more likely to record status if the person has reported smoking rather than in the case that person reports that he or she is not smoking. This is because currently in physiological measurements the smoking value unit is smoking status reported as a pack-years rather than as a binary value. Problem is that the FINRISK calculator takes as an input the smoking status in binary format, and we cannot assume that all persons are non-smokers if we can't find the recording of the smoking status from Kanta PDR. In contrast, smoking information was found in structured format only for 1.5% of the persons in the dataset of this study. The smoking data in the FINRISK calculator is a simple yes or no, and this cannot be directly mapped to any of the three structured smoking definitions which are based on cigarettes per day [18], pack-years [18], and a scale of nine steps for smoking habits [23].

Conclusions

The results highlight the need to trace the flow of information required by risk calculation starting from the moment it is created, as only studying the Kanta PDR does not reveal where the data went missing. This would enable pinpointing where better system integration is needed.

Other possible solutions for the lack of input data could be mining it from text data in the Kanta PDR or asking patients to fill in the required information in questionnaires saved into the Kanta Personal Health Records (PHR). Data mining from text could open several years of existing data stored in the Kanta for research. Measurement data such as cholesterol level and blood pressure have been found to be more frequently available in the Kanta PDR in recent years, thus for them, new approaches for acquiring data may not be needed [7]. The biggest improvement for utilization of laboratory results in risk assessment would be the unified coding system for all laboratory studies recorded to Kanta. Currently, all the laboratory results made in Finnish healthcare are stored in the Kanta, but we are not able to utilize all the results because we lack the unified coding system for laboratory studies.

As Kanta does not support structured format information about family-related incidents it would be a great improvement to Kanta data quality to add family-related incidents as supported information to Kanta. For each patient, we could mark if the person knows about the incident in the family which would affect the person's risk of developing certain diseases. In these cases, we won't need the information about who has it, only the information about incidents in the family would improve the performance of this risk model and other risk models where family-related information is related to the risk of disease. In these cases, information cannot be validated by the healthcare professional if the incident has really occurred, but it still would be beneficial for the risk assessment as it would guide a person to correct tests if there is a higher risk for a certain disease.

Kanta PDR offers an excellent basis for automated risk assessment as from patient point of view, no matter which healthcare service provider a person goes to, the data is always available in the same nation-wide register. There are improvements which need to be considered before Kanta can achieve full potential as a data source of automated risk assessment. There are many benefits in utilizing NEHR data for risk assessment rather than using other data sources supporting the risk assessment. Also, integration to one national data source over multiple local data sources is more cost-effective.

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Conflicts of interest

The authors Viljami Männikkö, Klaus Förger, Henna Urhonen and Joona Munukka work for Atostek Oy. Atostek Oy provides an eHealth API Gateway service which enables healthcare and social welfare providers a fast and easy connection to Finland's national Kanta services. The publication is related to quality of data stored in the Kanta archive and improving the quality of the data could have positive impact for the Atostek's services. We do not consider this to be a conflict of interest as the improving the quality of the data in the national Kanta archive is possible only through constructive criticism of the current situation.

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