SITRA

PUBLICATIONS

NOVEMBER 2018

FROM BIG DATA TO MYHEALTH

– DATA ANALYTICS AS A TOOL FOR HUMAN-DRIVEN WELL-BEING

ANDREW SIRKKA (ED.)

Sitra studies 141

From Big Data to Myhealth

ISBN 978-952-347-086-6 (paperback)
ISBN 978-952-347-087-3 (PDF) www.sitra.fi
ISSN 1796-7104 (paperback)
ISSN 1796-7112 (PDF) www.sitra.fi

Erweco, Helsinki 2018

SITRA STUDIES is a publication series which focuses on the conclusions and outcomes of Sitra's future-oriented work

The accessibility of the publication has been improved in the summer of 2020..

Preface

Healthcare is undergoing profound change. Whole-genome sequencing and high-resolution imaging technologies are key drivers of this rapid and crucial transformation. Big data in health can be used to improve the efficiency and effectiveness of prediction and prevention strategies or of health services. Exploiting data is key to value-based healthcare, personalised care, as well as patient involvement.

Data is the primary component of building new health services in citizen-centric way. As the world moves further into the digital age, generating vast amounts of data and born digital content, there will be a greater need to deploy this information in the healthcare routines. Our passion has been not only to find out but also to develop disruptive tools and methods to break down barriers of accessibility for healthier life of future generations.

The potential of "big data" for improving health is enormous but, at the same time, we face a wide range of challenges to overcome urgently. In healthcare, analytics and the use of collected data is still in their infancy. We are very proud of some of our leading-edge projects; however, the truth is that there is the big gap between these novel tools and the reality how they are deployed in healthcare. Operational culture needs to change.

There is also a need for a citizen-centric, "my data" approach to improve healthcare services in Europe. Instead of current volume-based healthcare we should concentrate on creating value and better health outcomes for people by better understanding their needs and supporting them towards healthy and happier living.

Unhealthy lifestyles are major public health issues in many European countries like Finland. Unmet medical care needs are relatively high, especially among low-income people in Finland*. For example, the amount of people seeking help for mental health problems has increased in Finland in recent years. Despite those changes in customers' needs, only minor improvements have been successfully made in the care chain, access to care and the service system.

These findings were the start of the Health Analytics Programme (HEAP) in the autumn of 2017. The aim of the HEAP training on analytics was to advance analytical and technological competence in order to facilitate the innovative and proactive use of health data reserves in health and social services. The project explored how the opportunities brought about by information technology could enhance the activity and engagement of clients in the service system.

The HEAP project was carried out in co-operation with Satakunta University of Applied Sciences (SAMK), the Pori unit of Tampere University of Technology (TTY) and the eMed laboratory of the Tallinn University of Technology (TalTech). I would especially like to thank Sari Merilampi, Doris Kaljuste and Andrew Sirkka for their invaluable work and encouragement, and the TTY and TalTech, under the leadership of Tarmo Lipping and Peeter Ross, for their ideas and support during the HEAP project.

Data analytics can be applied in healthcare in many forms and across all stages of the healthcare service chain. It is of the utmost importance for decision-makers and management to identify the need to educate new kinds of healthcare professionals. Finally, healthcare institutions should become learning and supporting organisations that are skilled at creating, acquiring and transferring knowledge, and at modifying their behaviour to reflect new knowledge and insights, together with their clients, citizens.

27.10.2018 Lappeenranta

TUULA TIIHONEN
Project director, Human-driven Health, Sitra

*State of Health in the EU Finland, Country Health Profile 2017, OECD and World Health Organization.

Tiivistelmä

Viime vuosina on puhuttu paljon big datan ja tekoälyn tuomista mahdollisuuksista. Niin myös terveydenhuollossa, missä kerätään ja tallennetaan päivittäin valtavat määrät tietoa. Näiden tietomassojen älykkäässä hyödyntämisessä otamme kuitenkin vasta ensi askeleita.

Tässä julkaisussa arvioidaan, kuinka hyvin osaamme hyödyntää terveys- ja hyvinvointidataa tällä hetkellä, esitellään hyvinvointianalyytikkojen koulutusohjelman (HEAP) pilottihankkeen kokemuksia ja oppeja sekä kerrotaan käytännön tapausesimerkkien avulla, miten tietoa hyödynnetään aivan uudenlaisissa terveyspalveluissa jo nyt. HEAP-pilottiprojekti toteutettiin yhteistyössä Satakunnan ammattikorkeakoulun, Tampereen teknillisen yliopiston Porin yksikön ja Tallinnan teknillisen yliopiston kanssa.

Kuten professori Tarmo Lipping kirjoittaa, hyvinvointianalytiikka voidaan nähdä lukutaitona, jonka arvo kasvaa jatkuvasti, varsinkin terveydenhuollon kaltaisessa monimutkaisessa ympäristössä. Niin ikään se on tärkeä keino parantaa ihmisten osallisuutta omassa hoidossaan.

Tulevaisuudessa tätä lukutaitoa tarjoavat yhä useammin tekoäly ja algoritmit, mutta sitä odotellessamme terveydenhuollon arjessa tarvittaisiin data-analyysin ammattilaisia, jotta tietovarantomme saataisiin hyötykäyttöön. Hyvinvointianalyytikot voisivat toimia erilaisissa rooleissa eri osissa terveydenhuoltojärjestelmää ja esimerkiksi tuottaa hyödynnettävää tietoa hoitotiimin tai johdon päätöksenteon tueksi. Analyytikko voisi koostaa ja analysoida mm. potilasdataa sekä asiakastietoa palveluohjauksen ja asiakaskokemuksen kehittämiseksi. Analyytikko voisi myös tukea yksilöllistä terveys- ja hyvinvointisuunnittelua ja -valmennusta datan avulla.

Pilottihankkeen tulos: matka on vasta alussa mutta paljon on tehtävissä jo nyt

HEAP-pilottihankkeesta saadut kokemukset ovat rohkaisevia mutta alleviivaavat myös sitä, että tehtävää on vielä paljon. Asiakasrajapintaa hoidetaan edelleen pääosin manuaalisesti terveydenhuollon arjessa. Toiminta- ja prosessiautomaatio on vasta aivan alkuvaiheessa moniin muihin toimialoihin verrattuna.

Pilotin myötä datan käytön esteiksi tunnistettiin esimerkiksi terveydenhuollon tietojärjestelmien monimutkaisuus, tiedon puute, käyttöoikeuksien rajoitteet ja tietosuojasäädökset (tässä järjestyksessä). Hyvinvointianalyysiohjelman, johon kuului myös hyvinvointivalmennusta, puolestaan nähtiin tuovan lisäarvoa niin ammattilaisille, asiakkaille kuin koko palvelujärjestelmälle. Erityisesti laadunhallinnan, muutosjohtamisen ja asiakasviestinnän arvioitiin parantuvan, jos hyvinvointianalytiikkaa käytettäisiin nykyistä enemmän.

Tulevaisuus näyttää kuitenkin valoisalta. Olemme parhaillaan matkalla kohti osallistavaa ja ennakoivaa hyvinvointia, terveys 1.0:sta älykkääseen terveys 4.0:aan. Tämä matka on aikoinaan alkanut erilaisten tietoaineistojen muuttamisella digitaaliseen muotoon, jatkunut eri tietoaineistojen yhdistelyn oppimisella ja etenee parhaillaan kohti entistä yksilöllisempien palvelujen kehittämistä. Matka jatkuu kohti tekoälyn ja algoritmien mahdollistamia yksilöllisiä päätöksenteon tukipalveluja ja parempaa asiakasymmärrystä. Suomi ja Viro ovat tämän matkan edelläkävijöitä.

Julkaisussa esitellään uudenlaisia, jo käytössä olevia keinoja hyödyntää dataa, kuten Terveyshyötyarvio, joka tunnistaa väestön hoitovajeita ja auttaa löytämään kullekin yksilölle tehokkaimmat ennaltaehkäisy- ja hoitovaihtoehdot sekä KardioKompassi®, joka auttaa arvioimaan henkilökohtaista riskiä sairastua sydän- ja verisuonisairauksiin genomi- ja elintapatietojen perusteella. Niin ikään esittelyssä on sähköinen Omaolo-palvelu, joka tarjoaa asiakkaalle apua ajasta ja paikasta riippumatta. Datan hyödyntämisen kokonaisuudessa merkittävä rooli tulee olemaan myös suomalaisilla tietoaltailla ja biopankeilla, joista kerrotaan luvussa 4.5.

Summary

In recent years there has been much talk about the opportunities offered by big data and artificial intelligence. This is also the case in healthcare, where large amounts of information are collected and stored every day. However, we are only taking the first steps in the smart use of this mass of data.

This publication evaluates how well we currently use data on health and well-being, presenting the experiences and teachings of the Health Analytics Programme (HEAP) pilot project and using practical examples of cases to illustrate how data is already being used in new forms of healthcare services. The HEAP project was a co-operation between Satakunta University of Applied Sciences (SAMK), the Pori unit of Tampere University of Technology (TTY) and the eMed laboratory of the Tallinn University of Technology (TalTech).

According to Professor Tarmo Lipping, data analytics can be seen as a kind of literacy, whose value becomes greatest in complex environments such as healthcare. It is also an important way to improve people's participation in their own care.

In future, this literacy will increasingly be offered by artificial intelligence and algorithms, but until then professional health analysts could enhance the day-to-day operations of the healthcare system, maximising the value of our existing knowledge reserves. Health analysts could operate in many different roles in various parts of the healthcare system and, for example, provide information that improves treatment or supports administrative decision-making. An analyst could compile and analyse information such as patient data and customer information for the development of service counselling and the customer experience. An analyst could also support individual planning for health and well-being and for coaching with the help of data.

Pilot project outcome: the journey is just beginning but much more can be done now

The experiences of the HEAP pilot project are encouraging, but they also underscore the fact that much remains to be done. The customer interface continues to be primarily handled manually as a part of healthcare routine. Production and process automation is only at the early stages compared with many other fields of activity.

The pilot identified some impediments to the use of data, such as the complexity of health information systems, the lack of information, restricted user rights and data protection regulations. Health analytics programme including customer coaching and case management, was seen as providing added value for professionals, customers and the service delivery system. In particular, it is envisaged that the greater use of data analytics will improve quality management, change management and communication with customers and their families.

Despite some reservations, the future looks bright. We are currently on our way towards inclusive and proactive well-being, from Health 1.0 to smart Health 4.0. This journey began with the conversion of various data into digital form, continued by learning how to combine various data materials and is currently moving towards the development of increasingly individualised services. The journey will continue towards individualised support services for decision-making and better understanding of customers, enabled by artificial intelligence and algorithms. Finland and Estonia are at the forefront of this journey.

This publication proposes new ways of using data that is already available and in use, such as the Health Benefit Analysis, which recognises care gaps in the population and helps find the most efficient alternatives for prevention and treatment, and the KardioKompassi®, which helps evaluate the risk of individuals contracting cardiovascular diseases by analysing genome and lifestyle data. Also presented is the electronic Omaolo service, which offers customers help no matter the time or place. Finnish data lakes and biobanks, also addressed in the report, will also have a significant role to play in maximising the use of personal data.

Contents

1

Introduction

ANDREW SIRKKA EdD, PRINCIPAL LECTURER, PROJECT MANAGER,
SATAKUNTA UNIVERSITY OF APPLIED SCIENCES (SAMK)

Since the first digitisations in the field of healthcare, the speed and extent of transformation has been increasing on an annual basis. Fast technology development of disruptive technologies and emerging trends like robotics, artificial intelligence, 3D printing, precision medicine or patient design affect the health industry globally. More and more fascinating and easy-to-use trendy applications arrive on the market that appeal to anyone who wants to monitor activity, sleep, blood pressure, ECG, pulse, nutrition levels – you name it. Any self-respecting modern individual wants these apps on their smartphone and feels the need to be actively involved in their own health and well-being.

The healthcare and social sector have traditionally been seen as information-intensive industries filing massive amounts of information intended for use in a person's care. A long time ago it became obvious that no one would be able to manually handle that amount of produced or filed information. The mass of data has become akin to hazardous waste! It is commonly accepted that this manually or electrically gathered information is not accessible and does not move between various services and professionals that badly need it when serving their customers. Moreover, digitalisation and modern technology solutions, among other things, only serve to multiply the amount of data available. This enormous increase in digital data needs to be utilised much more effectively to meet customers' health and well-being needs. What we need is better deployment of data analysis and analysts within the service delivery systems.

The mass of data has become akin to hazardous waste!

This publication is one of the outcomes of a two-year project (2017–2018) called Health Analytics Programme (HEAP). The project was initiated and funded by Sitra, and was conducted as a collaboration between Satakunta University of Applied Sciences (SAMK), Tampere University of Technology (TTY) and the eMed Lab of the Tallinn University of Technology (TalTech). The purpose of the project was to provide evidence of the impact of analytical solutions and their suitability in healthcare and social services. The project envisaged an education package to provide the expertise required for the use of the data analytics. The education programme consisted of theoretical studies (30 ECTS, European Credit Transfer and Accumulation System) and a pilot phase (20 ECTS) with data analytics projects in students' working environments introducing data analytics into practice.

Added to a Steering Committee, the project established a Working Life Committee representing the service provider organisations in the target region, Satakunta, Finland. Students enrolled in this pilot education programme formed two simultaneously progressing groups, one in Pori, Finland and one in Tallinn, Estonia. The students in the Estonian group had backgrounds from areas other than healthcare, unlike the Finnish students who all were healthcare professionals. The heterogeneity of the student groups enriched the education remarkably, widening the horizons of data analytics and its applications in service design.

This publication discusses the key topics related to big data, and its use in healthcare and social services. The publication consists of three main parts: 1) the "big picture", as a knowledge base for the project, discussing global trends and transformations in the health industry; 2) the implementation of the HEAP project and pilot education experiences; and 3) interesting novel means and methods for data analytics in healthcare and social services. As participants in the project, we found the topics very intriguing to discuss and work with. I hope that this publication conveys the same enthusiasm and motivation to its readers, to make future healthcare and social services more flexible and individualised based on effectively deployed data analytics.

Finally, as the HEAP project manager and the editor of this publication, I would like to express my sincere appreciation and gratitude to all the experts and students for their priceless contributions to the project and this publication.

What we need is better deployment of data analysis and analysts within the service delivery systems.

HeAP

2

The future of healthcare – from health 1.0 to health 4.0

MADIS TIIK, MD, SENIOR ADVISOR, SITRA

This article discusses the transformation in the healthcare concept since the first digitisation in the Health 1.0 concept and up to the future smart Health 4.0. The technology-driven development has generated new ecosystems and enabled new potential in health services. However, the new ecosystems require new competences and outstanding changes in working patterns.

Health 1.0 – Digitisation

The widely deployed and popular computer application, the electronic medical record (EMR), is in its basic version a digitised version of the regular traditional paper-based medical chart for everyone. It contains all the patient's medical and clinical data history in a single facility, such as a hospital, clinic or GP's office. It is used by healthcare providers to monitor and manage care delivery within the facility. At the same time, there have been different services and devices which collect data for everyone's own personal health record (PHR). At this stage, they are stand-alone solutions – one device or service which has its own data storage.

Health 2.0 – Integration

An electronic health record (EHR) is shared instantly and securely among multiple healthcare facilities within a community, region and state, or, in some cases, the whole country. Effective implementation of EHRs can be done after healthcare organisations have adopted complete EMR systems. Like EMRs, EHRs are longitudinal patient-centred records containing a patient's full health profile (or, more accurately, a sickness profile, because it carries primarily your medical history) starting from the first attendance at or admission to the facility. The primary aim of the EHR is integration, data sharing between healthcare providers, automation and streamlining of a healthcare provider's workflow. It is very important to ensure that the information generated in the EHR is timely, accurate and available all the time.

PHRs are also developed for the ecosystems of different services and devices but are still separate from the EHR. A health information exchange (HIE) is a centrally collected dataset from local EMRs, and enables data exchange between different EMRs, with data passing from one to the other over the HIE platform (Figure 1).

Health 3.0 – Personalisation

The first precondition for Health 3.0 is a personal health account (HA), which consists of both PHR and EHR-generated data and which can be fully controlled and managed by individuals themselves. The PHR and EHR service providers feed HA with data. From the perspective of the individual, the process must be simple and easy to manage.

The EU General Data Protection Regulation (GDPR) enables people to take over the control of data, but there is a lack of infrastructure and standards for doing so. Moving towards Health 3.0, we have to build trust and security around the health account. Once those components are in place, everyone can connect with other data sources, like genome bank data or data from various registries. That´s why Sitra, the Finnish Innovation Fund, started (2018) an international project IHAN® to enable us to move our personal data between different service and data providers, including our personal health data.

Why IHAN? Because more and more services that we use are digital, which also means global. IHAN gives us the ability to collect data from different providers. For that, clear and open standards are needed. The closest example of IHAN number (a part of the IHAN concept) is IBAN, the international bank account number, which gives us a simple address for a person's bank account. Why not use a similar solution for health information? (See Figure 2.)

The second precondition is consent management. Making decisions about which service to use, every inidivual also has to give a certain level of consent to the service provider. This can be solved using the MyData model – a model that equips individuals to control who uses their personal data, stipulates the purposes for which it can be used and gives informed consent in accordance with personal data protection regulations. It makes data collection and processing more transparent and it helps companies or other organisations implement comprehensive privacy protection policies (Poikola, Kuikkaniemi and Honko 2015).

Sitra will create an international consept for a human-centric and secure data exchange and part of it will be standardised by European standardisation process. Sitra is also working closely with MyData Alliance.

FIGURE 1.
The healthcare process today

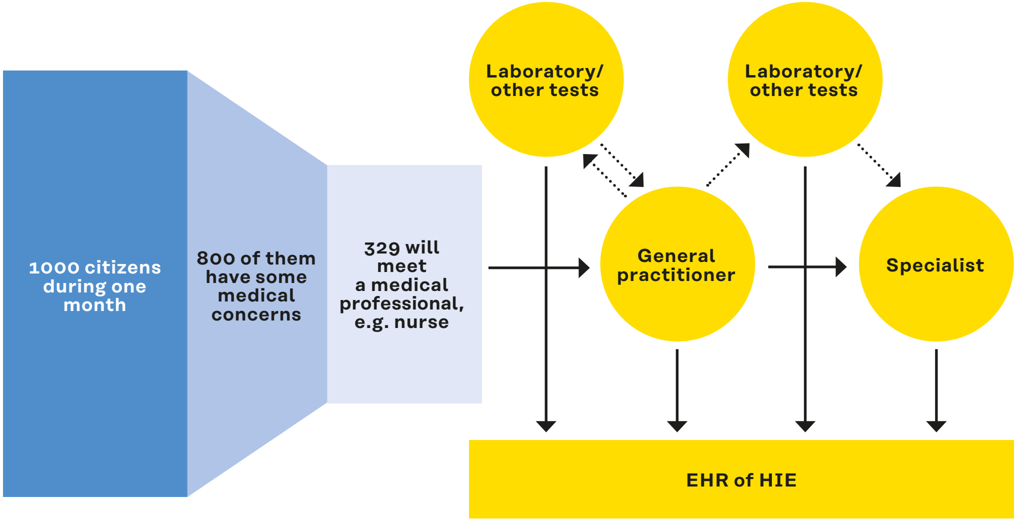
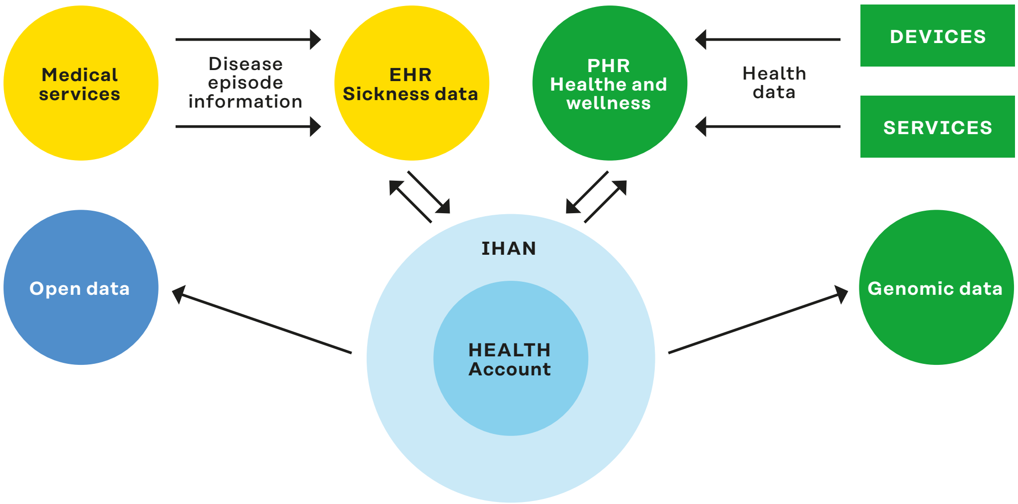


FIGURE 2.
Health 3.0 – A health account and IHAN enabling a patient-centred approach



Health 4.0 – AI empowered decision-making services

While Health 3.0's focus is more on securing data exchange under the control of an individual, Health 4.0 is more concerned with the opportunities and services enabled by a health account and proper consent management. It is evident that in this stage the main role will be taken by artificial intelligence (AI; Figure 3). Decision support and triage systems for better decision-making have been in use already for 20 years, but thanks to modern machine learning and advanced analytics we can go much deeper and closer to personalisation. Different kinds of analytical services can be built around a health account; maybe we even need new professionals to deal with that – health analysts?

The health account can be also seen as a market place for different services – one person may open his or her dataset and realise they need further assistance. The market can work like a matchmaking environment, where knowledge and health problems face each other and the individual acts as a kind of conductor, who allows or denies access to the personal dataset.

With all the necessary components in place, we can design a new process for how people should interact with healthcare services. First, the 800 people who had health-related concerns could have started to solve them together with AI. A symptom checker, decision support tools and access to existing medical history would form the basis of analytical tools, which will help to clarify and specify the existing condition.

After triage, some problems could be solved by a healthcare professional, but most of the problems could be solved elsewhere. The health account is the connecting particle between the dataflow from EMRs and other services, but also feeds the AI for better analytics (Figure 4).

Conclusions

Although we have spent a lot of money and time on integrating EMRs, allowing personal access to the data, we really do not have better health outcomes. One reason for that might be that the focus has been wrong – concentrating too much on data collection and digitisation, rather than building patient-centric services and using data analytics. GDPR and IHAN will lead the new era of healthcare, where integration is carried out with the consent of data owners, people, and artificial intelligence is used to make better decisions. This will lead to the empowerment of the patient and may have a positive impact on personal well-being (Figure 5).

FIGURE 3.
AI-empowered decision-making services.

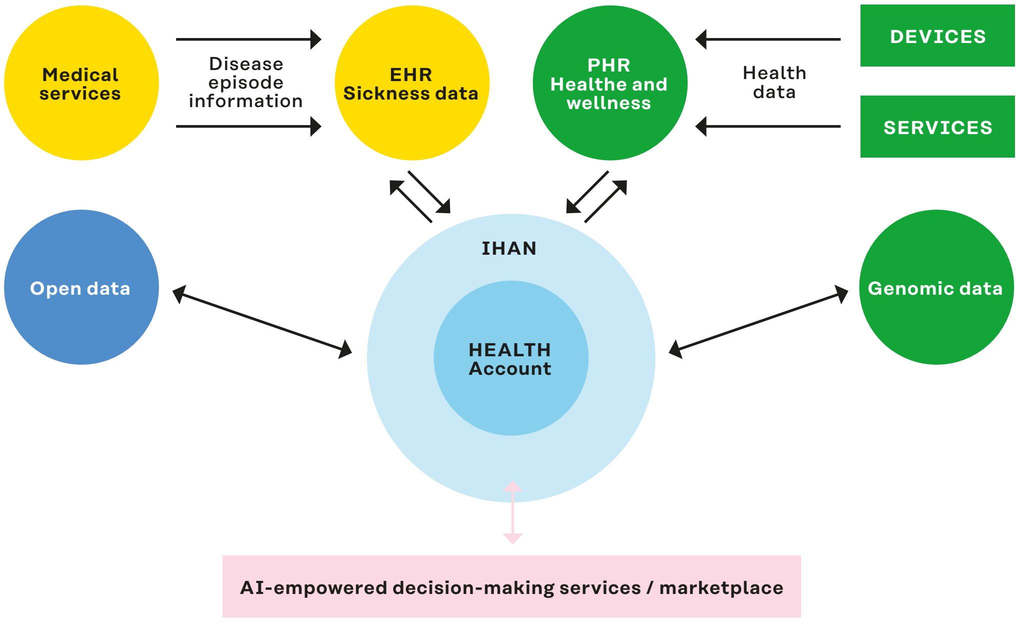


FIGURE 4.
The healthcare process in the future

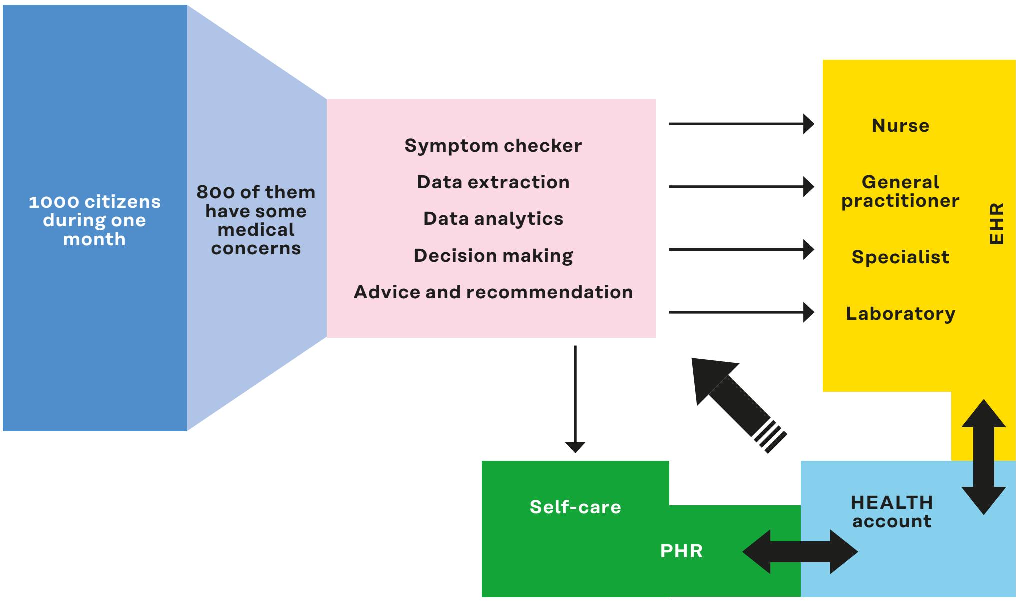
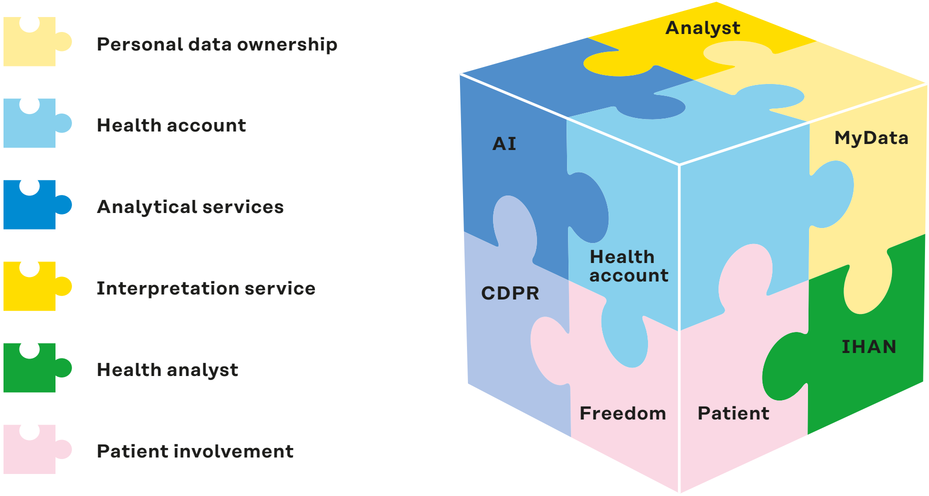


FIGURE 5.
The preconditions for Health 4.0



2 References

1. Green L. A., Fryer G. E. Jr., Yawn B. P., Lanier D. and Dovey S. M. (2001), *"The ecology of medical care revisited"*, New England Journal of Medicine, 344(26): 2021–2025.

2. Sitra (2018), *the Human-Driven Data Economy:* www.sitra.fi/en/topics/human-driven-data-economy/#what-is-it-about.

3. Poikola A., Kuikkaniemi K. and Honko H. (2015), *MyData – A Nordic Model for human-centered personal data management and processing,* Ministry of Transport and Communication, Finland: www.lvm.fi/documents/20181/859937/MyData-nordic-model/2e9b4eb0-68d7-463b-9460-821493449a63?version=1.0.

3

DATA ANALYTICS TRANSFORMING HEALTH SERVICES TOWARDS MYHEALTH SERVICES

3.1

Teaching healthcare analytics – a new curriculum in healthcare education

PEETER ROSS, PROFESSOR, EMED LAB, TALLINN UNIVERSITY OF TECHNOLOGY, ESTONIA

Increasing amounts of health and medical data, collected from different data sources and present on healthcare professionals' desktops, brings a need to aggregate this data and information and present it in condensed form. In an ideal situation, collected data could be processed with digital tools using artificial intelligence and decision support systems. Unfortunately, current data in electronic medical and health record systems is not of sufficient quality for computer processing in most cases. The health analytics profession might cover this gap in the coming years. Below is an overview of the content of the curriculum for health analysts.

The teaching of healthcare professionals, doctors and nurses, traditionally concentrates on problems of a particular individual or understanding the development of specific diseases. This has been an efficient way of passing on professional experience and introducing scientific evidence to medicine for centuries. Nowadays, when the amount of data collected about patients is exceeding analytical limits of the human brain, the traditional synthesis of data by one professional is not possible. In addition, research in biomedical sciences is producing so much professional knowledge that keeping the diagnostic and treatment skills of a doctor or nurse up to date requires aggregation and presentation of this new information with the help of computers, in an easily understandable way.

This situation is ideal for introducing artificial intelligence tools to help healthcare professionals handle ever-increasing amounts of information. However, despite the high expectations for computer-aided detection of diseases and digital decision support systems, a real breakthrough regarding the above-mentioned tools has not happened.

Insufficient use of digital tools can be contributed to the low quality of the collected data and the diverse information systems that have low interoperability with each other. In addition, bringing in new technologies to conventional medical service provision demands smart change management approaches, to avoid resistance by healthcare professionals that are already overwhelmed with continuous changes in their daily work. The current situation supports the introduction of a new type of healthcare professional, who understands how health and medical data from different databases can be integrated and updated into an easily usable, standardised format. The knowledge of this profession should be based more on the understanding of types and sources of data, and how collected information can be presented to the decision-maker (rather than solving the problems of one particular individual).

Thus, the health analyst is a professional that potentially covers the existing gap between insufficient handling, high volumes of medical data and the universal implementation of artificial intelligence. The role of the health analyst would be to find relevant data from the various databases, decide on the quality of data, and present data to the decision-makers or enter it into digital decision support tools.

Core components of the healthcare analyst's curriculum

Three universities in Finland and Estonia (Satakunta University of Applied Sciences, Tallinn University of Technology and Tampere University of Technology) developed a curriculum for the health analyst profession. The curriculum consists of the following basic components: 1) primary and secondary use of data; 2) content and trends in e-health; 3) digital tools in healthcare; 4) theoretical basis of data analysis; 5) service design and change management; 6) information systems in healthcare and their integration; 7) digital decision support systems; 8) artificial intelligence; 9) practical design of a health analyst's work processes; 10) patient empowerment; 11) smart healthcare services; and 12) internship in health analytics.

Primary and secondary use of data

Data is the primary component of building e-health services and digital tools. Data in information technology is the same as cells in medicine – while cells are foundations of organs, tissues and the human body, data is the foundation of e-services and digital tools. Data has no meaning without the context. Adding context to data generates information. The same data could carry different information, depending on the surrounding environment. In medicine, data is often mixed with information. In the analogue world, a clinician's notes might include some conclusions in free text without presenting the source data. This hinders reuse of collected notes because they are not computer processable. To make clinical notes available for digital decision support systems they should be standardised and as context specific as possible. Furthermore, the more granular the data, the wider the spectrum of e-services and tools that could be developed.

Healthcare professionals have to understand that the quality of e-services applied on different information systems depends on the quality of the data they are entering into the information system. The entering of data and its use at the point of care is the primary function of data. This is a part of the modernisation of healthcare and brings some efficiency into processes, but it has relatively limited value compared to the secondary use of data. Secondary use of data is taking advantage of the already collected data by other users, in different locations. It is the use of data collected by other professionals in different locations and circumstances. Accordingly, the reuse of free, unstructured and non-standardised free text is cumbersome and time consuming, while structured and standardised data that is easily computer processable allows for the provision of added-value services (not only for the person who has entered the data, but more widely for all parties in the health domain, including the patient, healthcare professionals and society).

Content of and trends in e-health

E-health is a term that defines the introduction of innovation and change management into healthcare through digitisation. Similar to banking, where digital transformation is seen to a large extent (and e-banking is so common that the term itself is rarely used any more), healthcare digitisation should also consign the e-health term to history, digitisation being an inherent part of ordinary healthcare. However, to make this transformation happen students must understand how digitisation can change processes and bring new innovative tools into healthcare. Another aspect of digitisation is that it involves new parties in health-related decision processes. This applies especially to the involvement of patients.

Digital tools in healthcare

Innovation is often related to disruption. Digital tools in healthcare are disruptive in nature, involving the redesign of processes, the involvement of completely new decision-makers and sometimes making traditionally highly specialised services a commodity. Understanding the opportunities of new tools while also having knowledge about their potential harm is an essential part of the curriculum.

Theoretical basis of data analysis

Data analysis is based on mathematical calculations and statistical analysis. Even though development of analytical tools is not a part of a health analyst's profession, the understanding of what lies under the hood of digital tools is of utmost importance. The user needs to decide what digital tools are reliable and evidence-based. While using decision support systems the health analyst takes responsibility for the reliability of the tools used and must be confident that they will not harm the patient.

Service design and change management

As discussed earlier, the implementation of innovative tools and shared services in healthcare is not possible without redesigning analogue processes. On the other hand, change is perceived as a stress factor by healthcare professionals, who are typically conservative in the nature of their everyday work. The health analyst profession is new to the healthcare environment and every activity performed by health analysts could be taken as an unwanted event in the health system's well-established environment. Every new service must be designed in such a way that change is almost undetectable by users. Alternatively, if the redesign leads to evident change in the responsibilities or working environment, proper change management should be in place in advance.

Information systems in healthcare and their integration

Although the health analyst will use several new digital tools in their workplace, most of the medical information is collected in healthcare providers' sophisticated electronic medical records. Teaching basic principles of design and architecture, data standards and user interfaces used in information systems are important elements. Also, how to integrate different electronic medical records and the data provided by them into patient-centric, electronic health records is essential knowledge.

Digital decision support systems and artificial intelligence

The introduction of digital decision support systems for the primary use of data (i.e. entering of structured data into standardised formats) and for the secondary use of data (i.e. to receive alerts, notifications, reminders, risk scores, visualisation tools, etc.) is part of the curriculum. Students have a chance to enter their personal health data into digital tools and see what kind of output is delivered. This practical exercise allows students to understand the importance of data availability and quality, because insufficient data would lead to no response from the decision support system.

Practical design of health analyst work processes; internship of health analysts

Different scenarios involving the health analyst's work responsibilities have been designed. Scenarios in which health analysts work in a GP's office and provide doctors with patient summaries collected from different healthcare databases before a patient visit is one option. Scenarios have also been tested in which health analysts work at medical call centres and as health coaches, providing out-of-pocket services for patients. Each student has a chance to conduct an internship of 20 ECTS credits in healthcare services.

> *Understanding the opportunities of new tools while also having knowledge about their potential harm is an essential part of the curriculum.*

The importance of patient empowerment is thoroughly discussed in the programme. Data used by healthcare professionals should be owned by the patient and is accessible only after approval from the person him/herself. Therefore, the benefits for the patient are analysed, and different e-services and digital tools for disease prevention and health promotion are investigated.

Practical experience

The pilot project for health analyst training, consisting of a total of 50 ECTS, was conducted at the Satakunta University of Applied Sciences (SAMK) and at Tallinn University of Technology (TalTech), during three semesters, in 2017 and 2018. There were 10 students in Finland and five students in Estonia participating in the pilot. Feedback from the students and lecturers was collected. Every student had to partake in a practical internship that provided additional information about the need and value of the health analyst profession. Input from different sources was analysed and several recommendations about the new profession's skills and roles in healthcare, and about the curriculum for health analysts, were provided. The results of the pilot from different perspectives are discussed in other chapters of this book.

To conclude, all participants in the pilot project were enthusiastic about the need for this profession and found the proposed curriculum comprehensive. However, the role of the health analyst in the management of health status and medical problems in the healthcare environment is not yet well defined. In addition, the design of services where the health analyst could be used is in progress. As a result, the curriculum might need some further fine-tuning in the future.

3.2

Data analytic skills required in the health and social sector

ANDREW SIRKKA, EdD, PRINCIPAL LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

Healthcare as an information-intensive industry

The Health Analytics Programme (HEAP) was launched as a reaction to the increasing need for data analytic competences in the health sector. The healthcare sector has traditionally been an information-intensive industry, collecting large amounts of information from various sources (society, patients, science, machinery, etc.) for several reasons (health statistics, patient health records, reports).

Healthcare collects huge quantities of data about patients, treatments and procedures in manual or electric records, forming vast repositories of health and care-related information. These repositories are like libraries – only the problem is that use of this library is blocked! A widely well-known constraint, especially in developed industrialised countries, is that because of strict data protection legislation, data is hard to access (even by the most relevant professional for supporting optimal care) and poorly transferred between various care providers (Baker 2013; Tiik 2018).

The value of building huge libraries with massive information repositories that are scarcely used (if ever) is questionable. Should the system instead pay closer attention to collecting smart data – data that is beneficial and usable on a wider scale? Should people have a greater ownership of their health data? Smart data collection and automated analyses at the patient registration phase could expedite and improve quality of care.

Digitisation expanding the quantity and quality of data available

Digitisation in the healthcare industry is moving with a great deal of speed all over the world, even in developing countries. This is pushing services and businesses towards product-as-a-service services, usable anywhere and anytime, incorporating personalisation and agile continuous improvement (Little 2017). Digitisation could mean anything: devices capable of managing digital signals; computerised media and communication systems to explain or understand aspects of contemporary social life (Brennen and Kreiss 2014); or big technology innovations radically transforming processes and services by means of information technology (Chilikuri and van Kuiken 2017). No matter what the definition, it is obvious that digitisation is constantly and with increased intensity transforming the world, life, work, services, economy and culture.

Digital transformation, together with the ideology of consumerism, requires major changes in service concepts, processes and means, in all kinds of organisations and business domains. User-orientation and consumerism are essential parts of modern digitised services. They are drivers for change in management and leadership models, in innovative service concepts and new business models, and in the incorporation of digitised assets and increased use of technology to improve and streamline the quality of services provided by/to organisations, employees, customers, suppliers, partners and other stakeholders. Digitised services also transform governance towards more customer-driven perspectives (Butcher 2015; Kadmon et al. 2016; McNichol et al. 2015; STM 2016).

Opportunities for digitisation have also been identified by the Finnish Government's key projects, introducing and implementing digital healthcare accessible to customers, relatives and professionals. Rapid digital innovation is also evidenced by numerous start-up events and exhibitions, where digital health is a strong presence. More and more digital tools are being generated, marketed and used to monitor one's health indicators, including fitness levels, muscle activity, heart rates, blood pressure and sleep. The current discussion debates the pros and cons regarding usability of the data provided by wearable trackers in official healthcare services. Despite active marketing, recent surveys indicate that only 20-22% of adults are using wearable health trackers in Finland and in the USA (eMarketer 2017; Statista 2018).

New competences required

Because of rapid digitisation, large datasets of information are commonly available. Advanced exploratory data analysis techniques are also available to identify potentially useful patterns in data. Use of these techniques could provide colossal benefits and value to organisations and professionals involved in service delivery, as well as to customers.

According to Chilukuri and van Kuiken (2017), digital transformation is more likely to succeed when organisations focus on four critical dimensions: capabilities, modern IT foundation, delivery engines and sources of value. These dimensions obviously set new competency requirements for anyone working in the sector of healthcare and social services.

Kaggal et al. (2016) presents a list of core competences that all healthcare professionals should possess, regardless of their discipline in the 21st-century healthcare system. Patient-centred (let alone patient-driven) care fails without genuine shared decision-making and management, working in interdisciplinary teams. Evidence-based practice, integrating the best research with clinical expertise and patient values for optimum care and active participation in research and learning activities, requires data analytic skills. Applying quality improvement implies analytic competencies to identify errors and hazards in care and patient safety, to constantly measure the quality of care in terms of structure, process and outcomes in relation to patient and community needs, and to design and test interventions with the objective of quality improvement. None of this would be possible without utilising informatics in terms of communicating and managing knowledge, and using decision-making support technologies.

A project to pilot education programmes on health analytics

The Health Analytics Education Pilot (HEAP) was launched in 2017, in collaboration with Sitra, Satakunta University of Applied Sciences (SAMK), Tampere University of Technology (TTY) and Tallinn University of Technology (TalTech). The project envisaged a study programme for health service analyst competences on the grounds of the challenges discussed above. The education programme contained a total of 30 ECTS theoretical and 20 ECTS practical studies to implement analytics in real-life services. The pilot group consisted of two student groups, one in Pori, Finland, and the other in Tallinn, Estonia.

Given the issues associated with rapid digitisation and its attendant challenges for healthcare, designing a one year-long education programme aimed at the furthering knowledge of data analytics for non-medical healthcare professionals was not a simple task. To get started, the project group had a few meetings to figure out the most essential elements and competency requirements to be met and to plan how to implement the identified contents in the programme. Also, a working life committee with representatives from the main healthcare service providers in the region was established, to discuss the needs and challenges organisations currently face regarding data analytics.

A special characteristic of this pilot education project was having two simultaneous groups of students in Finland and Estonia. Additionally, the Estonian students had a variety of professional backgrounds compared to the healthcare professionals in the Finnish group. Heterogeneity in the healthcare services and student groups turned out to be a strength and a huge resource, rather than a challenge. Even though in the commerce and retail sector customer orientation is expected to be a centrepiece, it soon became very obvious how similar the challenges and shortages were both in commerce and healthcare (or social services) today. Analytical skills are not well known, let alone a core competence, in either industry.

The students found the pilot period very eye-opening in many ways.

The structure of the education programme consisted of the following theoretical studies: 1) e-health and telehealth, Health 1.0-4.0 strategies, comparing digitised health services at national levels; 2) decision support systems and tools that focus on data analytics, and technology tools provided to support decision-making in healthcare; 3) client involvement and smart services and digitools to implement customer engagement and client-centredness in services; 4) service design and case management; 5) a practical period piloting analytics in healthcare services.

Studies consisted of online studies using video lectures and online sessions. Weekly face-to-face workshops were held to facilitate the work of the two groups and to keep up with the progress of the studies. As expected, the data analytics part turned out to be quite a challenge for all the students. To support international aspects and get a deeper insight into commonalities and diversities in service deliveries between the two countries, a couple of intensive campus weeks with a variety of workshops and seminars (including public seminars on the theme) were held (Figure 1).

Working on the given assignments the students faced difficulties, even as professional staff in the organisation, in accessing the required data in the systems. Many flaws in documentation were identified, which resulted in either limited access or a total lack of the required information. Most documentation is still in unstructured narrative form, which requires natural language processors (NLP) to analyse. The massive quantities of collected data in the organisations was poorly accessible and used in surprisingly scarce ways. The students found the pilot period very eye-opening in many ways. In particular, students realised how even small-scale analysis can identify bottlenecks and critical points, in addition to the opportunities to streamline services. The student's pilot projects are discussed in more details in the article 3.5 in this publication.

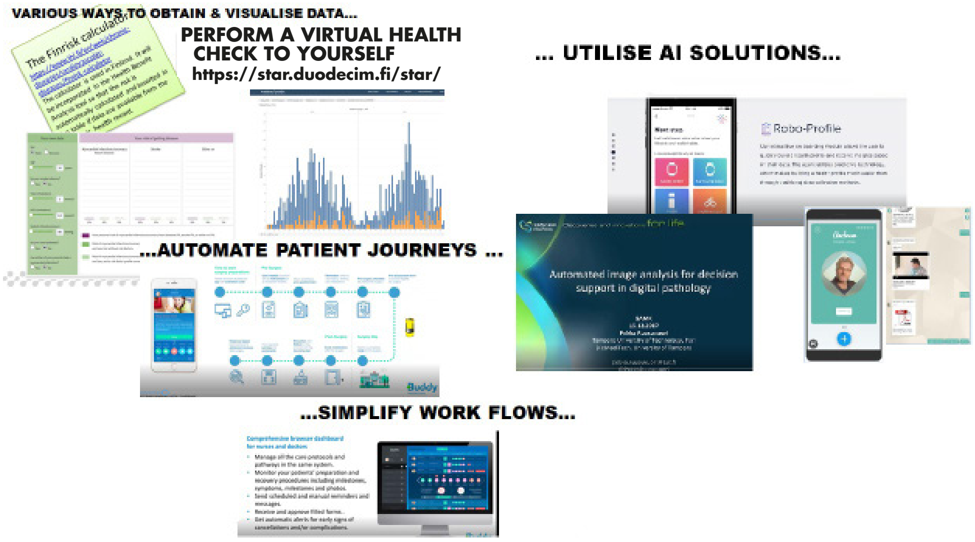
To conclude, the pilot education programme provided a lot of new perspectives. New skills were also attained regarding how to handle and visualise data, and how to automate and streamline customer services through process mapping and use of AI solutions (Figure 2).

FIGURE 1.
Health analytics was carried out as a form of multimethod education

Multimethod education

- Weekly tutoral classes
- Video lectures and student assignments in Moodle e-learning environment
- Intensive programmes
- Service and tech demos
- Seminars and workshops
- Multiprofessional joint classes
- Close collaboration with companies, service provider organisations and projects

FIGURE 2.
Some of the main learning outcomes in Health Analytics Education



3.2 References

Baker B. (2013), *"Great patient care begins at registration"*, in Health Management Technology, April 2013, Vol. 34 Issue 4, p. 17.

Brennen S. and Kreis D. (2014), *"Digitalization and Digitization"*, in Culture Digitally, cited 12 September 2018.

Butcher L. (2015), *Consumerism Hits Healthcare,* H&HN: Hospitals & Health Networks, February 2015, Vol. 89 (2), pp. 22-27.

Chilukuri S. and Van Kuiken S. (2017), *"Four keys to successful digital transformations in healthcare"*, McKinsey & Company, cited 13 September 2018.

eMarketer (2017), *"Wearables Still Far from Mass Adoption"*, cited 19 September 2018.

Kadmon I., Noy S., Billig A. and Tzur T. (2016), *"Decision-Making Styles and Levels of Involvement Concerning Breast Reconstructive Surgery: An Israeli Study"*, Oncology Nursing Forum, January 2016 Supplement Online Exclusive Articles; 43 E1-E7. 7p. ISSN: 0190-535X.

Kaggal V. C., Elayavilli R. K., Mehrabi S., Pankratz J. J., Sohn S., Wang Y., Li D., Rastegar M. M., Murphy S. P., Ross J. L., Chaudhry R., Buntrock J. D. and Liu H., *"Toward A Learning Health-care System – Knowledge Delivery at the Point of Care Empowered by Big Data and NLP"*, Biomedical Informatics Insights 2016: 8(S1) 13-22 doi: 10.4137/BII .S37977.

Little A. D. (2017), *"Digital transformation in developing countries – Promotion and adoption should be the main actions for companies and government"*, cited 19 September 2018.

McNichol E., McKay A., Milligan C., Bennett K., Hulme R. and Joy H. (2015), *"A patient-led approach to product innovation in patient education and wound management"*, EWMA Journal, April 2015; 15(1): 47-51. 5p. ISSN: 1609-2759.

Statista (2018), *"Fitness band, connected car system and smartwatch ownership in Finland 2017"*, cited 19 September 2018.

STM (2016), *"Digitalisaatio terveyden ja hyvinvoinnin tukena Sosiaali- ja terveysministeriön digitalisaatiolinjaukset 2025"*, Sosiaali- ja terveysministeriön julkaisuja 2016:5, cited 10 September 2018.

Tiik M. (2018), *"Miksei tieto kulje?"*, Tekniikan maailma, March 2018, pp. 77-83.

3.3

Data analytics for decision support in healthcare

TARMO LIPPING, PROFESSOR, TAMPERE UNIVERSITY OF TECHNOLOGY

Analysis of health-related data is a diverse topic spanning from health coaching to complex environments of intensive care, with various goals, requirements and practices. Health data analytics is used at the point of care, in real time; but it is also invaluable in developing healthcare service chains, treatment standards and guidelines, and reducing the overall costs of healthcare while maintaining high service quality. Health data analytics may be integrated into commercial clinical decision support (CDS) systems, but it can also be used by healthcare experts locally by collecting relevant data from their immediate work environment and analysing data to better understand the impact of their work. In this paper, both types of health analytics applications are considered. In the first part, general workflow from data collection to decision-making is discussed. The training projects performed by the students in the HEAP programme belong mostly to this category; the relevant topics were covered in the Decision Support Technologies course of the HEAP programme. In the second part of the paper, I will consider CDS systems, their functions, features, aspects of implementation and challenges of adoption. These topics were covered in the Decision Support in Healthcare course of the HEAP programme.

Data analytics and decision support technologies

Although data analytics is increasingly integrated into various healthcare information systems, there are (and will always be) lots of data collected at various points of the healthcare service chain that cannot be incorporated into centrally maintained data repositories. Also, even if data analysis is outsourced to the tools and routines of commercial information systems, exploiting data and data analytics in everyday clinical work is a matter of attitude. To use and trust the analysis results, one has to have basic knowledge of how these results are obtained. In addition, data analysis can only be as good as the data it relies on. The data is collected by humans and it is difficult to motivate oneself to carefully register data if the data is not used, or if those who collect the data never receive feedback on its usage. It is not uncommon to see tables of clinical data filled with non-informative predefined entries, or with fields left empty.

The general steps of data analysis are shown in Figure 1. The workflow starts with data collection. Studies where data collection has been performed poorly are often referred to as “garbage in, garbage out”. Nowadays, when there is a lot of discussion about big data and artificial intelligence, many organisations decide to collect as much data as possible, without a good strategy on data usage. While this might be justified in some cases, much better results are obtained if the purpose of data collection is well specified and there is a clear strategy regarding the usage of the collected data. The more the data collection requires the time and effort of medical staff, the more important it is to carefully design the structure of the data to be collected. It is important to implement data collection so that there is no need to manually insert the data that can be retrieved from other repositories (electronic health records (EHRs), for example), or that can be collected semi-automatically (by building interfaces to measurement equipment, for example). This reduces the workload of data collection and makes it less prone to errors.

Repeated manual insertion of the same data is demotivating for the staff involved. If relevant, well-defined protocols for data collection should be designed and observing these protocols should be ensured and monitored by respective checklists or apps. No analysis can compensate for negligence in data collection.

During the HEAP project, there has been a lot of discussion on who should actually perform the data analysis and where in the service chain the health data analyst should step in. There is no single answer to this question. It is desirable that medical staff have at least some preliminary skills to visualise data available in common formats such as Excel or CSV. Performing statistical analysis requires more skills and carefulness. The tools of statistical analysis usually make certain assumptions and if these are not fulfilled, the results may be misleading. At the higher end of the scale of data analysis methods are the various classification, machine learning and time series modelling tools, the application of which almost always requires involvement of a data analyst.

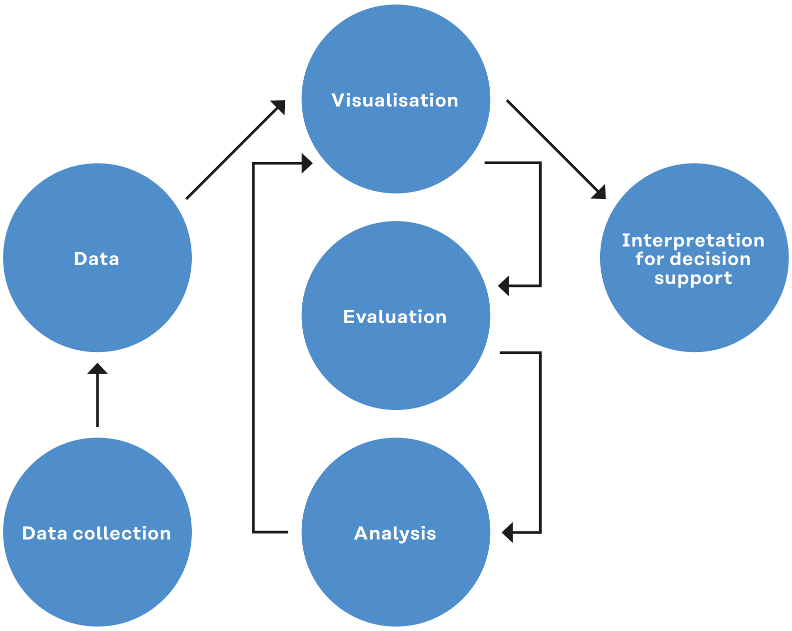
Designing the analysis framework is often an iterative process where the knowledge and skills from both fields – medical and engineering – are required. This iterative process usually contains the steps of data visualisation, evaluation of the results, and performing data analysis to produce new results for visualisation (Figure 1). It is often mistakenly expected that the data analyst, when provided with the data, will perform a trick and come up with useful interpretation after spending some time with his/her computer code and calculation gadgets. This does not work in most cases. Designing the analysis framework requires experts from both fields.

Let's take an example of collecting patient data in a department carrying out a certain kind of treatment. We might end up with a table containing demographic data of the patients such as age, gender, level of education, diagnosis, BMI, use of alcohol, etc., as well as the type (assuming that there are several alternative treatment types) and outcome of the treatment. A generic objective of data analysis might just be: "what does the data tell us?" The data analyst can calculate and visualise various correlations, such as those between the age or BMI of the patient and the treatment result, for example, or study the practices adopted in the department by considering the relation of the assigned treatment type to the level of education and gender of the patient. Statistical analysis can also address questions such as if women tend to have better treatment results and what is the statistical significance of the finding. Using machine learning methods, the data analyst can build a model to predict the treatment outcome based on what is known about the patient.

After performing the calculations and visualising the results, the data analyst and the medical expert go through them and decide what is meaningful, what deserves more detailed insight and what is the best way of visualising the findings. This triggers a second round of analytics. It may also be

To use and trust the analysis results, one has to have basic knowledge of how these results are obtained.

FIGURE 1.
Steps of data analysis



considered if any reference data is available and what are the limitations of using them. Obviously, for most common treatments, such correlations have been studied already and the results can be found from literature. However, the data may also describe some site-specific processes in patient care, or some common practices in a specific unit; nobody else will do the work of comparing these processes and practices with common standards but the staff in the particular unit.

Decision support in healthcare

In this section, CDS systems, usually integrated into the healthcare information system and often commercially developed and maintained, are considered. Decision support based on data analytics can be applied at various points of healthcare. In its simplest form, decision support may be provided, for example, by interactive forms where, based on the information retrieved from the EHR, certain fields are prefilled or the information to be filled in can be limited to a certain range or selection of values. At the other end of the scale are high-end applications generating, for example, alerts in intensive care based on complicated data analysis and machine learning algorithms.

Most commonly however, CDS systems refer to software designed to assist doctors at the point when they make decisions about treatment. These systems are often called Computer-based Provider Order Entry (CPOE) systems. The EBMeDS system by Duodecim falls into this category (see www.ebmeds.org/).

Common functions provided by a CPOE are:

- providing reference knowledge such as guidelines or drug specifications;
- anticipating needs (for example, when ordering certain drugs, related lab results can be displayed);
- generating alerts and reminders; the most common alerts are those indicating drug-drug and drug-allergy adverse effects;
- providing order sets; by listing all orders commonly placed in case of a certain diagnosis helps to avoid mistakenly leaving some of them out;
- providing feedback;
- performing calculations (related to dosage of drugs, for example).

According to Johnston et al. (2003), it has been estimated that in ambulatory settings in the USA the usage of CPOEs could avoid two million adverse drug effects and 190,000 hospitalisations, providing yearly savings of $44 billion.

CPOEs can also improve the quality of patient care processes by:

- ensuring legibility of medical documentation;
- enabling unambiguous storing in her;
- improving communication of orders to entities carrying out the orders;
- helping to monitor completion of orders;
- when connected to resource planning software, enabling more efficient billing.

An important compromise in designing a CDS system is the way the information is presented to the user. The system may provide links or info-buttons so that the user can look up relevant information by themselves or, alternatively, pop-up windows may be used. When drug-drug or drug-allergy conflicts are detected, the system can either generate an alarm, require an explanation why the conflicts are ignored or prevent the user placing such orders altogether. Also, some of the functions of CDS systems are activated before the decision is made, some are meant to be performed at the moment of decision-making and some should take effect afterwards.

Several meta-analyses have been performed to assess the effectiveness of adoption of CDS systems (Bright et al. 2012; Moja et al. 2014). These analyses may evaluate different aspects of the CDS systems such as:

- clinical outcome (length of stay in hospital, morbidity, mortality, occurrence of adverse effects, reduction in redundant laboratory tests, etc.);
- management (smoothness of workflow, productivity, etc.);
- user experience and acceptability.

The meta-analysis by Moja et al. (2014), for example, found that the usage of CDS systems does not affect mortality, however prevents morbidity and reduces costs slightly. Evaluating CDS systems is not an easy task and the results are often contradictory. Adoption of CDS systems requires changes in workflow and habits. The best experiences come from institutions where CDS has been adopted gradually, function by function, and in close co-operation with doctors. If some functions or features are not accepted or cause alarm fatigue, they should be modified or removed. Unfortunately, often the introduction of information systems is carried out as a development project, closed as soon as the software is in place and operating, and making further improvements based on the feedback is expensive. Bates et al. (2003) point out that in order to be acceptable, the CDS should fit well into the workflow of the users, should offer support in real time, should not deliver irrelevant information and should not force the user to discontinue her/his flow of activity. They also found that the users are very willing to change direction according to the recommendations provided by the CDS if a superior alternative is offered.

From the implementation point of view, CDS systems involve various components such as a user interface, knowledge base and execution engine (see Figure 2). Various aspects should also be considered, such as the information model to be used, specification of results to be passed from the execution engine to the user and the process of invoking the execution engine. These components and aspects are not static but should continuously evolve as new knowledge builds up, new methods of data analysis become available and new ways of data acquisition and information modelling are developed. A common way to update an outdated information system such as a CDS is to replace the whole system with a new one having modern features and capabilities. This means that for some time before the new system is to be installed, the development of the current system is halted and after the new system is in place, it takes time before it can be fully exploited. The solution to this problem is a modular design of the CDS system so that its components can be updated separately. Greenes proposes a design where the CDS forms a separate module within the application environment, with the latter containing the clinical information system serving as the interface between the CDS and the user (Figure 2; Greenes 2014). Within the CDS module, the knowledge base and the execution engine can also be separated so that, for example, new data mining and machine learning algorithms can be implemented without redefining the knowledge base or the information model. The structure of Figure 2 presents a general view on CDS. Although a specific system may not be designed according to this structure, the components and functions presented here can be recognised in almost all applications involving CDS.

Conclusions

Data analytics can be applied in healthcare in many forms and across all stages of the healthcare service chain. Exploiting data is key to evidence-based medicine, personalised care and patient involvement. Probably most of the data analytics will stay below the hood – within commercial healthcare information systems and patient monitors. However, using these systems and interpreting their results requires at least basic skills in data analytics. These skills are currently not included at sufficient level in curricula of study programmes. On the other hand, the usefulness of the output of any data analysis application is limited by the quality of the data. To perform high-quality data collection usually requires at least some knowledge of how the data will be used and what will be the outcome of the analysis. Data analytics can be seen as a kind of literacy, becoming increasingly valuable, especially in complex environments such as healthcare. It remains to be determined in what form data analytics skills will be included in study programmes in the future. I consider the study module developed and piloted in the HEAP project as an excellent start.

Data analytics can be seen as a kind of literacy, becoming increasingly valuable, especially in complex environments such as healthcare.

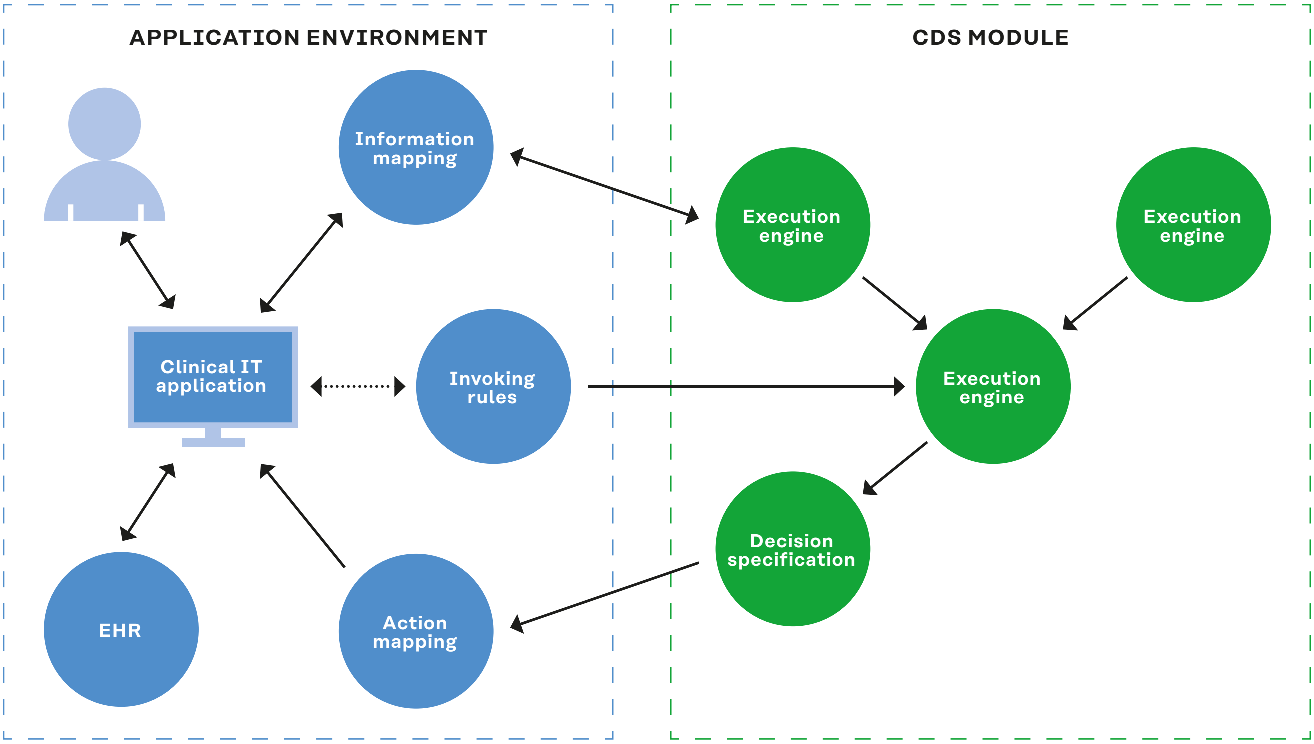


FIGURE 2.
Modular structure of a CDS system (redrawn from Greenes 2014)

3.3 References

Bates D. W. et al. (2003), *"Ten commandments for effective clinical decision support: making the practice of evidence-based medicine a reality"*, JAMIA. 10 (6), pp. 523-530.

Bright T. J. et al. (2012), *"Effect of Clinical Decision-Support Systems: A Systematic Review"*, Ann Intern Med. 157 (1), pp. 29-43.

Greenes R. A. (2014), *"Features of Computer-Based Clinical Decision Support"*, in Greenes R. A. (ed.), Clinical Decision Support: The Road to Broad Adoption, 2nd edition, Academic Press.

Johnston D. et al. (2003), *The Value of Computerised Provider Order Entry in Ambulatory Settings, Center for Information Technology Leadership, Boston, MA.*

Moja L. et al. (2014), *"Effectiveness of Computerised Decision Support Systems Linked to Electronic Health Records: A Systematic Review and Meta-Analysis"*, An J Public Health, 104 (12), e12-e22.

3.4

Visualisation as a tool for data analytics

ESA RAHIALA, SENIOR ADVISOR, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

Visualisation can be useful to help people understand summaries or specific aspects of larger amounts of data. There are many competent software tools to make relatively easy visualisations from various data sources. This article presents and comments on the key principles illustrated with some examples of the data used in Health Analytics Education classes.

This article goes through some basic points about using visualisations in analysing data. Visualisation is not to be used as a replacement for statistical tools, but may accompany them in one way or another. This article contains some figures about a demonstration using real-life, although anonymised, hospital data related to stroke cases.

Abbreviations for the type of stent used in the figures below are BAS (Bioactive stent, Titanium Nitride Oxide) and DES (Drug-eluting stent). Diagnosis for the incoming patient can be nstemi, stemi or uap. As a result, there can be a MACE (major adverse cardiac event, including also deaths) in the follow-up period, but hopefully not any. Several health risk attributes of each person are also included in this demonstration data.

What is your data?

The basis of a visualisation is the data, from a single table or from several databases (or any combination of those). Data preparation can be very different depending of the case. In this case the data set was rather small, consisting of 827 rows (patient cases) and 79 columns (attributes or classifications describing each patient case), and it was received in tabular form as a single SPSS format file.

During the first phase, the case data (which was originally collected for a research project) was anonymised, with only the patient's age and gender remaining in the data table. In the second phase the data was prepared for the visualisation software by omitting four rows which did not have, for some reason, age or gender. Then, data in relevant columns was replaced with more descriptive names/abbreviations and values. This was desirable, as binary type notation (which may be useful for statistical programs) may not be useful for visualisation software, which uses field/column names and values directly in the construction of a visualisation.

Visualisation tools can actually help to find outliers or errors in the data. Whether an outlier is actually an outlier, an error or a missing piece of data depends on the case. Consideration should also be made of the data-collecting procedures and how reliable they are.

What is your message?

When composing the visualisations, the purpose and the audience has to be kept in mind. What is the message that has to/can be taken out of data? One specific question is visualising changes in time or comparing them (for more information see Wexler et al. 2017).

In our demo case, the goal was to communicate the proportion of MACE in different subclasses. In particular, considering whether there were some situations that should receive more attention (even though this number of cases is rather small and statistical analysis preferably requires more cases).

Keep visuals simple and to the point you want to make

It is possible to make very exotic visual impacts, however focusing on a simple key message is important to ensure understandability. Use of several visual elements has to be done with care: graph types, number of visual elements, use of colours and textual elements has to be controlled.

Typically, visualisation software has standard colour sets depending of the number of elements, field names, or attributes (colours are typically automatically allocated). Often using default settings is very fluent. On the other hand, making exceptions takes considerably more time to fine-tune the figure.

Making a graph always involves many choices. Figure 1 identifies the number of patients with different diagnoses, also showing the stent type they received in hospital. Stacked bars make total volumes easily observed. In this figure, the orange colour indicates cases with MACE occurrence.

Figure 2 indicates mortality among the same basic frame, using a darker colour to indicate a higher number of deaths among patients (in the follow-up period). When comparing the figures, it has to be noticed that Figure 1 shows all MACE incidents, whereas Figure 2 only identifies deaths. Although the visualisations have the same shape and total numbers of patient cases, the message is different.

FIGURE 1.
Number of patients with different diagnoses based on the stent type

FIGURE 2.
Mortality among the same basic frame as Figure 1. The darker colour indicates a higher number of deaths among patients during the follow-up period.

FIGURE 1.
MAJOR ADVERSE CARDIAC EVENT BY STENT TYPE

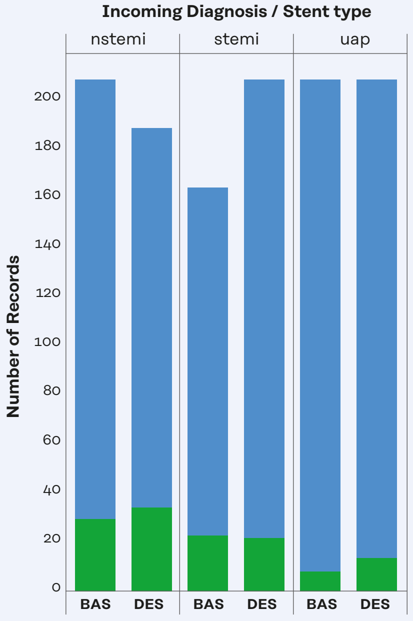
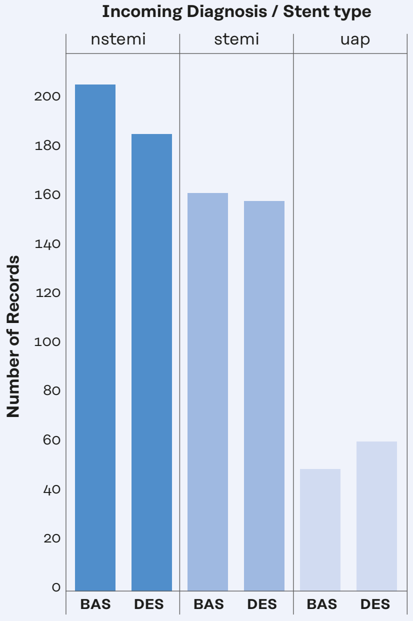
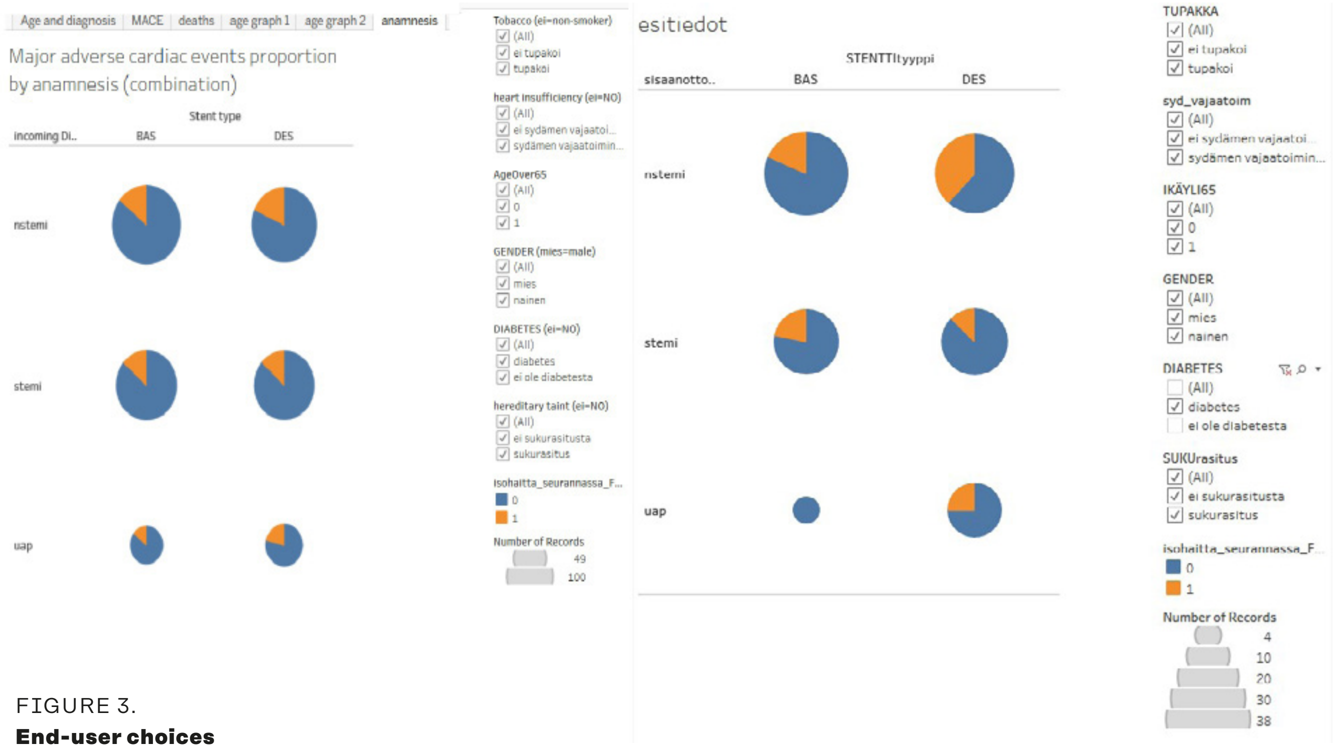


FIGURE 2.
HEART BASED DEATHS DURING FOLLOW-UP





Tobacco (ei=non-smoker)
☑ (All)
☑ ei tupakoi
☑ tupakoi

heart insufficiency (ei=NO)
☑ (All)
☑ ei sydämen vajaatoi...
☑ sydämen vajaatoimin...

AgeOver65
☑ (All)
☑ 0
☑ 1

GENDER (mies=male)
☑ (All)
☑ mies
☑ nainen

DIABETES (ei=NO)
☑ (All)
☑ diabetes
☑ ei ole diabetesta

hereditary taint (ei=NO)
☑ (All)
☑ ei sukurasitusta
☑ sukurasitus

isohaitta_seurannassa_F...
🟦 0
🟧 1

Number of Records
49
100

TUPAKKA
☑ (All)
☑ ei tupakoi
☑ tupakoi

syd_vajaatoim
☑ (All)
☑ ei sydämen vajaatoi...
☑ sydämen vajaatoimin...

IKÄYLI65
☑ (All)
☑ 0
☑ 1

GENDER
☑ (All)
☑ mies
☑ nainen

DIABETES
☐ (All)
☑ diabetes
☐ ei ole diabetesta

SUKUrasitus
☑ (All)
☑ ei sukurasitusta
☑ sukurasitus

isohaitta_seurannassa_F...
🟦 0
🟧 1

Number of Records
4
10
20
30
38

FIGURE 3.
End-user choices for patient health risk factors: the left figure includes all patient cases, the right figure only includes diabetes patients.

Giving users the choice to see data from different perspectives

Modern visualisation tools make it easy for the end user to apply filtering or highlight selected cases (or combinations out of the data), though the designer has to make those choices available to the end user. Figure 3 presents a limited demo, allowing end-user choices for displaying patient health risk factors: the left figure includes all patient cases, the right figure only includes diabetes patients. Now the proportions of MACE (orange) are different, but also the numbers of patients in each category are different (as seen in the scale in the lower-right corner of each figure).

Some comments on software tools

The 2018 Gartner Magic Quadrant for Business Intelligence (BI) and Analytics report about BI tools names as leaders: Microsoft PowerBI, Qlik and Tableau (here in alphabetical order). A tool that is well known and already available to many is Excel. Some comments about these four tools (from a visualisation point of view) can only be made on a general level, because certain products may have special strengths in a specific application case and/or in different ICT infrastructures. All products are developed in continuous cycles and competition seems to enhance the products year by year (these comments were made in summer 2018).

Excel works fine for many everyday purposes, but for big data use it has a limitation of one million rows for basic use. However, when using the data model features of the product, that limitation is no longer a problem. Calculating/programming is performed in a different way, using DAX expressions for rows/columns instead of (directly pointed) cell functions.

Microsoft PowerBI can be described as the next level product compared to Excel, because it is intended for visualising larger amounts of data using a data model approach. The product has Extract-Transfer-Load features for communicating with data sources. A free, end-user version is available, however larger, administered use in an organisation requires a licence fee.

Qlik Sense is intended for self-service business intelligence use (more than the older and well-established product QlikView, from the same company). It works with large amounts of data and it has Extract-Transfer-Load features for communicating with data sources. A free, end-user version of Qlik Sense is available, however larger, administered use in an organisation requires a licence fee.

Tableau is intended for self-service analytics and it works with large amounts of data. However, it has bit limited Extract-Transfer-Load features to manipulate data. On the other hand, it can load/connect to many forms of files. It was used in this demonstration because it could read SPSS-files directly (those named above did not). A time-limited trial version is available and larger, administered use in an organisation also requires a licence fee.

It seems typical that the above products offer free public sites, which means that data, model and visualisations can be uploaded to be shown in public. This is an interesting possibility for data with general interest and no sensitivity. One must also define whether the underlying data can be seen by viewers or not (prohibited in this demonstration, even though no personal identification is included).

Software trial versions and large amounts of product specific learning resources about the above-mentioned tools can be found from:

- www.tableau.com/
- www.qlik.com/us/
- https://powerbi.microsoft.com/en-us/

The demo graphs above can also be found on the following site, where it is possible to use filtering in practice:

- https://public.tableau.com/profile/esa.rahiala#!/vizhome/stenttivertailu4/Ageanddiagnosis

3.4 References

Wexler S., Shafer J. and Cotgreave A. (2017), *The big book of dashboards: visualising your data using real-world business scenarios,* John Wiley & Sons Inc., Hoboken, NJ: www.bigbookofdashboards.com/.

3.5

Small-scale working life pilots pave the way to data-driven personalised care services

ANDREW SIRKKA, EdD, PRINCIPAL LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

SARI MERILAMPI, PhD (TECH), PRINCIPAL LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

This article summarises the experiences and concludes the lessons learned during the Health Analytics pilot education and working life pilots. The conclusions are made by analysing the piloting reports and minutes of the working life committee meetings, and a questionnaire sent to organisations involved in the project (piloting organisations).

Key results of the pilot projects

The pilot phase of the Health Analytics Education Project (HEAP) focused on introducing data analytics within the student's working environment. The pilot phase started with identifying the vast variety of data available. For most of the students, finding, collecting and analysing data related to the selected themes, and how the data and results of the analysis could be better utilised in designing customer-centred services, was a completely new concept. As an outcome of the pilot phase, students provided a written report of applied analytics and results. The project reports also aimed to discuss the meaning of the findings, in regard to service design and management of service delivery.

The student analysis projects varied a lot in terms of themes and approaches (Table 1). Some of the students faced challenges in data access that forced them to change either the theme or the approach. However, no matter how small-scale the pilot project turned out to be, everyone obtained valuable findings, revealing some strengths but also bottlenecks, irrationalities and a clear need to improve and streamline services. Some of the pilot projects are described here in more detail as examples.

Testing a clinical decision support system

One of the pilots tested a demo version of the EBMeDS decision support system (generated by Duodecim) in screening patients arriving for their first appointment in a cardiac outpatient clinic. The aim was to test how EBMeDS would assist in making a comprehensive situation analysis of patients, to expedite and improve appointments. Data from 38 patients (N=38) was used in this analysis. Since only a demo version of the system was available, all patient data was collected from electronic patient records and manually transferred into the decision support system (included labs, medication, diagnoses, previous treatments and operations).

The second phase was to compare the data available in the doctor's referrals and in the EBMeDS system for each patient. Relevant and up-to-date data for 17 patients (out of the 38 tested in this pilot project) would have been available in the data system or in the referral, but was omitted, resulting in unnecessary and overlapping examinations.

TABLE 1.
Topics and contexts of student pilot projects

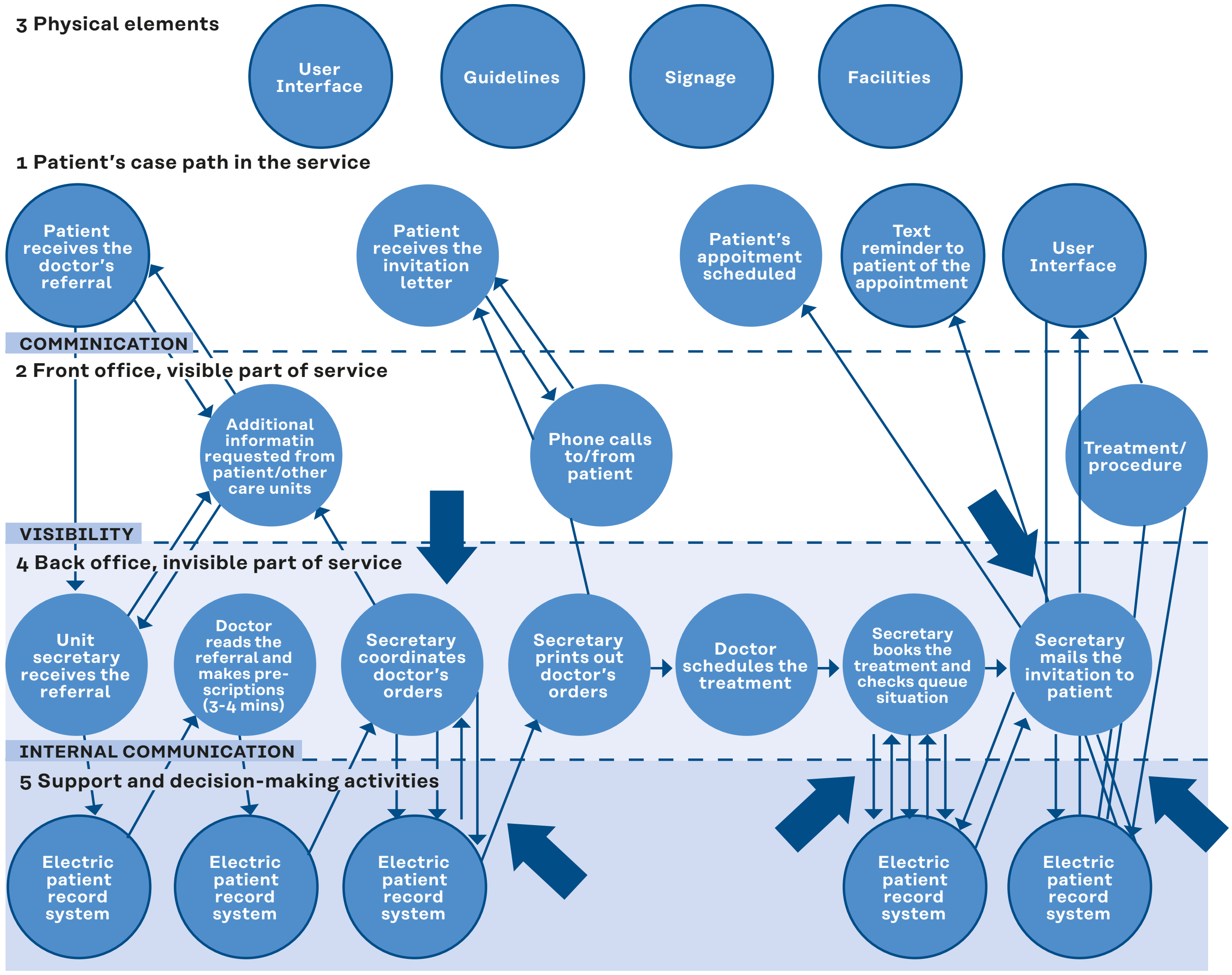
Topic of analysis	**Service**
Analysis of the Vivago® safety and activity monitoring system's usability and suitability in psychiatric care contexts. System tested with two voluntary patients.	Psychiatric nursing, specialist hospital care, Finland
Documentation analysis of patients frequently visiting a health centre acute unit with the diagnosis of "Cannot manage at home".	Primary healthcare, healthcare centre, Finland
Analysis of new customer-centred Well-being Coaching Services and their impact on customers' lifestyle changes.	Rehabilitation, regional hospital, specialist healthcare, Finland
Use and experience of e-health check tools in women's health inspections in a gynaecological unit.	Gynaecology, regional hospital, specialist care, Finland
Patient flow in an A & E unit and analysis of wait-keepers due to flow blockages.	A & E, specialist hospital healthcare, Finland
Analysis of cardiac patients' care path and EBMeDS as a means in clinical decision-making.	Cardiac unit, specialist hospital care, Finland
Analysis of rTMS practices in Finnish specialist care hospitals.	Clinical neurophysiology, specialist care hospitals, Finland
Documentation analysis to improve patient documentation in a urological unit.	Patient documentation, surgical care, urology unit, specialist care hospital, Finland
Assessing care needs and use of triage in phone consultations with customers.	Primary healthcare, healthcare centre, Finland
Analysis of documentation and care path for alcohol abuse services in Estonia.	Substance abuse care services, social services, Estonia
Analysis of the use of e-PAK portal in Estonian general practitioner (GP) practices.	E-health services, primary healthcare, Estonia
Analysis and generation of patient health status summaries in GP information system in Estonia.	Patient documentation, primary healthcare, Estonia

The EBMeDS experiment resulted in several benefits. Apart from improving the use of existing relevant patient data, the decision support system expedited planning of the necessary examinations, care procedures and medication by providing relevant remarks and warnings (like drug interactions, follow-up examinations and tests), and by assessing various risk factors by providing comparative population-based data. The system also supported the drafting of various types of referrals and medical statements for the patient or other parties in the care chain. The EBMeDS system would also be useful in research purposes (e.g. searching for various patient or treatment profiles).

Service process mappings

A few pilot projects used process mapping methods to analyse current services. The method clearly highlighted bottlenecks causing unnecessary loss of time, effort and money. A customer-centred approach in service requires reassessment and renewal of conventional ways of working. In the above-mentioned EBMeDS analysis, one of the side results of patient path mapping highlighted how information flow progressed in the cardiac unit. The process map pointed out several points to streamline service processes in the unit (Figure 1).

FIGURE 1.
Process map of a patient care path in a cardiac outpatient clinic



The data and patient flow analyses

Common features of these analyses were that related data was unstructured and scattered, requiring a lot of searching. This problem in patient documentation systems emerged as an outstanding constraint in streamlining health and social care services.

The patient information required in alcohol dependence treatment in ambulatory care is unstructured social and lifestyle information by nature. Because of this, currently the data is not collected by family doctors (unlike somatic patient data). The project resulted in generating a structured document for collecting data in the alcohol dependence treatment department and modifying the database in the target organisation to automate the process of collecting and transferring the data to necessary locations.

The patient flow analysis from A & E units to other care units also revealed some outstanding bottlenecks to be resolved (Figure 2). Over the test period, a total of 62 patients (out of 74) spent a night in the emergency room as a result of flow blockage from the emergency room to other relevant care units. The data for this analysis was collected from patient documentation systems (Effica and ExReport), from unit statistics and from a questionnaire targeted at emergency room secretaries and nurses.

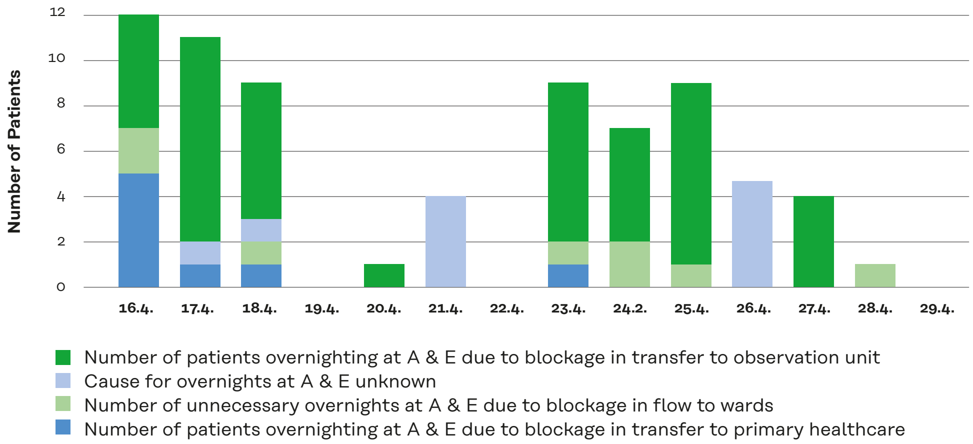
The aim of this analysis was to map the situation related to patient flow and observed challenges in the target organisation. Patients had been allocated inappropriately in various units, even overnighting in the corridors because of blockage in patient flow to more appropriate facilities. A rather large number of wait-keepers (patients waiting to be transferred to more appropriate care facilities) was due to blockages in the patient flow between specialist and primary healthcare facilities. In addition to unnecessary discomfort for patients and staff, the blockage also created outstanding expenses in the system.

The implementation of serial magnet simulation therapy (rTMS) practices were analysed in different operating units in Finland. International publications describe several different treatment protocols and a variety of treatment responses. As a new therapy, rTMS care practices are being updated actively on the basis of the information provided by recent scientific studies.

Treatment practices varied between hospitals. There was more variation in pain treatment practices than in depression therapies. Variation occurred at all stages of therapy. Based on the findings of the survey, treatment charts were created for the most common care parameters, and models of the division of labour among the various actors

FIGURE 2.
Patient flow in the A & E unit

Number of patients staying overnight at A & E in a 2-week period of time



and of the implementation of rTMS therapies were identified.

Reviewing the rTMS process through process mapping proved to be a beneficial way to streamline the therapy process. Previously used Excel spreadsheets became useless, since the data was recorded immediately in the patient information system, making the information available to all parties at the same time. The process diagram also made it possible to identify weak points in the care chain. Job distribution has been developed already to avoid the process being only in the hands of one operator.

The patient documentation challenges emerged again in the results of patient record analysis in a primary healthcare organisation. Patients who repeatedly visit the primary care emergency services with the diagnosis “cannot manage at home” were more deeply analysed by a student in one of the Finnish health centres. The aim of the study was to find out how the patient’s need for services had been documented in the patient information system. Data was collected on targeted terms: functioning, indicators and care plan. The importance of measuring functional ability is noted whenever planning the care. In this analysis the point was to search how those measurements are utilised and registered in the patient information system.

A total of 10 (N=10) patient records were analysed. The study indicated that functional measurements were used fairly well, either before, after or during care periods in the health centre. Yet, the information was scattered in the system, which makes it difficult to find and support long-term care plans. The patients’ physical functioning was analysed in nine (n=9) cases out of 10, mental or cognitive status in eight (n=8) and social status in three (n=3) cases out of 10. In seven out of 10 patient documents the functioning was assessed by a professional, in three cases (n=3) together with a relative, and in two (n=2) cases the patient was involved in the assessment. Three patient documents did not reveal who had performed the assessment. The care plan with set objectives and means was accomplished in four (n=4) cases out of 10, while the long-term overall care plan was completed in only in three (n=3) cases out of 10. The patient’s own assessment of their health situation was not mentioned in four (n=4) cases, and only partly commented in six (n=6) cases out of 10 (Table 2).

Based on the analysis, most attention was paid to assessing physical and cognitive functioning, by means of standardised RAVA and MMSE/CERAD measurements. Relatives were involved in assessments only in four cases out of 10 and the patient’s own assessment was mostly documented (with few comments in this sample). Social factors were less assessed and most of the patients lacked an overall care plan, even for patients frequently visiting healthcare emergency services because of challenges with living at home.

The results of the pilot projects generated lively discussion, both in the working life committee and in various workshops and seminars, where the project outcomes were presented in confirmation of the importance of constant reassessment and analyses of services.

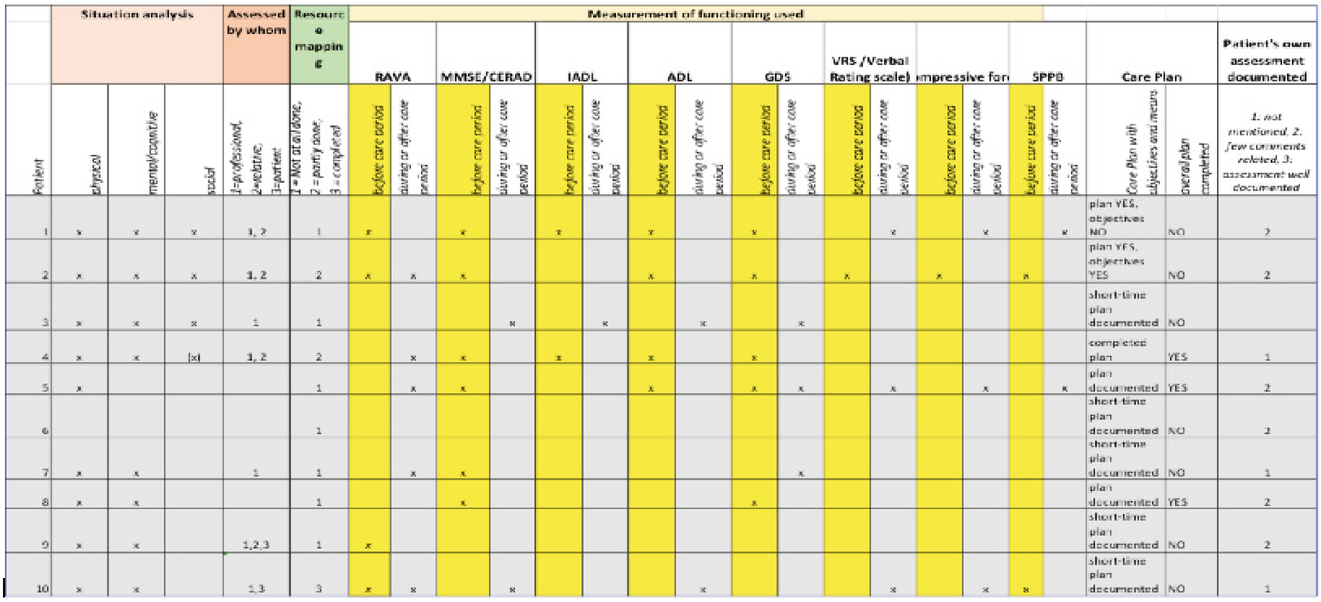
Digital tools in care services

The Vivago® activity monitoring system was introduced for the first time in psychiatric nursing. Two patients volunteered to test the activity watch for few weeks. The activity follow-up data visualised clearly the effects of obtained treatments and also the impact of the patient’s environment in the overall situation. This pilot gave a large quantity of data indicating clear constraints in the care chain, especially between hospital and ambulatory care services.

For digitised customer services, the usability of the e-PAK portal (generated by general practitioner Diana Ingerainen in Estonia) was analysed from the customer point of view. The portal aims to bring together primary healthcare providers and their patients, in response to the identified need for an electronic solution for patient–physician communication. Alongside secure messaging possibilities, the portal aims to provide more patient empowerment and prevention-oriented healthcare, with the functionality of a patient health diary. The way the portal is integrated into service providers' workflows differed a lot. Most commonly it was a tool for family nurses and was only checked by GPs when a specific question was to be answered by them. In the analysis, three different modes of using e-PAK emerged: 1) one nurse was mainly responsible for checking and responding to e-PAK and regular e-mail messages throughout the workday; when a certain question that needed a GP's opinion arose, the response was typically still entered into the system by the nurse; 2) all nurses were responsible for using e-PAK in addition to other responsibilities like answering the phone and performing procedures; GPs were told to check e-PAK only when a specific question needed their answer; and 3) nurses and GPs both checked e-PAK as part of their everyday routine.

The key findings of the e-PAK portal service indicated that in all practices, electronic communication makes care delivery much easier and more efficient and assists with managing the workflow of the GP practice. Most healthcare workers in the practice were not familiar with the patient's view of e-PAK. The staff who were acquainted with the patient site identified the health diary as not very user-friendly and, in general, a potentially useful tool for patient empowerment rather than a direct tool for the GP. In all practices, the view on lifestyle decision support tests and calculators was very positive, motivating and empowering customers in their health-related questions without healthcare workers having to provide too much input. It was even thought that the system could alert patients according to their health data figures. When patients get concerning results in lifestyle-related tests, then it is part of the family nurse's (or GP's) work to provide them with counselling. This was definitely not seen as an extra place for a health analyst.

TABLE 2.
Patients diagnosed as "cannot manage at home" – Documentation analysis results



	Situation analysis			Assessed by whom	Resource mapping	Measurement of functioning used																		
						RAVA		MMSE/CERAD		IADL		ADL		GDS		VRS /Verbal Rating scale)		mpressive for		SPPB		Care Plan		Patient's own assessment documented
Patient	physical	mental/cognitive	social	1=professional, 2=relative, 3=patient	1 = Not at all done, 2 = partly done, 3 = completed	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	before care period	during or after care period	Care Plan with objectives and means	overall plan completed	1: not mentioned, 2: few comments related, 3: assessment well documented
1	x	x	x	1, 2	1	x		x		x		x		x			x		x		x	plan YES, objectives NO	NO	2
2	x	x	x	1, 2	2	x	x	x				x		x		x		x		x		plan YES, objectives YES	NO	2
3	x	x	x	1	1				x		x		x		x							short-time plan documented	NO	
4	x	x	(x)	1, 2	2		x	x		x		x		x								completed plan	YES	1
5	x				1		x	x				x		x	x		x		x		x	plan documented	YES	2
6					1																	short-time plan documented	NO	2
7	x	x		1	1		x	x							x							short-time plan documented	NO	1
8	x	x			1			x						x								plan documented	YES	2
9	x	x		1,2,3	1	x																short-time plan documented	NO	2
10	x	x		1,3	3	x	x		x				x				x		x	x		short-time plan documented	NO	1

3.6

The value and impacts of advanced analytics in the healthcare ecosystem

TARJA VUORELA, MASTER OF SCIENCE IN ECONOMICS AND BUSINESS ADMINISTRATION, MASTER OF ARTS IN TECHNICAL COMMUNICATION.

A recent study reveals that employing advanced analytics in healthcare generates value for several stakeholders, including healthcare service organisers and providers, and individual patients, as well as for the general health of the population. It also impacts upon the value co-creation practices in the healthcare ecosystem and sets new requirements for healthcare professionals' competence. Introducing advanced analytics to healthcare is beneficial, as it provides those in the healthcare ecosystem valuable insights into making informed strategic choices and designing new and better-targeted health services. It also ensures better health outcomes for individual patients and helps to reduce health inequalities among the population.

Increase in advanced analytics in healthcare

Employing advanced analytics in healthcare is expected to increase in the near future. It will disrupt traditional healthcare business and service models, the way of working and healthcare professions. To understand the potential benefits and impacts of advanced analytics in the healthcare ecosystem, it should be viewed from different perspectives.

The analysis of "big health data" using specific algorithms developed for the purpose helps to identify care gaps among the population, organise and provide the right care, at the right time and in the right venue (Rose and Burgin 2014) and give patients more decision-making power over their own care. This creates value for healthcare service organisers and providers, for individual patients and for the general health of the population. The generated value can be identified when evaluating the impacts of using a specific analytical tool, the Health Benefit Analysis, for the purpose. For example, the results of health benefit analyses help doctors and other healthcare professionals to make the right clinical decisions and give the patients a chance to make informed choices between suggested interventions. Moreover, the results provide an essential input for the healthcare service organisers and providers for successful health service targeting and service design, as they provide a better insight into what kind of health services are needed for the population in a given region.

Value to stakeholders through several benefit dimensions

The studied stakeholders can benefit from the results of advanced analytics in operational, managerial, strategic and organisational dimensions (Shang and Sheddon 2002). Value is gained for the health service organisers and providers through benefits and improvements in performance as measured by several indicators. The value for individual patients is seen in better patient experiences. And the general health of the population improves as a result of fewer health inequalities, based on the improvements and benefits the service organisers and providers have gained.

Advanced analytics generates operational benefits for healthcare service providers as it improves productivity through an accelerated and increased health data usage rate. It enables improved operational quality monitoring and contributes to the quality and accuracy of clinical decisions. Both quality monitoring and the accuracy of clinical decisions are significant core issues when employing advanced analytics in healthcare. Value for the health of the whole population and of individuals is generated, for example, when a virtual health check is conducted in a patient data repository with an analytical tool, and those in need of a specific health service are proactively invited for a doctor's appointment based on the results.

The gained managerial benefits generate business value through improved care planning and decision-making procedures leading to better performances. It also provides business intelligence, which is valuable for managing the improvement of personnel management and employee satisfaction. Advanced analytics helps the management of the healthcare service providers by prioritising healthcare resources to produce the needed services for those who benefit most from them, which in turn generates value for individual patients and the health of the overall population.

> *The gained managerial benefits generate business value through improved care planning and decision-making procedures leading to better performances.*

In strategic issues, employing advanced analytics creates business value as the healthcare service providers can gain a competitive advantage through differentiation. It also supports the development of additional health service innovations and contributes to the shift towards value-based healthcare, where the definition of value is determined by the betterment of the patients' health.

Advanced analytics generates organisational benefits by improving teamwork, supporting multidisciplinary problem-solving and enabling cross-functional communication. It can also be claimed that organisational learning takes place when the achieved statistical knowledge is used for process development and quality improvement in the organisations of the healthcare ecosystem.

The expected benefits and performance that generate value to the stakeholders are presented in more detail in Table 1.

Impacts on value co-creation practices and healthcare professions

An important aspect for the healthcare service providers to consider are the impacts of advanced analytics on value co-creation practices in healthcare service production and in healthcare service design. The decision- makers in healthcare organisations need to consider their strategic choices and business scope redefinitions, which are needed when shifting the focus from measuring key performance indicators, such as the number of patient visits, to more knowledge-based and data-driven healthcare, what is known as value-based healthcare (Porter and Teisberg 2006), where value is determined through shared decision-making, health outcomes and the betterment of the patient (Porter 2010). It is evident that using advanced analytics provides the healthcare service providers with opportunities to develop new innovative data-driven healthcare services.

When advanced analytics in healthcare is introduced, governmental decision-makers and the organisational management of the healthcare ecosystem should ensure a smooth transition to new healthcare service business models and facilitate changes in healthcare practices. The impacts of these changes are expected to be cross-sectoral as the social care sector is expected to become more involved in the patients' healthcare, especially that of elderly people and the care

TABLE 1.
Expected potential benefits and performance that generate value to stakeholders (Vuorela 2018: 89-90).

Benefit dimensions	Indicated expected benefits	Value generated to
Operational benefits	Improved workflow efficiency Productivity improvement Cost reduction Improved and accelerated use of information Quality monitoring Target treatments to those who benefit most Accuracy of clinical decisions Improved health outcomes Active participation in own care Influence in selected interventions Improved customer experience	Healthcare service provider Population health Individual patient
Managerial benefits	Improved care planning and decision-making Improved performance Improved allocation of resources Business intelligence Improve direction and management of staff Improve employee satisfaction Reduce health inequalities in the population Narrow the discovered care gaps Prevent cases of overtreatment	Healthcare service provider / organizer Population health Individual patient
Strategic benefits	Facilitate discussion among decision makers Gain comprehensive view for meeting future needs Contribute shift to value-based healthcare Implement the selected vision and maintain focus Build competitive advantages Build new business innovations and alliances	Healthcare service provider / organizer
Organisational benefits	Improve team work Cross-functional communication Solve multidisciplinary problems quickly Organizational learning from clinical reports Process and quality development Learn to know the patients better Ensure seamless patient experience	Healthcare service provider Individual patient

cycles for children. The evolving value co-creation practices set requirements for those in the healthcare ecosystem, as they need to conform to new ways of working with patients and professionals from other sectors and levels of the healthcare ecosystem.

It is also of utmost importance for the decision-makers and management to identify the need to educate new kinds of healthcare professionals. There is a need for completely new competences, especially in conducting health analytics and interpreting the results. A new healthcare profession could be, for example, a health analyst, who is expected to play a key role in conducting advanced analytics and interpreting and discussing the results with the patients. New skills are also needed in the structured recording of patient data and holistic personalised care planning. In addition to new healthcare professions, doctors, nurses and other healthcare professionals are expected to have new roles, for example as hospitalists and care managers.

To conclude, the impacts and changes of employing advanced analytics indicate digital disruption and transformation of healthcare services and professions. This, however, requires courage and willingness to accept that there will be new practices and professionals in the healthcare ecosystem. There are also opportunities for professional development, as information technology and analytical skills are increasingly needed to meet the requirements set by new care practices and the demand for health coaching services among health service consumers and patients. Opportunities for innovation and development will also be created for the educators of healthcare professionals, as they are in a key position when transferring knowledge, practices and working culture to the future healthcare professionals.

The text is based on Tarja Vuorela's MSc (Econ.) thesis on Strategic Business Development, "Value co-creation and potential benefits through big data analytics: Health Benefit Analysis". The thesis was published in 2018, University of Vaasa Theses, Tritonia Academic Library.

3.6 References

Porter M. E. and Teisberg E. O. (2006), *Redefining Healthcare: Creating Value-based Competition on Results, Harvard Business School Press, Boston, MA.*

Porter M. E. (2010), *"What is Value in Healthcare?"*, The New England Journal of Medicine, 363:26, 2477-2481.

Rose J. and Burgin M. (2014), *"Disrupting healthcare through big data and predictive analytics"*, Managed Care Outlook, 27:1, 11-12.

Shang S. and Sheddon P. B. (2002), *"Assessing and managing the benefits of enterprise systems: The business manager's perspective"*, Information Systems Journal, 12:4, 271-299.

Vuorela T. (2018), *"Value co-creation and potential benefits through big data analytics: Health Benefit Analysis"*, (Master's thesis, University of Vaasa).

3.7

Echos from the health analytics programme (HEAP)

DORIS KALJUSTE, PROJECT MANAGER, DEPARTMENT OF HEALTH TECHNOLOGIES, TALLINN UNIVERSITY OF TECHNOLOGY

This article reports the student and course moderator feedback about the pilot programme. The student feedback was collected by an e-questionnaire after each module, and the course moderator feedback was collected by an email questionnaire at the end of the programme in September 2018.

Introduction

The Health Analytics Programme (HEAP) was a learning programme not only for students but also for the lecturers carrying out the educational programme. The feedback gathered from the students and course moderators is of great value, as it helps to choose the path forward.

The programme was divided into a theoretical part and a practical part. The theoretical part was distributed between three universities, Satakunta University of Applied Sciences (SAMK), Tampere University of Technology (TTY) and Tallinn University of Technology (TalTech). Feedback was collected from the students after every theoretical course and from the course moderators at the end of the programme. It should be noted that in addition to e-learning, both student groups, Estonian and Finnish, held regular student seminars with somewhat different homework tasks. However, both groups reported the seminars to be highly efficient for acquiring the course topics.

A survey carried out among the students in the pilot scheme, at the beginning of the programme, showed that more than 80% had over 10 years' experience in the field of health analytics. More than 65% of the students had a nursing background, but the students also had backgrounds in natural sciences, economics and physiotherapy. Among the students, 50% were currently working as nurses. The course moderators were professors from the participating universities, Dr Andrew Sirkka (SAMK), Prof. Tarmo Lipping (TTY) and Prof. Dr Peeter Ross (TalTech).

Course moderators' perceptions of health analytics

Currently, an enormous amount of data is being collected in the field of healthcare. Most of it is for primary use and only a small fraction of it can be used for secondary purposes. Collecting huge amounts of health data has no value if it is not made use of afterwards, which is sadly the situation we are currently in. Rather, healthcare should focus on collecting smart data – only the data that makes sense and is used in services. One way to deal with the waste of data is to search for answers from data analytics. Data analytics in general is an essential part of digitisation to improve and streamline services, and, luckily, year by year, the rigid healthcare system is slowly opening up to it.

It seems that there is a large gap between what is done in the leading-edge development projects and how things are actually being done in the field. For maximising the opportunities that data analytics provides, experts working in healthcare have to have a general idea at least about the process of data analysis and how to interpret the collected results.

The request for higher-quality data should not only come from the supervisors. The potential that collecting high-quality data has for improving the quality of healthcare services should be clear for every healthcare professional. This can only happen if the healthcare professionals recognise that they are not collecting the data just for reporting purposes, but for colleagues in the health and social care sector. Most importantly, the data should be collected so that a person has the best possible care in the future, thanks to the valuable information available at the right time. This, however, can only be achieved when the professionals can use up-to-date information systems supporting their everyday work and data management.

From the indicators that already existed before and from the experience gathered during the programme, there is a clear need for more comprehensive knowledge about data analytics and the skills to actually use it in practice. The programme lifted the curtain to discover and to understand the opportunity to develop a new profession, which could have a very clear role and position in healthcare, despite the fact that today there is no compelling need or demand from the healthcare providers, industry or market to finance a new health analytics profession. It is truly a profession of the future, ahead of reality.

eHealth and Telemedicine

The Health Analytics Programme (HEAP) started with the introductory course called “eHealth and Telemedicine”, moderated by Prof. Dr Peeter Ross from TalTech. The aim of the course was to give an overview of different aspects of eHealth, healthcare innovation, health and eHealth literacy and the legal/regulatory aspects of eHealth. The course consisted of 16 video lectures given by six different lecturers.

According to the students, the most useful topics were about the trends, new models of care and the evolution from Health 1.0 to Health 4.0. The “Hospital IT-matrix and health analytics” and “Health analytics” lectures were also appreciated by the students. The participating students did not see the usefulness of the “Data management” lecture and the lectures about assessment of different eHealth solutions. As a recommendation, the students suggested that they would have wanted to learn more about interconnections between health databases, international experience and how everyone can measure health data by themselves and how the data can be utilised and analysed.

According to the Finnish group, the topics were clearly seen as interesting and relevant. Additional value was gathered by comparing the Estonian and Finnish healthcare systems and their developmental phases. Both groups agreed that it was a great way to start the course and the videos were presented by people who believe in the potential of this area of study. The lecturers shared their ideas and views, giving the students interesting thoughts to dwell on, and the course was fascinating for its novelty and somewhat futuristic insights.

Decision Support Systems

The “Decision Support Systems” course was divided into two simultaneous modules: “Decision support in healthcare” and “Statistical analysis and decision support technologies in CDS systems.” The course consisted of 21 video lectures given by Professor Tarmo Lipping from Tampere University of Technology. The aim of the course was to give the students an understanding of the essence of CDS (clinical decision support) systems, what components they contain and how the systems should be designed and evaluated. The statistical data analysis module concentrated on explaining the whole chain from data collection to decision-making and on giving the preliminary skills needed to perform a basic analysis.

In the first module, all topics received quite similar feedback from the students, regarding the usefulness of specific lectures. The lectures “Types and functions of CDS systems” and “Knowledge basis of CDS: Big Data and personalisation” were marked as most useful, but other topics were not far behind. As a recommendation, the students would have liked to learn even more about big data and personalisation, and to have gained more practical knowledge of how to work with different databases and how to make queries, for instance.

In contrast to the first module, the second module “Statistical analysis and decision support technologies in CDS systems” featured a clear favourite with regard to the lectures – the “Data description and visualisation” lecture was considered the most useful and the other lectures not so much. The lecture about “Population central values and confidence intervals” had the lowest score compared with the other lectures in the module. The students highly valued the newly acquired knowledge about data visualisation and would have liked to know even more about it. Like the first module, the students highlighted the need to add a more practical approach to the course on the CDS systems. According to the course moderator, Professor Lipping, statistical analysis could in the future be taught in two separate courses, one for preliminaries and overall understanding, and the other for a more advanced optional course for those who have time and opportunity to get “carried away” by the flow of playing around with the data and software tools.

The students found that the decision support systems course was the most specific and informative in the programme and it offers a lot of potential for giving the students many different practical assignments on calculations, tables, graphs, formulas and analytics tools. This course represents the “the essence” of health analytics. In the future, Professor Lipping would like to make the course more interactive and give the students the chance to be more engaged in practical work from the very beginning.

Customer engagement

Like the “Decision Support Systems” course, the “Customer engagement” course had two different modules: “Client Involvement and Smart Services” and “Service Design and Case Management.” Altogether, six different lecturers shared their knowledge of customer engagement in 11 video lectures. Customer engagement is an essential part of implementing health analytics in practice, in terms of streamlining and individualising services to meet the customer’s needs. The aim of the course was to give the students an understanding of customer aspects in services and value for monitoring a customer journey. In addition, specific skills on how to make various types of service process mappings and measurements over the service delivery processes were another aim.

In the “Client Involvement and Smart Services” module the “Measuring customer engagement” lecture was considered the most useful by the participating students. The students reported that the module was somewhat self-evident and more focus on how things should be done in practice, as well as real-life examples, would have been a good addition to the module. The groups recommend adding more lectures about user perspective and smart services.

In the “Service Design and Case Management” course, the most useful lectures according to the students were “Health coaching” and “Health coaching technology.” The students reported that, similar to the “Client Involvement and Smart Services” module, the “Service Design and Case Management” module would benefit from involving more real-life experience, specific examples and expertise.

Overall, the course gave a good overview of how important service design is, especially in the healthcare field. One can develop nice tools, but if the users do not adopt them, the tools will end up being useless.

Organisational side

From the organisational side, the students recommend having a clear schedule for the programme with the list of tasks to be done beforehand. Also, more e-learning elements, like short tests after every video lecture, was recommended. The most liked form of videos were the slides and a small video of the lecturer at the foot of the screen. That way both elements of the lecture could be captured – the supporting material at all times and the emotions and drive of the lecturer given through facial expressions and body language.

> *The current programme created by the co-operation of three educational institutions is a good stepping stone.*

The wide variety of people with different backgrounds, who were included in this curriculum, was a huge benefit for the students. However, in some cases, the lack of English language skills of the lecturers was noted.

The path forward

The course moderators would see the format of the studies as a one-year curriculum at a master's or vocational education level. In applied higher education, health analytics could also form a study module including practical training. The programme would have to be multi-professional and would require prior competences so that the student could comprehend the purpose and value of analytics. This could mean, for example, a minimum of a bachelor's degree in healthcare and basic research/analytic thinking skills.

The best background for the students would be knowledge of three different skills: medicine, information technology and change management. As there are only very few people with this background, the most important of them would be knowledge of medicine. This could be either at a nursing level or from other work experience in the healthcare field (IT, quality management, etc.).

The current programme created by the co-operation of three educational institutions is a good stepping stone. The content of the curriculum is already very comprehensive, and the basic content and study methodology are well set up. The programme is currently created so that it starts with an overview of eHealth, moves into analytics and finally discusses the means and ways to implement that knowledge in real-life healthcare services.

The first run provided a lot of new knowledge and ideas on how to improve the current programme and study experience. During the programme, the students need motivation and indication that analytics actually can lead to smoother processes, higher quality of care and more personalised medicine. The course moderators suggested that the programme would benefit from adding more statistical and qualitative analysis studies, and possibly some clinical courses where students have the chance to observe clinicians' work. There could also be some options for those who would like to go deeper into using data analysis tools and those who are more interested in the impact of analytics. To teach the usage of the tools, a kind of sandbox with test data would be useful.

In summary, the programme was a successful co-operation project between the three universities. The co-operation enhanced the wide expertise available among the partners, which was well used in the programme. The project opened up opportunities for new networks and partners in the field of future endeavours, and this development, very much like health analytics, is not something that any professional can do alone.

3.8

Lessons learned in the health analytics programme (HEAP)

SARI MERILAMPI, PhD, PRINCIPAL LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

ANDREW SIRKKA, EdD, PRINCIPAL LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

This article discusses the observations and lessons learned from the Health Analytics Programme (HEAP) project in 2017-2018. The project's aim was to generate an education programme to introduce Health Analytics, required in future customer-centred healthcare and social services.

Current situation and bottlenecks in data use

As described by the other articles in this publication, customer-centred thinking, rapidly evolving technology, big data and data analytics are revolutionising healthcare services. However, the implementation of the latest advances in research and service provision is not very easily processed, as a result of the characteristics and history of the healthcare sector (Chilikuri and van Kuiken 2017; Duggal et al. 2018; Rodriguez 2018).

The experience from the pilot education programme identifies data analytics itself as the most challenging part of the education. One reason for this is the lack of earlier experience and practice of maths, statistics and data analysis, which are not playing a major role in the curricula of healthcare-oriented programmes. This also affected the piloting part of the education. Only very basic analytics (if any) were included within the development pilots.

During the piloting phase, one essential finding was the huge amount of data that is collected during healthcare processes. Despite the large quantity of data, the use of this data is minimal. For example, data related to treatment history and medical records, or the patients' self-produced data, are surprisingly infrequently used. The secondary use of data in process development and measurement is even less. Over this project, the following bottlenecks hindering data use were identified: the data itself, the information systems, the skill levels and the working culture.

Data and documentation

There is huge variety in the data quality produced by different service provides in health and social care. Some data is structured, whereas some is text (such as referrals and most of the social care-related data). If the data is not structured, the content of the data may be very ambiguous. Compatibility of the information provided in patient documentation is challenging, since in some cases the text is very detailed while in other cases the data only contains mandatory expressions and phrases (giving insufficient information about the overall condition of the patient). Documentation routines vary between service providers and the routines have changed over time.

Information systems

The stored health data is fragmented in many places and the system integration is still inadequate, making the handling and use of important patient information cumbersome. This currently requires the user, being aware of the logic and structure of their information in the system, to support the location of relevant data.

Analytic competences

Data handling and measuring requires adequate competences, in addition to generic research skills. The knowledge of health informatics in general is limited among health and social sector professionals, let alone the ability to identify measures and metrics in the data system provided for measuring, analysing or interpreting and visualising results.

Working culture

The culture in the health and social sector encouraging the secondary use of health data, or health data analytics in general, is obviously restricted to certain managerial actions in the health and social sector. Successful patient services would require health analysts to support the active deployment of patient record data for care purposes, and to assist in measuring how and which treatment/care measures are efficient. Patient confidentiality and data protection regulations are of high importance, but they should not block improving and streamlining customer services.

The project groups both in Finland and in Estonia faced remarkably similar challenges and experiences during the pilot programme. To summarise, healthcare-related tools and health data are not meant for secondary use at present; for example, for companies, students and researchers to develop further. Crowdsourcing is made impossible, which slows down the progress, and makes the health and social sector an exceptional industry.

Opportunities for data analytics and the role of an analyst in health and social services

Surprisingly, even the simplest pilot projects without any deeper, big data analysis produced significant findings. With small-scale analytics, it was possible to identify bottlenecks and development ideas, improve customer/patient experience and assist health professionals streamline their work, improve decision-making and management towards knowledge management, and elevate the patient/customer as a resource in both preventive and curative care.

A lot of employers' time and efforts are spent on documentation, data handling and searching for data in numerous different systems. By improving documentation towards more structured approaches, the information system would serve everyone more effectively. Either artificial intelligence or an analyst could provide patient information in a more appropriate and updated format for each appointment. This allow would healthcare professionals to focus on communicating, examining and caring for the patient. The clinical support systems using patient record data is also a safety issue, assisting professionals in clinical decision-making in terms of providing remarks like drug interactions or preventing unnecessary procedures. By using patients' previous data more effectively, several unnecessary operations could be avoided, like overlapping laboratory tests. The timing of patients' other services could be also be co-ordinated simultaneously, instead of booking multiple appointments over different days, causing unnecessary travel, arrangements and inconvenience.

An immediate change should take place concerning documentation. In particular, thinking about the core issues in documentation to provide usable data for the patient's or customer's overall care. This would make documentation more structured, focused, meaningful and motivating, also reducing unnecessary quantities.

Educating data analytics could be used as a tool for professionals to analyse and produce evidence on the outcomes of their services. Data analytics is a way to highlight challenges and opportunities, helping professionals develop outcome measures for their own work. A successful way to reduce change resistance is to encourage staff to analyse and develop their own work and current practices.

Another obvious beneficiary of data analytics is management, in terms of knowledge management. This includes all management levels from operative management to regional and interregional management of healthcare services. Data analysis clarifies, improves and monitors service processes and therefore assists in planning the service supply, having a positive impact on the customer journey and customer service experiences. This would benefit everyone.

Customer engagement and health coaching were topics studied and discussed in the health analytics programme. Data analytics also offers huge opportunities for developing ways to engage clients, as well as preventing diseases. Although shifting the focus towards personalised care and customer-engaging services requires huge changes in service delivery, big data with data analytics offers evidence and tools for risk detection, like lifestyle and genetic factors. Visualisation of different options in lifestyle choices or treatments would intensify patient/customer education and engagement. Everyone has individual needs, values and goals, which could be taken into account when selecting these different treatment options. Simply asking what the patient/customer wants could lead to significantly improved customer experience and outcomes.

Although health analytics offers huge opportunities, it is crucial to understand that the health analyst is not able to fix all the problems or develop service systems on their own. The analyst can identify problems and possibilities, but multidisciplinary teams are needed to interpret the data and find solutions to the situation. The deployment of new digital tools, analytics and possibly analysts in use requires changes to existing practices.

One key question in the successful use of analytics is to discuss the place of a health data analyst within the customer journey/care path, and in the organisation. Identified roles for health analysts include: 1) assisting professionals in their work (providing patient summaries, outcomes); 2) supporting patients (coaching, guidance, customer engagement); and 3) intensifying management (knowledge management). To conclude, an analyst would be needed across many different levels of care services. It is essential to realise that this important profession, with required competences and jurisdiction, is missing in the current service system.

Analytic competences through flexible education

Based on the experiences and results of the HEAP project, a specialist education programme was drafted to meet the identified competence needs in digital healthcare and social sector services. The pilot education programme resulted in a specialist education curriculum to improve the current situation in health data analytics. The pilot education indicated clearly that the future transformation in healthcare and social services requires new competences, both in analytics itself and in integrating its results into customer services. That is why the specialist education was planned to include some elective modules to welcome all professionals, whether they be interested in pure data analysis or data-based client engagement and coaching.

Apart from the specialist education curriculum, the developed course content will be integrated into existing courses offered as further education and Open University studies. Open University studies are infrequently used for in-service education to update and transfer required new competences to working life. This project also identified an international market for health data analytic education, since the needs and challenges for transformation in health and social service deliveries are global.

Working life feedback

The HEAP project established a working life committee with 13 members representing both primary and specialist care provider organisations in the Satakunta region. The working life committee had regular meetings to discuss and reflect on the project's progress and outcomes in light of the current situation and transformation that is occurring in healthcare and social services in the region. Working life feedback was gathered by an e-questionnaire that was distributed by email to all members and to the student nursing officers in the organisations concerned.

Out of 19 persons contacted, 12 responded to the questionnaire, making the response rate as high as 63%. The structured questionnaire focused on enquiring into the possible impacts of the project in the respondents' thinking. As to the challenges in the use of the health data available, the most commonly identified challenges were a lack of an analytic thinking culture, the lack of time and lack of data analyst services. In addition, the respondents pointed out the reluctance to change working patterns, the lack of understanding of the possibilities that data analytics could bring to services, and the fact that currently the data is scattered in many places and in fragmented formats requiring lots of time and specialist competences to search for and interpret.

The project helped in identifying developmental needs, like outstanding in-service education needs related to data analysis, for renewing operating models in the organisation. The need to improve knowledge and information transfer between various operating units was identified by the majority of the respondents. As for the competences required in customer-driven case management, 25% were happy about the way things are at present.

The complexity of health information systems, the lack of information, restricted user rights and data protection regulations (in this order) were named as the biggest obstacles to using data. Data analytics was seen as providing added value to professionals, customers and the service delivery system by all of respondents. In particular, quality management, change management and communication with customers and their families were predicted to improve, if data analytics were more highly used.

The health data analytics project (HEAP) was complimented for addressing a very current topic that should be included in all levels of education throughout healthcare and social services. In addition, the project had offered the working life committee members a vantage point from which to observe some remarkable opportunities, but also some huge challenges. It opened their eyes to new aspects, but also to the constraints in efficacy and cost-effectiveness of the current system. However, only nine of 12 respondents (75%) reported having discussed those identified issues in their organisation.

The project implementation and key results were presented in several seminars and workshops. Without exception, the feedback from the audience was encouraging, with numerous comments on the importance of introducing data analytics to streamline services in the healthcare and social sector.

3.8 References

Chilukuri S. and Kuiken S (van). (2017), *"Four keys to successful digital transformations in healthcare"*, McKinsey & Company, cited 13 September 2018.

Duggal R., Brindle I. and Bagenal J. (2018), *"Digital healthcare: regulating the revolution"*, British Medical Journal, 2018; 360: 6.

Rodriguez G. (2018), *"Technology and innovation: A healthcare revolution"*, cited 10 October 2018.

Based on the feedback, results and lessons learned in the HEAP project, the future scenario for a Specialised Education Programme is presented in the Annex 1.

4

ANALYTIC METHODS AND TOOLS FOR DIGITAL CARE SERVICES

4.1

Care gap and health benefit – tools for value-based care

ILKKA KUNNAMO, MD, PhD, RESEARCH DIRECTOR, DUODECIM MEDICAL PUBLICATIONS LTD, HELSINKI, AND GENERAL PRACTITIONER, SAARIKKA, CENTRAL FINLAND

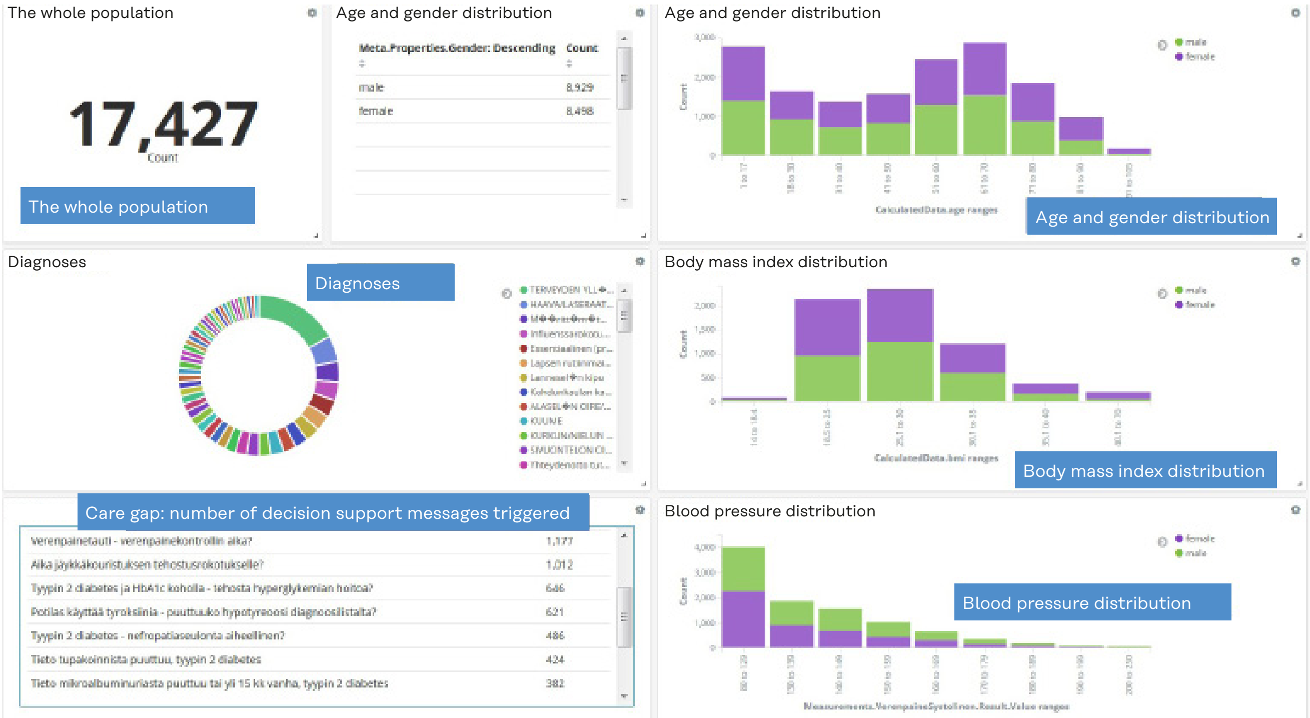
Health Benefit Analysis identifies care gaps in the population, and helps in selecting the most effective treatments for individuals by estimating their health benefits. Health Benefit Analysis is a new tool that has been developed by Duodecim Medical Publications Ltd. It is built on the EBMeDS clinical decision support service and can be integrated into any electronic health record system. The tool has been piloted in 2018 in primary care in the City of Helsinki, and in Saarikka, a primary healthcare and social care provider in Central Finland. The tool creates population health dashboards, finds care gaps, measures the quality of care and calculates the health impacts of healthcare interventions.

Population health dashboards

The data of all people in the population stored in the electronic health record (EHR) is needed for analysis in coded format. The problem list and medication list of the patient, laboratory test results, measurements such as blood pressure, weight and height, and risk factors such as smoking, are collected from the EHR, and anonymously sent to a database maintained by Duodecim's clinical decision support service.

Risk estimates, such as the risk of myocardial infarction or stroke, an estimate of renal function (the glomerular filtration rate), and many other health indicators are calculated from the data and stored in the database. Care gaps, quality measures and health benefit estimates, as described in the next paragraphs, are also stored in the database. Figure 1 shows part of the main dashboard, showing data of all the people cared for by Saarikka. Figure 2 shows the dashboard after filtering by diagnosis and when selecting all patients with diabetes.

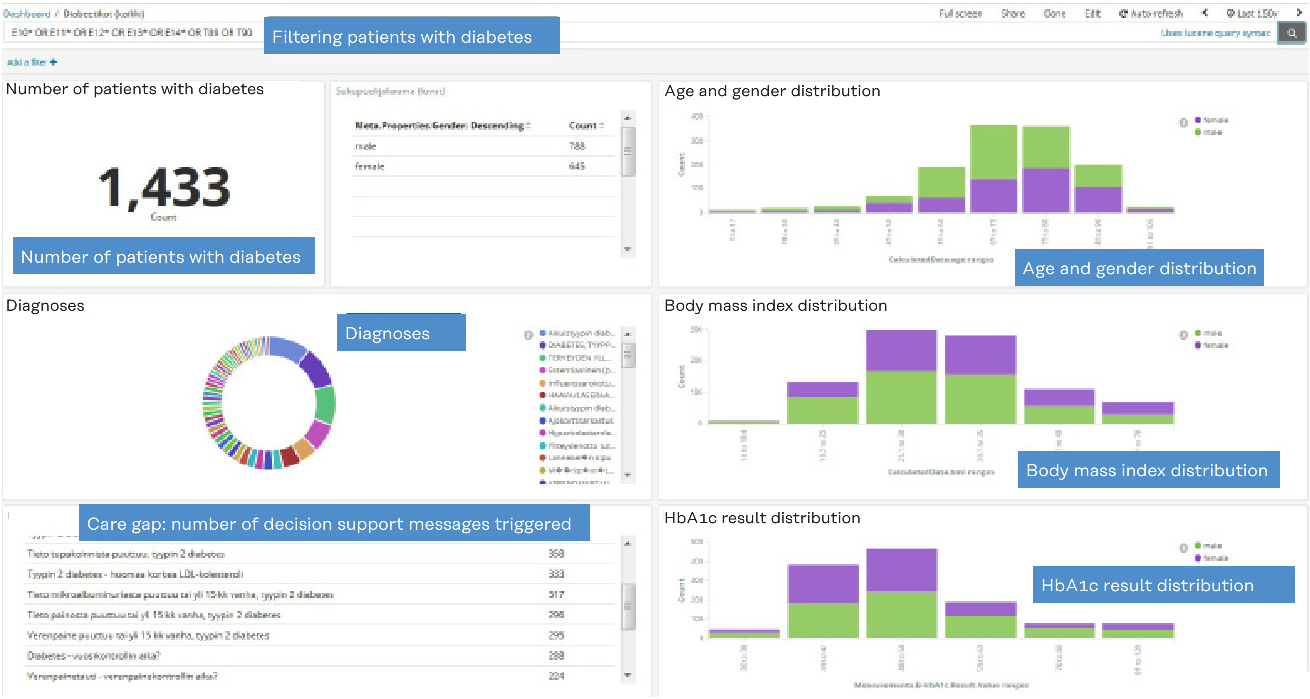
FIGURE 1.
Health data dashboard of all people cared for by provider organisation Saarikka



Meta.Properties.Gender: Descending	Count
male	8,929
female	8,498

Verenpainetauti - verenpainekontrollin aika?	1,177
Aika jäykkäkouristuksen tehostusrokotukselle?	1,012
Tyypin 2 diabetes ja HbA1c koholla - tehosta hyperglykemian hoitoa?	646
Potilas käyttää tyroksiinia - puuttuuko hypotyreoosi diagnoosilistalta?	621
Tyypin 2 diabetes - nefropatiaseulonta aiheellinen?	486
Tieto tupakoinnista puuttuu, tyypin 2 diabetes	424
Tieto mikroalbuminuriasta puuttuu tai yli 15 kk vanha, tyypin 2 diabetes	382

FIGURE 2.
Health data of diabetes patients filtered out of the population cared for by Saarikka (All the graphs are automatically filtered and show the data of diabetes patients only.)



E10* OR E11* OR E12* OR E13* OR E14* OR T88 OR T90

Meta.Properties.Gender: Descending	Count
male	788
female	645

Tieto tupakoinnista puuttuu, tyypin 2 diabetes	358
Tyypin 2 diabetes - huomaa korkea LDL-kolesteroli	333
Tieto mikroalbuminuriasta puuttuu tai yli 15 kk vanha, tyypin 2 diabetes	317
Tieto painosta puuttuu tai yli 15 kk vanha, tyypin 2 diabetes	298
Verenpaine puuttuu tai yli 15 kk vanha, tyypin 2 diabetes	295
Diabetes - vuosikontrollin aika?	288
Verenpainetauti - verenpainekontrollin aika?	224

FIGURE 3.
Examples of care gaps identified by decision support rules, extracted from the full list of care gaps in the population of Saarikka, and corresponding quality measures calculated by the rules.

Reminder by decision support rule	Care gap	Quality measure (percentage of patients with adequate care)	Number of eligible patients
Hormone replacement therapy and advanced age – stop or replace with transdermal	209	52	438
Type 2 diabetes and LDL cholesterol over 2.5 mmol/l	203	82	1113
Aspirin used for primary prevention – consider stopping	173	92	2267
Moderately high blood pressure and high cardiovascular risk – start medication	128	69	409
Atenolol as antihypertensive drug – replace with a more effective drug	36	48	69

Care gap and quality measures

In an ideal world, every person should be offered healthcare interventions that improve health and that are safe. This is accomplished by practising evidence-based medicine. The best available research evidence is used as the basis for clinical decisions, when treatments are selected for the patient from all available treatment options.

We want to find out which patients receive adequate care and which patients do not. If they have not received care that benefits them, or they receive care that is ineffective or harmful, a care gap exists. In order to determine the care gap, we need the data of all people in the population to be analysed against evidence-based guidelines which recommend treatments they should receive.

Using clinical decision support rules derived from guidelines is a good method of identifying care gaps. Each rule checks first if the patient belongs to the target group of an intervention (treatment), and whether the patient's characteristics make him/her unsuitable for the intervention. The rule then checks if he/she has already received the intervention. If he/she has not received a beneficial intervention, or is receiving a harmful intervention, a care gap has been found. The care gaps in the population are reported as a list of interventions, with numbers of people who have a care gap (Figure 3).

Quality measures are calculated as the ratio of the number of patients who have received adequate care (and did not have a care gap), and the number of patients eligible to the intervention (Figure 3).

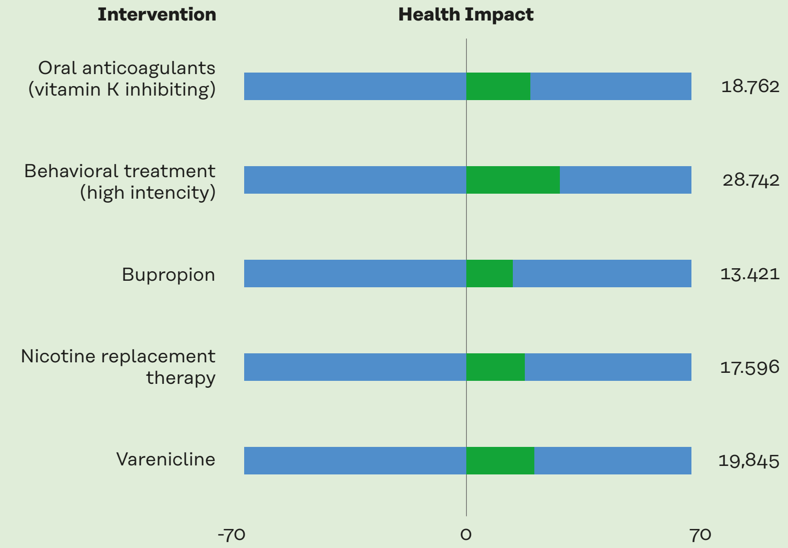
Estimating health benefit

Most interventions have many different outcomes. Beneficial outcomes include avoiding death, alleviation or disappearance of symptoms or disability, or improvement in the quality of life. Harmful outcomes include adverse effects including death, annoying symptoms and burden or inconvenience. An intervention is beneficial if the sum of beneficial outcomes outweighs the sum of harmful outcomes – in other words, its net effect is positive.

FIGURE 4.
Health benefits from five interventions for a single patient: starting an anticoagulant drug for atrial fibrillation, and four different interventions to assist smoking cessation

Health Benefit Analysis

Visual Dashboard



The amount of expected net health benefit from each suggested intervention is given. The larger the number (the longer the bar), the larger the net benefit. If harms outweigh benefits, the bar goes left from zero line, and turns red.

The table view lists the same interventions, and also gives the health condition for which the intervention is aimed at. Green arrows indicate benefit, and red arrows indicate harm. The Detailed view shows all effects (outcomes) of the intervention, including benefits and harms, and their magnitude. The bottom line gives the new effect (benefits minus harms).

Using clinical decision support rules derived from guidelines is a good method of identifying care gaps.

The estimation of net effect is not easy. First, we need to know the evidence for each outcome: by how many per cent does the intervention reduce or increase the likelihood of the outcomes (relative effect). We also need to know the risk of each outcome if no intervention is given. With patients at high risk, the amount of absolute risk reduction by the intervention is larger than with patients at low risk. The third factor we need to know is the importance of each outcome for the patient. Avoiding death is more important than avoiding obstipation. If we know the magnitude of all these three factors, we can calculate the health benefit or harm of an intervention for each outcome as relative effect x risk without intervention x importance of the outcome. We are building a database that contains the relative effects (the evidence), estimates of risk in different types of patients and estimates of the importance of different outcomes. Using this information, we can calculate the net effects of different interventions so that they can be compared with each other.

Health Benefit Analysis is a new tool for implementing value-based care and personalised medicine.

When a care plan is made together with the patient, the importance of outcomes can be changed according to the patient's values and preferences, and the net benefit estimate changes accordingly. The baseline risk of the outcomes can be calculated individually for the patient, if a risk calculator exists. Self-care interventions and lifestyle changes will be included as interventions alongside interventions provided by healthcare professionals, and their effects, can be compared with each other. The data recorded by patients themselves in personal health records will improve the accuracy of the tool.

Conclusion

Health Benefit Analysis is a new tool for implementing value-based care and personalised medicine. It can be applied to populations in order to find people who would benefit most from better care. In this way the tool is expected to reduce health inequalities. In shared decision-making for an individual patient, the comparison of net health effect of different interventions will help in selecting the treatment options that bring the largest health benefit for the patient.

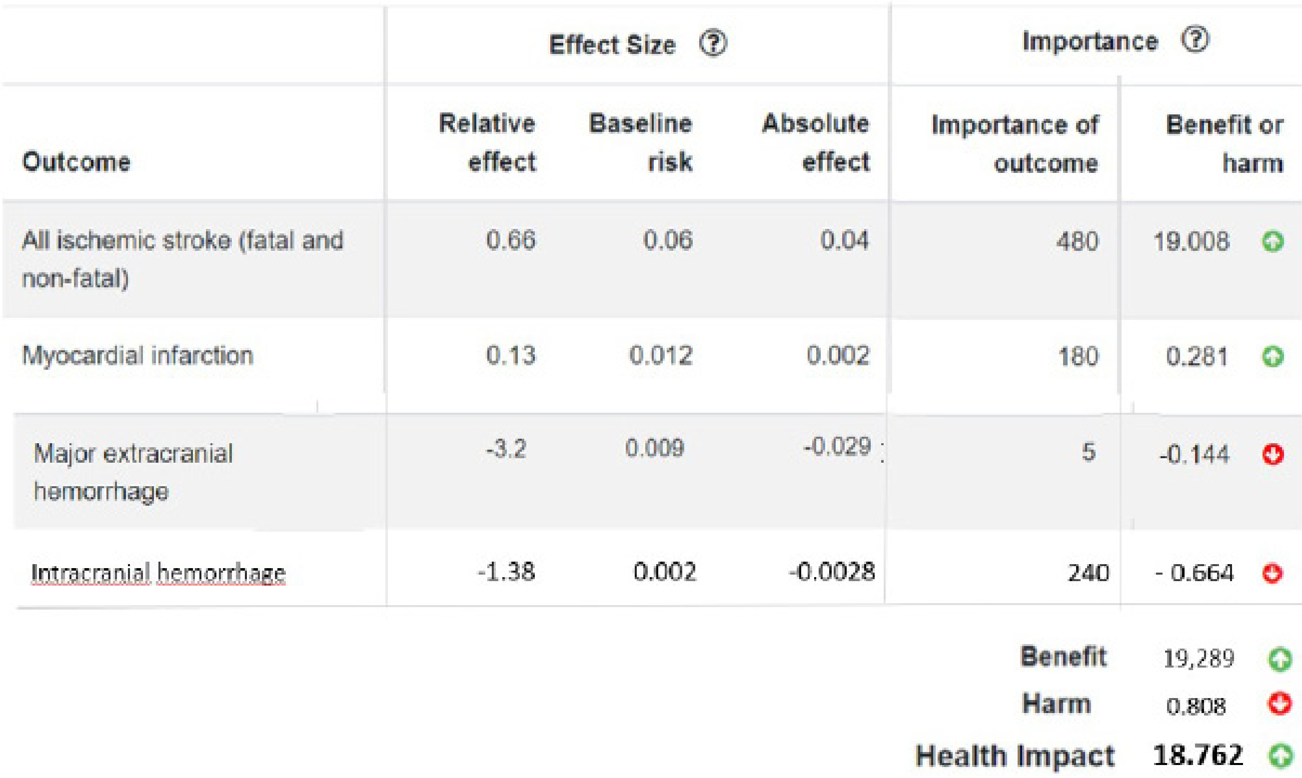
Acknowledgements

Sitra has supported the piloting of Health Benefit Analysis in Helsinki and Saarikka. CGI has implemented the decision support service of Duodecim in the Pegasos EHR system, enabling Health Benefit Analysis of the population. EBSCO Health contributes as the source of evidence-based knowledge providing the current best effect estimates for benefits and harms of medical interventions used to determine net health benefit.

FIGURE 5.
Calculation of net health benefit from an intervention – the baseline risk and importance of outcome can be individually edited

Intervention

Oran anticoagulants (vitamin K inhibiting)



	Effect Size ?			Importance ?	
Outcome	**Relative effect**	**Baseline risk**	**Absolute effect**	**Importance of outcome**	**Benefit or harm**
All ischemic stroke (fatal and non-fatal)	0.66	0.06	0.04	480	19.008 ⬆
Myocardial infarction	0.13	0.012	0.002	180	0.281 ⬆
Major extracranial hemorrhage	-3.2	0.009	-0.029	5	-0.144 ⬇
Intracranial hemorrhage	-1.38	0.002	-0.0028	240	- 0.664 ⬇

Benefit	19,289	⬆
Harm	0.808	⬇
Health Impact	**18.762**	⬆

4.2 Omaolo service

HANNA NORDLUND, ICT-PROJECT DIRECTOR, SOTE-DIGI OY

Public health and social services are in transition in Finland. Digitisation and smart services are drivers for change, which is also supported by a structural reform. In addition, the expected reform requires purposive change management, process renewal and a new business culture. The Omaolo service is an electronic service that provides silo services to customers, regardless of time and place. The service package allows customers to assess their service needs, plan the care and services together with a professional, store follow-up data, and deploy electrical health coaching services. The service promptly directs the customer to the appropriate service based on identified needs. A major activity modification has taken place along with the construction of the electronic service platform.

Background

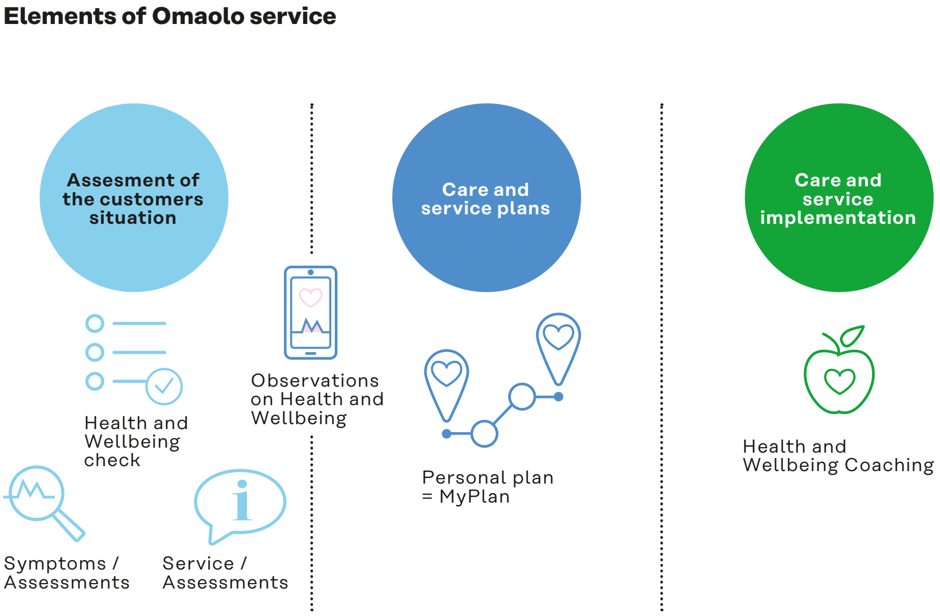
Public services in the health and social sector are under huge reform at present. The Health Data Strategy 2020 from the Ministry of Social Affairs and Health (STM 2014) states that the difficult economic development of the past few years, the sustainability gap and the growing need for services for the future form an equation that requires structural reform and the introduction of new operating models in the organisation and production of services. A small minority consumes most of the health and social services. For the majority, this is perceived as poor access and availability, with long queueing times for services. At present, the structure and situation of reform is attracting significant public debate in Finland. Technology opportunities are also widely discussed in terms of required changes, both in clients' and professionals' actions. Structural changes and technology deployment can help to solve these problems. In addition, there is a need for purposive change management, process renewal and a new kind of service culture, both among professionals and customers. The reform objectives set for healthcare and social services are achieved only by increasing customer accountability with respect to health and by increasing efficiency, productivity and developing new methods and models for service delivery systems.

Omaolo service

The Omaolo service is an electronic service that provides silo services to customers, regardless of time and place (Figure 1). The service package enables customers to assess their care or service needs, plan care and services together with a professional and store related follow-up information, as well as deploy eHealth coaching services. The service promptly directs the customer to the appropriate services. For a customer, this offers the ability to assess their situation in the comfort of their own home, avoiding unnecessary queues or waiting times and providing quick guidance to the right services and processes, without running from one professional to another. With the Omaolo service, each customer chooses the best way to deal with authorities. This will leave professionals with more time for those who use traditional channels (Kuntaliitto 2018).

The Omaolo service has been developed as part of a key, Finnish government project (ODA; in Finnish: Omat digiajan hyvinvointipalvelut). The starting point involved a functional change in customer and service processes, requiring smarter digital services (i.e. services that increase the customer's role in assessing their situation and improving well-being). ODA has its roots in a

FIGURE 1.
OMAOLO service elements



virtual clinic pilot project developed by Sitra and the city of Hämeenlinna in the year 2014. The Omaolo service offers a potential solution to identified bottlenecks in assessing care and service needs, planning care and service processes, and supporting life and lifestyle changes.

Existing systems and services can often appear as unco-ordinated, whereby the client is subjected to duplication or repetition of processes with different professionals (due to inefficiencies, lack of appropriately recorded data or segmentation of data within existing systems). This creates uncertainty about the patient's progress, reinforcing the feeling that there are no solutions to the problem, particularly in multiple problem/condition situations. An inevitable consequence is a poor customer experience and prolongation of the problem. Process changes and digital service development have gone hand in hand in the Omaolo project, in an effort to promote engagement for both customers and professionals. Through Omaolo, relevant and reliable information that traditionally was accessible only for professionals is made available to customers when needed. The research evidence, care recommendations and other standardised services are equal for all customers.

In Omaolo, the customer can assess individual symptoms and the need for service, as well as the overall picture of one's well-being. Symptom assessments allow the customer to assess the urgency of their symptoms and provide guidance to the appropriate service. The customer can choose where and when to use the service and will receive instructions immediately. If the situation is resolved without a professional, or just using electronic channels, the customer avoids unnecessary travel to their health centre (for example). In situations where a customer needs professional help, the data is ready for the professional, assisting diagnosis and problem-solving. By means of service assessment, the customer can likewise get an immediate estimation of their right to certain social services and guidance based on the assessment results.

By doing a welfare check, the clients evaluate their own well-being comprehensively. The welfare review recommends and encourages lifestyle changes by providing information on life expectancy, health risks, the state of well-being and functioning, and oral health. From this information, the customer learns how to improve their well-being. The service also guides the customer to the right professional when necessary. The welfare check can only be done for oneself and can be used in conjunction with a long-term follow-up, or even with an unemployment service process (together with a professional). The well-being check also provides population level information.

Omaolo assists professionals in their work, providing standardised processes that can be customised when needed.

After evaluating the customer's situation, the Omaolo service helps to plan the care or a service process. The goal is for each customer to know what to do next and what the professional will do next. If the customer so wishes, the plan will allow more professionals to become connected to the process and the customer will no longer have to go through the same procedures with different professionals several times. Information moves and saves everybody's time. Omaolo assists professionals in their work, providing standardised processes that can be customised when needed. The client can receive various instructions and tasks related to the care plan as reminders. Through this plan, the customer can store different monitoring information within their plan and, if desired, make it available to a professional. This way, for example, tracking processes can be partially electrified and customised to suit the customer's situation.

Customers often need support for lifestyle changes, but professional resources are often too limited to be able to serve everyone face to face. Customers can be supported by online health coaching that provides help for lifestyle changes in nutrition, sleep, exercise and stress management.

New action models and ways of working

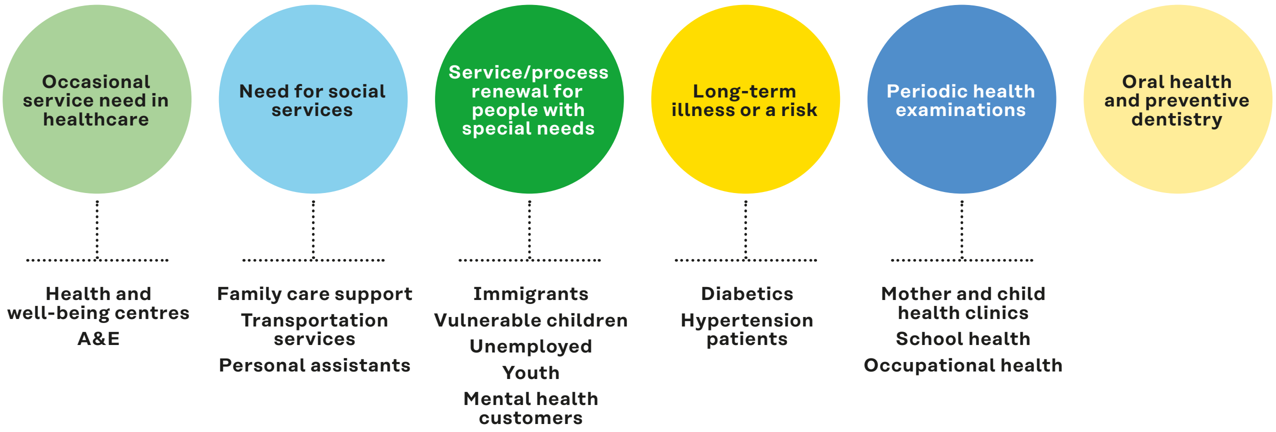
The Omaolo service is suitable for various customer groups (Figure 2). These customer groups have been involved in developing processes for their associated services. As a result of this collaboration, new roles and even units have emerged in organisations, such as the digi-nurse job description and the digital teams/units. Alongside the process development, new working patterns and service models have been generated.

For people in need of multiple services the focus is set on improving co-ordination. For example, new methods for multi-professional work have been created. When traditionally a customer has been invited to attend several long meetings with a variety of professionals, now the professionals are brought together to the same meeting with the customer. This saves everyone's time significantly, expedites required support and assistance services and improves co-operation between professionals. Also, appointing a primary person, who acts as an advocate for the customer among other professionals, has improved the co-ordination and efficiency of services.

The customer no longer needs to be responsible for contacting all the different professionals. These kinds of small changes have strengthened the service process and allow professional resources to be used more cost-effectively. For example, with service needs assessments, whenever a C-statement (i.e. statement regarding the health condition's long-term impact to the patient) is not necessary the decision will be made

FIGURE 2.
The Omaolo service is suitable for various customer groups

Omaolo Benefits Various Target Groups



faster and the physician's working time is saved for more essential care activities (rather than making unnecessary statements).

The client's access to physiotherapist appointments without the doctor's referral has expedited care, for example, of lower back pain. Rationalising the conventional treatment and registration practices of professionals has considerably accelerated application processing and decision-making. The "all completed in one visit" model (kerralla kuntoon) in dental care substantially reduces the need for further appointments, bringing mutual savings and comfort.

Along with digitisation, it is necessary to harmonise procedures. Defining criteria for certain customer groups, like those who need multiple services, or vulnerable children, has enabled the creation of policies that serve customer groups more effectively. Systematic assessment criteria for treatment allows the introduction of symptomatic evaluations. At the same time, services have expanded to cover previously excluded customer groups. Common guidelines for self-care, both for customers and professionals, have improved the quality of services and clarified the client's point of view. Better customer information and data has accelerated decision-making in professional appointments.

In addition to process impacts, these changes and digitised services are expected to significantly impact upon customers' health and well-being. However, these changes will be realised in the longer term and therefore the changes will continue to be monitored.

4.2 References

Kuntaliitto (2018), *ODA-projekti*:

STM (2014), *Tieto hyvinvoinnin ja uudistuvien palvelujen tukena – Sote-tieto hyötykäyttöön -strategia 2020*: .

4.3

KardioKompassi® – using genomics to accurately predict and prevent cardiovascular disease

ELISABETH WIDÉN, MD PhD, ASSOCIATE PROFESSOR, INSTITUTE FOR MOLECULAR MEDICINE FINLAND, UNIVERSITY OF HELSINKI

The systematic use of genomic risk information to guide clinical decision is expected to significantly improve both risk assessment and prevention of common multifactorial disease, such as cardiovascular and coronary heart disease. Hitherto this opportunity has remained largely untapped, partly due to insufficient knowledge of the underlying genetic architecture. The field, however, is rapidly changing.

During the past few years, technological advances and systematic large-scale research have propelled a major scientific breakthrough resulting in the discovery of numerous genetic loci affecting the risk of multifactorial disorders. These discoveries have indicated that the underlying genetic architecture is complex, consisting of thousands of genetic variants influencing disease risk. Thus, a prerequisite for bringing these genetic discoveries to the clinic is the development of novel practical procedures to manage and use large-scale genomic data, and to communicate the risk information to patients and healthcare professionals.

Taking coronary heart disease prevention to new level

Coronary heart disease, which is a common and severe disease, is a prime example of a common complex disorder where genomic information may provide significant improvement of disease prevention procedures. While coronary heart disease continues to be a leading cause of death in Finland and elsewhere (WHO 2017), there are efficient means for prevention available, if individuals at high risk are identified in time. The cornerstones for prevention are well established and include not smoking, weight control, regular exercise and efficient medical treatment of diabetes, elevated blood pressure and elevated blood lipids. Unfortunately, current clinical methods used for disease risk prediction are imprecise and insufficient, leaving almost half of individuals who develop disease undetected. Despite the fact that half of the disease risk is mediated through genetic factors (Wienke et al. 2001), current clinical methods do not make use of genomic information.

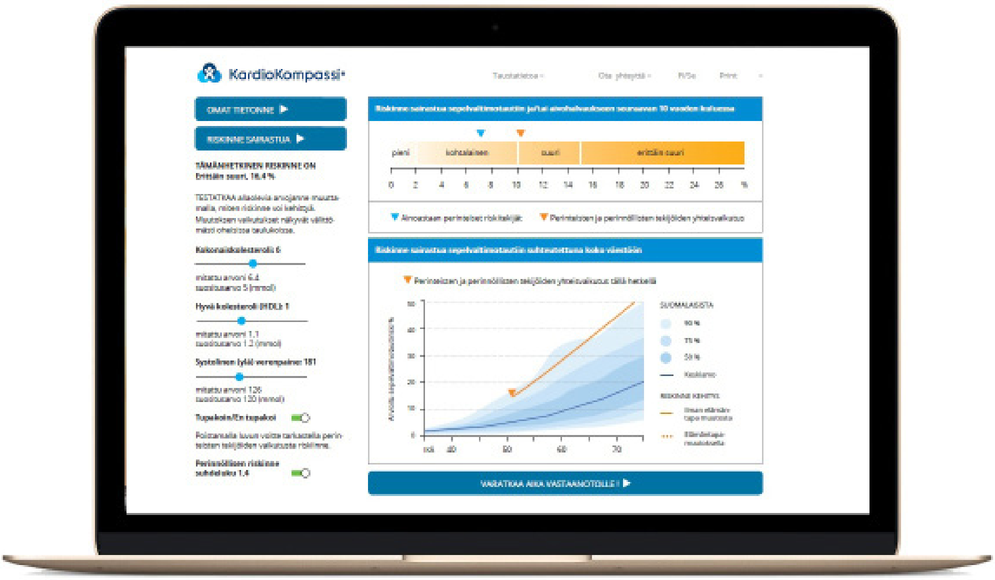
Therefore, to facilitate the practical use of genomic research findings and to empower individuals to undertake risk-reducing interventions, we have developed an interactive tool, KardioKompassi®, for patients and doctors to predict and prevent cardiovascular disease. KardioKompassi is developed and owned by the Institute for Molecular Medicine Finland, University of Helsinki. This risk calculator uniquely combines newly discovered genomic risk information with traditional medicine and provides a more accurate disease risk estimate than any current clinical method. It currently estimates an individual's risk of developing coronary heart disease during the coming 10 years, based on both traditional health information and a genetic risk score including 49,000 genetic variants associated with the disease risk (Abraham et al. 2016). The impact of the genetic score on the disease risk is significant, i.e. it is comparable to the combined risk of smoking, blood cholesterol and blood pressure levels. Through KardioKompassi's interactive graphical interface, users can also test how different lifestyle changes, such as quitting smoking, may impact on their risk (Figure 1).

Findings from KardioKompassi pilot studies

So far, we have piloted KardioKompassi in the academic research setting in the ongoing GeneRISK study (FIMM 2018), which includes 7,350 customers from both public and private healthcare providers in Finland. All study participants have received personal information on their 10-year risk for coronary heart disease using KardioKompassi. The preliminary study results are encouraging. Based on initial data obtained from the first follow-up study, 90% of participants reported that their personal disease risk information motivated them to take better care of their health. The data on lifestyle changes is also promising: roughly 15% of participants had managed to permanently lower their body weight, while 14% of smokers had stopped smoking. The group with the highest genetic risk more often took action to lower their disease risk. The data thus seems to suggest that combining genomic and traditional health information and communicating this information back to individuals can provide an efficient means for disease prevention.

To further promote its clinical application, KardioKompassi will next be used in an Estonian study to be launched this autumn, where family doctors and their patients are testing new and proactive strategies to prevent cardiovascular disease (see Chapter 4.4 in this publication). With the more precise risk assessment provided by KardioKompassi, individuals get the opportunity to lower their disease risk and enjoy healthier lives while the ever-increasing societal healthcare costs may be reduced.

FIGURE 1.
KardioKompassi estimates an individual's 10-year risk for coronary heart disease and displays the risk in many different ways. This screen shot shows the overall disease risk of a 50-year old male, and how his risk develops as a function of age in comparison with the average population risk.



4.3 References

Abraham G., Havulinna A. S., Bhalala O. G., Byars S. G., De Livera A. M., Yetukuri L., Tikkanen E., Perola M., Schunkert H., Sijbrands E. J., Palotie A., Samani N. J., Salomaa V., Ripatti S. and Inouye M. (2016), "Genomic prediction of coronary heart disease", European Heart Journal, Volume 37, Issue 43, 3267-3278.

FIMM (2018), "Finnish Genomes Empowering Personalised and Predictive Health".

WHO (2017), Factsheets – Cardiovascular diseases (CVDs).

Wienke A., Holm N., Skytthe A. and Yashin A. (2001), *"The Heritability of Mortality Due to Heart Diseases: A Correlated Frailty Model Applied to Danish Twins"*, Twin Research, 4(4), 266-274. doi:10.1375/twin.4.4.266.

4.4

Proactive cardiovascular prevention in subjects with a high hereditary risk by using the KardioKompassi tool in Estonia

MARGUS VIIGIMAA, PROFESSOR, DEPARTMENT OF HEALTH TECHNOLOGIES, TALLINN UNIVERSITY OF TECHNOLOGY

Cardiovascular diseases (CVD) are the main cause of death in Estonia. The aim of the present study is to evaluate the health impact and feasibility of a proactive prevention strategy for CVD in Estonian primary healthcare patients with a high polygenic hereditary risk of CVD by using the KardioKompassi® tool. Taking into account the high CVD mortality in Estonia, it may be expected that preventive treatment of CVD based on a personalised overall CVD risk or a CVD proactive prevention strategy would help to reduce CVD morbidity and mortality in Estonia.

Introduction

Cardiovascular diseases (CVD) are the main cause of death in Estonia, causing 55% of all deaths. This disease makes a significant contribution to potential years of life lost (25%) and kills approximately 10,000 people per year. For every 100,000 residents ≤65 years old, 250 men and 80 women die of CVD each year, which surpasses the corresponding indicator of most developed countries (Abajobir et al. 2016).

CVD morbidity and mortality can be reduced with effective prevention. Taking into account the high CVD mortality in Estonia, it may be expected that preventive treatment of CVD based on a personalised overall CVD risk or a CVD proactive prevention strategy would help to reduce CVD morbidity and mortality in Estonia.

The aim of the present study is to evaluate the health impact and feasibility of a proactive prevention strategy for CVD in Estonian primary healthcare patients with a high polygenic hereditary risk of CVD by using the KardioKompassi tool.

Theory part

For the estimation of the for CVD in primary prevention, the European Society of Cardiology (ESC) suggests the Systematic Coronary Risk Estimation (SCORE) instrument (Piepoli et al. 2016; European Society of Cardiology 2013), which evaluates an individual's cumulative 10-year risk of CVD mortality (ischaemic heart disease, stroke, hypertension, heart failure, occlusion of peripheral blood vessels). SCORE has been developed based on the data from 12 European countries, and it takes into account the impact of major CVD risk factors including sex, age, systolic blood pressure, smoking and the level of total cholesterol. The European CVD prevention and treatment guidelines are based on a SCORE estimate (Piepoli et al. 2016). Estonian family doctors also use the SCORE instrument for risk estimation (European Society of Cardiology 2013).

An analysis conducted on the cohort of 30 to 74-year-old (age at recruitment) gene donors in the Estonian Genome Centre of the University of Tartu (EGCUT) database (n=30,473) indicated that close to 50% of 70-year-old men had been diagnosed with

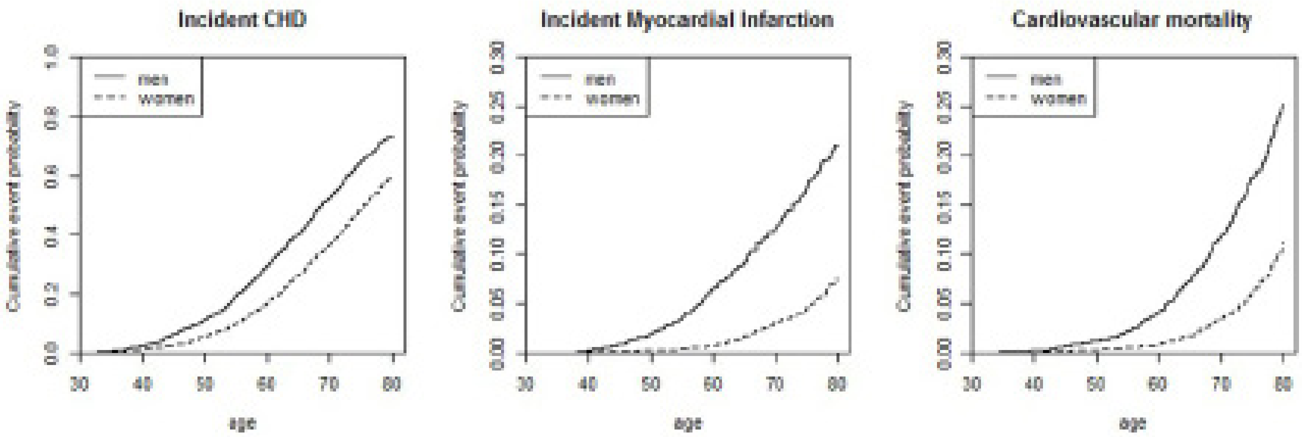


FIGURE 1.
Mean cumulative risk of any CVD, myocardial infarction and cardiovascular mortality of the gene donors in the Estonian Genome Centre database (n=30,473, age at recruitment 30-74)

CVD and a large proportion (15%) had experienced myocardial infarction (Figure 1). According to the SCORE risk estimate, close to 50% of men and 20% of women in the cohort would have needed CVD preventive treatment with statins, although only 4% received it.

In addition, the CVD risk was estimated with the help of genetic analysis. There is evidence from large-scale international studies that CVD has a strong hereditary background and is influenced by many genetic factors. It has been shown that the risk for CVD events in the highest quintile (or in individuals with higher polygenic hereditary risk) is considerably higher (Mega et al. 2015). The Estonian data confirms this. A preliminary analysis of 3,157 subjects with high-quality genotype data in the EGCUT database (aged 30-69 at recruitment) indicated a considerably higher risk for acute CVD events in individuals with a high polygenic risk (Figure 2). In addition, the efficacy of statin treatment is considerably higher in individuals with a higher risk in the primary prevention of CVD (Mega et al. 2015). Thus, primary prevention is indicated primarily for individuals with a higher polygenic hereditary risk.

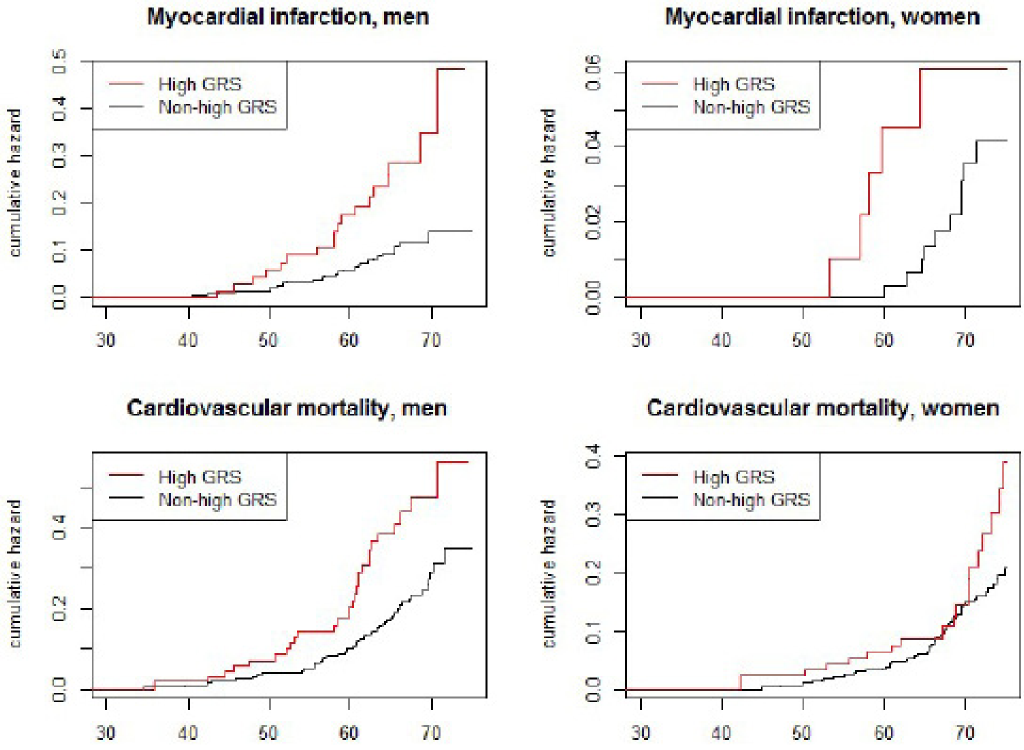


FIGURE 2.
Cumulative risk of myocardial infarction and cardiovascular mortality in the EGCUT gene donor cohort (n=3,157, aged 30-69 at recruitment) in subjects in the highest polygenic CVD risk quintile (or with the highest hereditary risk) compared to the rest of the cohort

A recent study based on large European cohorts, including more than 12,000 individuals from Finland (Abraham et al. 2016), has demonstrated that integration of a polygenic risk score with a conventional non-genetic risk score like SCORE makes the prediction of a CVD risk even more exact (Abraham et al. 2016; Sitra 2018; FIMM 2017). Thus, the overall CVD risk based on the individual polygenic hereditary risk and other SCORE-based risk factors should be evaluated when prescribing preventive treatment.

In the present study, men aged 30-65 and women aged 40-70 with a high polygenic hereditary risk of cardiovascular diseases (1,000 subjects in total) are recruited from the database of the Estonian Genome Centre, University of Tartu.

The participating sites are the Estonian Genome Centre, the University of Tartu and Estonian family health centres. The project is chaired by Prof. Margus Viigimaa (North Estonia Medical Centre, Tallinn University of Technology).

Participating subjects with a high and moderate overall risk are given counselling regarding healthy choices and their family doctor will apply preventive treatment, if required. All subjects will be treated according to the European Society of Cardiology (ESC) treatment guidelines corresponding to their risk score (Piepoli et al. 2016). Although such an approach to the patients is in line with current primary care practice, upgraded Estonian intervention guidelines will be drawn up in the framework of the study making up part of the pre-study training of family doctors. The intervention guidelines consist of risk assessment, lifestyle counselling (giving up smoking, physical activity, nutrition, body weight), approach to dyslipidaemia (diagnosis, need for statin treatment, statin choice, monitoring) and hypertension (diagnosis, treatment).

The study subjects are randomised into two groups: the intervention group includes up to 500 subjects and the control group up to 500 subjects. The names and hereditary risk data of the intervention group subjects will be forwarded to family doctors by the EGCUT at the beginning of the study. The family doctor (or family nurse) will arrange an initial visit with the subject by phone. During the visit, the family doctor explains the study to the subject, obtains informed consent for participation in the study (added to the application), states the subject's hereditary risk and calculates the overall CVD risk, performs study activities presented in the data collection form (added to the application), advises the subject and starts/changes preventive treatment if needed. During the study, the intervention group subject visits the family doctor's office three times; the first visit will take place at the beginning of the study, the second after three months and the third after 12 months.

Taking into account the high CVD mortality in Estonia it may be expected that preventive treatment of CVD based on a personalised overall CVD would help to reduce CVD morbidity and mortality in Estonia.

Tools and applications

More accurate risk assessments can help people take better care of their health. The human genome contains more than 50 candidate genes for cardiovascular diseases. A comprehensive heart disease risk assessment will be performed on subjects participating in the present study.

The KardioKompassi (Helsinki, Finland) is a unique tool that has been developed for this purpose. In the KardioKompassi project, a cardiovascular risk profile is drawn up for members of a test group by combining genetic data with information about each individual's lifestyle and health. Participants can estimate their risk for developing CVD with the help of the KardioKompassi.

The KardioKompassi is a risk calculator taking advantage of a new type of digital genome data. It is a web-based solution, which exploits the genome data (information obtained on the entire human genome). The genome data are combined with traditional health data, such as information about lifestyle.

The KardioKompassi is an example of how genetic risk factors are taken into account and combined with traditional risk factors in the prevention of cardiovascular diseases. In this study, it will be used in 1,000 Estonian middle-aged subjects with a high polygenic hereditary risk of cardiovascular diseases, which is a good start for international co-operation in using the KardioKompassi.

A secure website for the use of the KardioKompassi will be created during the study. Family doctors as well as patients can use it. All family doctors participating in the study will undergo training in the use of the KardioKompassi before the beginning of the study. The patient, who has been informed about his or her increased hereditary CVD risk, can see his or her overall CVD risk and its possible reduction by changes in risk factors (smoking, being overweight, etc.) with the help of this instrument. The website intends to make accessible relevant health promotion materials (for example publications by the National Institute for Health Development and World Health Organization).

Participating subjects benefit from the use of the KardioKompassi website. Although they cannot change their CVD hereditary risk, it is possible to reduce the overall risk through healthy choices. The subject sees his or her overall risk on the graph and how much it can be reduced, for example by stopping smoking.

Expected results and conclusion

The general objective of the study is the evaluation of the health impact and feasibility of the CVD proactive prevention strategy in Estonian primary healthcare patients with a high polygenic hereditary risk of CVD. The hypothesis is that a proactive prevention strategy is effective in the primary prevention of atherosclerotic CVD in individuals with a high hereditary risk. The strategy is implementable in the Estonian primary healthcare setting.

In the current study, we use the KardioKompassi as a web-based solution that exploits the genome data (information obtained from the entire human genome). The genome data are combined with traditional health data, such as information about lifestyle. A secure website will be created for the use of the KardioKompassi during the study. Family doctors as well as patients can use it.

Today's healthcare requires combining personal eHealth profiles with the genome data and offering personalised advice to those with a high genetic risk. Taking into account the high CVD mortality in Estonia it may be expected that preventive treatment of CVD based on a personalised overall CVD risk or a CVD proactive prevention strategy would help to reduce CVD morbidity and mortality in Estonia.

4.4 References

Abajobir A. A. et al. (2017), "*Global, regional, and national age-sex specific mortality for 264 causes of death, 1980–2016: a systematic analysis for the Global Burden of Disease Study 2016*", The Lancet, September 2017 (cited 15 September 2017); 390(10100): 1151-210.

Abraham G. et al. (2016), "*Genomic prediction of coronary heart disease*", European Heart Journal, 14 November 2016 (cited 19 February 2018); 37(43):3267-78.

ESC (European Society of Cardiology) (2013-2014), *SCORE Risk Charts (cited 8 March 2018).*

FIMM ¬– Institute for Molecular Medicine Finland (2017), *Personal Genomics Projects (cited 8 March 2018). Available from.*

Mega J. L. et al. (2015), "*Genetic risk, coronary heart disease events, and the clinical benefit of statin therapy: an analysis of primary and secondary prevention trials*", The Lancet, 6 June 2015 (cited 19 February 2018); 385(9984): 2264-71. Available from.

Piepoli M.F. et al. (2016) *2016 European Guidelines on cardiovascular disease prevention in clinical practice: The Sixth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice (constituted by representatives of 10 societies and by invited experts) Atherosclerosis, 1 September 2016 (cited 5 March 2018); 252: 207-74.*

SITRA (2018), "*KardioKompassi: towards better cardiac health with genome data*" (cited 8 March 2018).

4.5

The Finnish biobanks and data lakes

ANU HOLM, PhD, HOSPITAL PHYSICIST, SATAKUNTA HOSPITAL DISTRICT; SENIOR RESEARCHER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

This article discusses the Finnish data lake project that provides a powerful data architecture with a unified location to help reduce silos across the healthcare enterprise, and which can be connected from trusted outside sources including funders, genomic research centres, public health databases, biobanks and social media feeds. The data lake allows for effective cross-data analysis and incorporates all internal data sources and trusted external sources for mining and analysis by clinical departments, business analysts and data science teams. Data lakes open up possibilities for integrating information from wearables and appliances built on the Internet of Things (IoT). This flexible and reliable platform offers a myriad of new opportunities to find trends and correlations, helping providers to create a data-driven, continuous learning environment.

Data lake platforms provide massive scalability, simple management and operational flexibility.

Biological samples and data lakes

Biological samples and related data represent an important opportunity for medical research. Biobanks collect biological samples and related clinical information for future medical research. Data lakes are platforms interlinking comprehensive electronic healthcare record information. This information can be used to study the aetiology of diseases, the development and validation of new diagnostic methods, and the development of personalised medicine and drugs.

In Finland, we have 10 biobanks, of which nine are publicly and one is privately funded (Table 4). The public-based biobanks have been established by hospital districts, universities, the national blood service and the National Institute for Health and Welfare in Finland (THL). The National Supervisory Authority for Welfare and Health (Valvira) directs and supervises the activities of Finnish biobanks. Biobanks collect and store samples and related clinical data for future research. Six of the biobanks operate within the hospital districts and four operate nationwide (in Finland).

The Finnish biobanks collaborate via the Biobanking and Biomolecular Resources Research Infrastructure network (BBMRI.fi), which is a national node of the European Research Infrastructure for Biobanking (BBMRI-ERIC). The BBMRI.fi aims to create a research infrastructure, providing support to high-quality research through use of comprehensive collections of biological samples and associated data (BBMRI 2018).

Data collection and storage

The biobanks contain a collection of biological samples and related clinical data for future medical research, not only for a specific research purpose. Biobank samples include blood cells, biological samples, etc. Clinical data contains information about a patient's healthcare.

The collection of samples is regulated by the biobank law, approved on 2 October 2012 (law 688/2012). The act entered into force on 1 September 2013 (Soini 2013). The old samples that had been collected before 1 September 2013 for treatment, diagnostic purposes or medical research have been transferred into the biobanks by permission of the regional Ethics Committee and the decision on the use of the samples for biobank research from Valvira.

TABLE 1.
Finnish biobanks

Biobanks and Founders	Operation
Auria Biobank The University of Turku and hospital districts of Southwest Finland, Satakunta and Vaasa www.auria.fi/biopankki/en	The first clinical biobank in Finland obtained its license to operate as a biobank in 2014. The biobank supports research into cancer, diabetes and cardiovascular diseases.
Helsinki Biobank The hospital district of Helsinki and Uusimaa (HUS), the University of Helsinki, Kymenlaakso Social and Health Services (Carea), and the South Karelia Social and healthcare District (Eksote) www.terveyskyla.fi/helsinginbiopankki/en	Covers 1.9 million inhabitants. Specialises in research promoting population health, identification of factors in disease mechanisms and development of products promoting population health and welfare.
Biobank of Eastern Finland The North Savo Hospital Districts, the South Savo Social and Healthcare Authority, Siun Sote – the Joint Municipal Authority for North Karelia Social and Health services, the Eastern Savo Hospital District, and the University of Eastern Finland www.ita-suomenbiopankki.fi/en	The development of diagnostics and treatment supports research addressing metabolic disorders, musculoskeletal disorders, neurological disorders, cancer and mental health.
Central Finland Biobank The Central Finland Hospital District and the University of Jyväskylä www.ksshp.fi/fi-FI/Potilaalle/Biopankki	Research area covers biological, medical, sport and health sciences, and product development.
Finnish Clinical Biobank Tampere Pirkanmaa Hospital District, the University of Tampere, Etelä-Pohjanmaa Hospital District and Kanta-Häme Hospital District www.tays.fi/fi-FI/Tutkimus_ja_kehittaminen/Tampereen_Biopankki	Samples specifically for cardiovascular disease, cancer, immunology and type 1 diabetes research.
Northern Finland Biobank Borealis Northern Ostrobothnia Hospital District, the University of Oulu, NordLab and the hospital/healthcare districts of Lapland, Länsi-Pohja, Central Ostrobothnia and Kainuu www.ppshp.fi/Tutkimus-ja-opetus/Biopankki/Pages/default.aspx	Promotes research into biomedical, clinical and health sciences, and into translational medicine.
THL Biobank https://thl.fi/fi/web/thl-biobank	A remarkable collection of population and family samples, as well as disease-specific samples for research purposes. The biobank focuses on identification and prevention of diseases and promotion of population health.
Hematological Biobank The Finnish Association of Hematology, Institute for Molecular Medicine Finland and Finnish Red Cross Blood Service www.fhrb.fi/front-page.html	Samples and data from patients with haematological disorders.
Finnish Red Cross Blood Service Biobank www.bloodservice.fi/Research%20Projects/biobanking	Specialises in health promotion, prevention of diseases and transfusion medicine. The biobank collects samples from blood donors during their blood donation. These samples can be used in medical research, for example, as a control group.
Terveystalo Biobank Finland https://www.terveystalo.com/en/Company/Terveystalo-Clinical-Research-/	Focuses on the population's health promotion, identification of factors involved in disease mechanisms and disease prevention (currently the only private biobank).

FIGURE 1.
Unidentified samples are stored in a freezer, where temperatures can be as low as −200°C

FIGURE 2.
Biobank storage containers/freezers are housed in a big room

New samples can be collected during normal healthcare and medical examinations, in various research projects or primarily for the biobanks. Healthcare personnel can ask for consent to collect samples and personal data for a biobank. In addition, leaflets and consent forms sent by post are used.

Donating samples is voluntary. The donor gives a written consent and it is valid until further notice. Voluntary donations can be used for understanding illness and for improving diagnostic and treatment processes for future patients. One can withdraw the consent and prohibit the further use of samples and data at any time.

Clinical data is integrated into data lakes from the hospital's databases, such as a hospital information system, pharmaceutical service system and radiological information system. The information includes, for example, demographic information, inpatient stays, outpatient visits and diagnoses in international ICD-10 codes. Also, non-structured information such as clinical notes are included in data lakes. Biobanks use data from data lakes, but data lakes can be used for register-based research also. To be useful for national and international research purposes, data needs to be organised and stored in an integrated manner.

Data and samples are stored in secure data storage, with high data security requirements. Data is pseudonymised, which means that a patient's identity is replaced with a code that the biobank personnel use to identify a sample. Personal information is kept separately in the code registry, which only certain personnel in the biobank have access to. Samples are stored in the biobank until they are needed for research purposes. Donors are also allowed to monitor the use of their samples. Release of the samples and data is carefully recorded.

How to access samples and data in biobanks and data lakes

First, a researcher with a research question contacts the biobank (or owner of the data lake), which will do a preliminary examination of the availability of data and samples. This process is typically free of charge. If enough data is available in the biobank/data lake, research permission from a biobank or hospital district is then required (Figure 3).

The biobank's or hospital's committee reviews the researcher's application and checks that the proposed project does not overlap with ongoing projects using the same datasets and samples. After a positive decision from the committee, an application for materials from the biobank/data lake can be assessed. There typically is a fee for accessing samples and associated data. The costs cover administrative services, sample and data processing and delivery. The researcher may inquire about a preliminary estimate of costs after receiving the biobank's statement of availability.

After a transfer of samples and data, research described in the research plan can be started. The researcher may use material only for the specified research project. The Finnish Biobank Act requires that the raw data obtained from the analyses is returned to the biobank, to be later available to other projects. Data is typically returned when the results are published. Biobanks treat the application and research plan as strictly confidential until published.

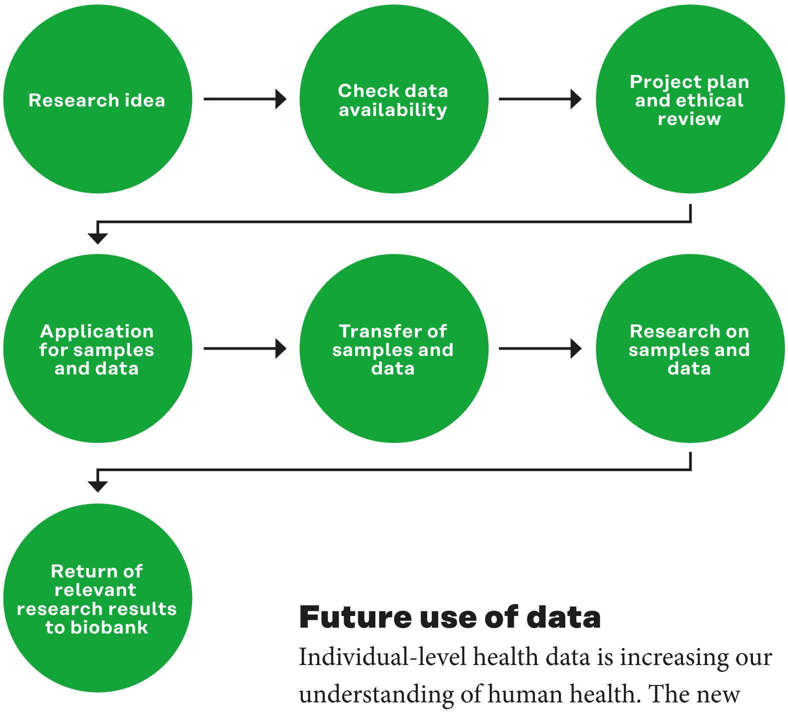


FIGURE 3. FROM **idea to research: how to access samples and related data.**

Future use of data

Individual-level health data is increasing our understanding of human health. The new legislation on personal data files is intended to ensure that the healthcare data stored in national and regional data files can also be used for secondary purposes, i.e. in applications where data is used beyond its primary purpose.

Use of secondary data makes it possible, for example, to compare healthcare providers. Information on the availability of a service (queue and appointment information), quality (e.g. hospital-acquired infections), price and costs of the service providers' activities, compatible with the agreed indicators, will be publicly available (THL 2018).

According to the Finnish eHealth and eSocial Strategy 2020, clinical decision-making support for the needs of healthcare professionals will be implemented as a national solution in the future. This ensures that decision-making is based on comprehensive and up-to-date information obtained from the Kanta service and hospital information systems.

A recent research report by the VTT Technical Research Centre of Finland (2018) recognised the potential of artificial intelligence (AI), specifically in the use of health data for secondary use. AI-based assistants could be used in eHealth services by providing automatic feedback and decision support. Also, AI could help in modelling different care paths in healthcare systems by user group segmentation. By identifying patients who need the most attention, more cost-effective and better timed decisions may be performed.

The Finnish National eHealth and eSocial Strategy 2020 aims to support well-being and service renewal in Finland. It highlights better use of information in research and innovation activities. Data lakes gather the hospitals' structured, semi-structured and unstructured data into one place in their native formats for later use. In high-quality research, data should be complete and accurate. The information should be available for researchers and developers in the easiest possible format. The national Isaacus project suggested centralised services for accessing national health and social welfare data resources (Sitra 2018). This one-stop shop with the new act on the secondary use of health and social data proposed by the government opens up new opportunities for new products and the individual targeting of healthcare services, health technology innovations and business-to-customer services.

4.5 References

BBMRI.fi (2018), *BBMRI Network,* cited 7 October 2018: www.bbmri.fi/.

Information to support well-being and service renewal. eHealth and eSocial Strategy 2020 (2018).

Lähteenmäki J., Ervasti M., Fagerström R., van Gils M., Pajula J., Ruutu S., Sigfrids A., Valovirta V. and Ylén P. (2018), *"Data-driven precision medicine ecosystem – stakeholder needs and opportunities"* (Research Report; No. VTT-R-03318-18), VTT Technical Research Centre of Finland: https://cris.vtt.fi, cited 7 October 2018.

Ministry of Social Affairs and Health, Finland Biobank Act, 688/2012.

Sitra (2018), *"Well-being data"*, cited 7 October 2018: www.sitra.fi/en/topics/well-being-data/.

Soini S. (2013), *"Finland on a road towards a modern legal biobanking infrastructure"*, European Journal of Health Law, 20 June 2013, (3): 289-94.

THL (2018), *"Kansallisen mittariston valmistelu (KUVA-indikaattorit)"*, cited 7 October 201.:

Yhteiskuntatieteellinen tietoarkisto (2016), *"Tietoarkisto palvelee myös terveystieteilijää"*, Tietoarkisto 46(3).

5

TOWARDS THE ERA OF MYHEALTH: CUSTOMER INCLUSION AND CUSTOMER-DRIVEN APPROACHES IN CARE SERVICES

5.1

Inclusion and involvement as a basis for the analysis of social decision-making and the efficacy of services

KIRSTI SANTAMÄKI, SENIOR LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

This article discusses the concepts of inclusion and involvement from a social perspective. The article focuses on the opportunities for older adults to participate in the development of their own services as an example of involvement. In addition, it explores the potential for enhancing inclusion and involvement in society.

Inclusion

Inclusion or social engagement (hereafter inclusion) is one of the core themes discussed in social policy and society. It has an important meaning for the well-being and activity of people. The importance of inclusion has been emphasised, in particular, for those groups in danger of social exclusion and for their role in the development of social and healthcare services. Inclusion and active involvement are especially important for those groups and individuals who have a poorer position in society than the majority or who have otherwise limited means to act and participate in social issues. Activation, involvement and empowerment are examples of ways to enhance citizens' rights and duties as social actors.

According to Raivio and Karjalainen (2013; Figure 1), social inclusion consists of: 1) adequate income and adequate and guaranteed welfare services and security; 2) a fair division of resources and opportunities to act, as well as opportunities for an individual to influence his or her own life; and 3) inclusion, community spirit and integration into society. In other words, inclusion involves both the aim of an action and, at the same time, it is one of the means to reach that aim. To achieve the goal of inclusion, it is necessary to enhance client expertise: the actions and involvement of the client as a developer or, simply, belonging.

Client inclusion can be defined and interpreted in a variety of ways. It is particularly important to make a difference between the concepts of participation and inclusion. Inclusion is a comprehensive concept, which includes participation. In comparison to participation, a prerequisite for inclusion is that the client can affect the service process. In other words, client inclusion means that the client participates actively in the planning and organisation of services, in developing the production of services and/or their evaluation (e.g. Leemann and Hämäläinen 2015). In order to make active inclusion possible, the clients need to be involved; in other words, situations that strengthen inclusion must be arranged in a systematic way. Involvement is also a strategic stand towards developing services and functions for the clients based on their needs and starting points.

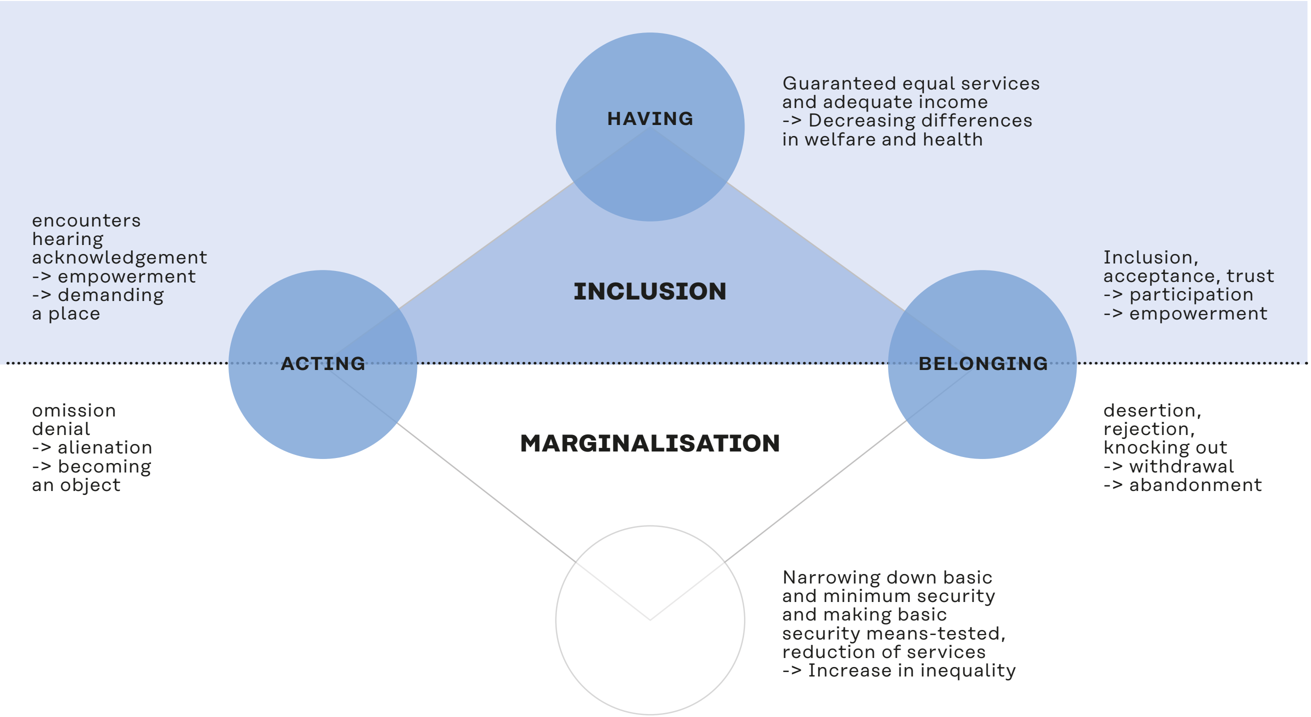
Mere collection of feedback from the clients remains at the level of false inclusion. The basic level of inclusion refers to the active involvement of the client/client groups in the planning of the different stages of the service process. The degree of inclusion and involvement increases when the client is actually participating as an equal and active participant in development with the service providers and those in charge of the services. The highest level of inclusion is represented by a situation where the clients themselves define the frames for services (service client as a decision-maker).

An essential question related to inclusion and involvement addresses the way they are evaluated, and who evaluates them. Does the client evaluate them or those who involve the clients? On the one hand, inclusion can be assessed on the basis of an individual's experience. On the other hand, it can be measured at the organisational level, i.e. how the different functions and services succeed in promoting inclusion (THL 2018). For evaluation to be successful, it is also vital to understand the levels of inclusion, so the real possibilities for inclusion can be evaluated. Assessment is not adequate if the client only has an opportunity to be heard.

Inclusion perspectives in Finnish society

In Finland, the Local Government Act (410/2015, § 22) states that the residents of a local authority area and service users have the right to participate and influence the functions of that local authority area. The

FIGURE 1.
Contents of social inclusion and marginalisation (adapted from Raivio and Karjalainen 2013)



council has to make sure that that there are different ways and opportunities to impact the functions. However, local authorities decide independently how and at what level the inhabitants are involved in the functions of the authority.

The Local Government Act gives a variety of examples on how citizens' participation and exerting influence can be promoted. The local authority can arrange discussions and public hearings as well as panels with local inhabitants to find out their opinions before making decisions. Representatives of service users can be elected onto local bodies and the local council can provide opportunities to participate in the planning of the economy of the local area. Services can be planned and developed in co-operation with the service users, and the residents, societies and other communities can be encouraged to plan and prepare issues unprompted.

The ongoing social welfare and healthcare reform places an emphasis on the active involvement of different actors in the counties. An important part of the reform is a public service promise, a description of those aims and values on the basis of which the county will provide those social and healthcare services it is in charge of arranging. Each county will give a separate service promise to its inhabitants (Sote-uudistus 2018). Counties are also obliged to state whether the services have been implemented as promised. Equal services for people in different age groups and with different needs are developed in multidisciplinary co-operation in the counties. The preparatory groups need to have adequate representation from different groups, and public hearings must be arranged before decisions are made so as to ensure that different perspectives on how to develop services will be taken into account. The results of public hearings must also be taken into consideration to actualise inclusion.

The ideology of involvement focuses on the active involvement of those citizens/groups whose perspectives would otherwise get scant attention. Although Finland is a country with one of the fastest-ageing populations, the active involvement of older adults in decision-making is only fairly recent. From the perspective of targeted services, prevention and health promotion, society cannot afford to leave older adults uninvolved.

Examples of involvement: services for older adults

Strength in Old Age Implementation

Strength in Old Age Implementation (2005-) is a project managed by the Age Institute. Its aim is to promote the ability of people over the age of 75 to cope independently, despite having a reduced capacity to live at home. To reach these targets, older adults get evidence-based counselling in physical exercise and strength and balance training, and outdoor activities are arranged for them. Over 100 local authorities participate in the project and new areas are being sought.

Physical exercise panels have been an important means of involving older adults in planning their own exercise. In these panels, real improvements in the opportunities to exercise have been made by older adults, local council representatives and decision-makers, the local representatives of the Strength in Old Age Implementation project and the mentors of the Age Institute. Open interaction as equal members in the panels is a manifestation of the kind of involvement required by the Local Government Act. It is important that the suggestions for improvements in services are actually implemented and their efficacy is evaluated.

I & O project

The aim of the I & O project (2016-2018) related to the social welfare and healthcare reform is to provide older adults, informal and family carers with more equal, better co-ordinated and cost-efficient services. The underlying practices of the project include increasing the involvement of older adults, making use of the potential of digitisation, managing by knowledge and co-operation of the management staff.

In this project, clients, family members and other stakeholders participate in defining things such as case management and dignified home care (client value) and thereby in the development of the content of home care (service promise). The kind of work that does not provide value for the client is reduced and new ways of work that promote the client's ability to cope with daily life are introduced. It can only be evaluated in the future how active involvement has affected the implementation of services and whether the projects have succeeded in making the services more user-friendly.

Involvement of elderly councils

According to section 27 of the Local Government Act, local councils have to establish elderly councils and make sure they can function so the opportunities for older adults to participate and exert influence are guaranteed. Several local authorities can share an elderly people's council. The elderly people's council must have an opportunity to influence the functions of different municipal bodies, the preparation and follow-up of issues that are important for older adults' well-being, health and inclusion. Other important issues for older adults include the environment, housing, transport and services, and coping with daily activities.

According to a survey of the Ministry of the Environment in Finland (2017) the elderly councils have actively made motions especially on the development of home care, public transport and accessibility. The representatives of the elderly people's councils take part in different working groups and in drawing up strategies. However, so far there have not been very many systematic assessments of the effectiveness of the elderly people's councils in influencing matters.

Prerequisites and necessities of involvement

Planned involvement is needed in the organisations providing welfare services to reach the aims set for the quality and targeting of services in an efficient and economical way. In this way, imbalance between the users and the organisers of services can be reduced (empowerment perspective). As a result, people accept and become committed to the support and service systems of society. Participation in itself has a positive effect and it improves people's self-esteem and civil skills, which in turn makes it easier to decrease the risk for social exclusion.

There is a need for knowledge and competence in analysing the present situation and the future needs, so involvement can be implemented in various and more profound ways. Analysis competence requires an ability to make use of the existing knowledge of service systems, to consider different options and to produce data on the basis of which the clients/client groups can make a real difference.

5.1 References

I & O – kärkihanke. *(I & O project).* Available at: https://stm.fi/hankkeet/koti-ja-omaishoito, *accessed 15 September 2018.*

Kuntalaki 410/2015 *(Local Government Act).* Accessed 18 September 2018.

Leemann I. and Hämäläinen R-M. (2015), *"Asiakasosallisuus. Sosiaalisen osallisuuden edistämisen koordinaatiohanke" (Client Inclusion. Project on Promoting Social Inclusion).* Accessed 18 September 2018.

Ministry of the Environment (2017). *Vanhusneuvostojen rooli ja vaikutusmahdollisuudet ikääntyneiden asumisen ja elinympäristöjen kehittämisessä. Ikääntyneiden asumisen kehittämisohjelman 2013–2017 työpapereita 1/2017*, ympäristöministeriö, 5.4.2017. Accessed 18 September 2018.

National Institute for Health and Welfare (2018), *"Osallisuuden edistäminen"* (Promoting Inclusion). Accessed 1 September 2018.

Raivio H. and Karjalainen J. (2013), *"Osallisuus ei ole keino tai väline, palvelut ovat" (Inclusion is not a means or tool, services are)*, in Era T. (ed.) *Osallisuus -oikeutta vai pakkoa (Inclusion – a right or obligation?).* Jyväskylän ammattikorkeakoulun julkaisuja 156.

Sote-uudistus *(Social Welfare and Healthcare Reform).* Accessed 1 September 2018.

Voimaa Vanhuuteen – Iäkkäiden terveysliikuntaohjelma *(Strength in Old Age Implementation).* Available at: www.voimaavanhuuteen.fi/, accessed 1 September 2018.

5.2

Customer inclusion in healthcare and social services

SEIJA OLLI, PhD, SENIOR LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

This article presents various interpretations and methods of customer inclusion implemented in current healthcare and social services based on literature reviews conducted during the HEAP project. Various aspects and methods and an analysis of how to measure customer inclusion were the main topics in the module “Customer Involvement and Smart Services”.

Introduction

One of the most important aims of the Health Analytics Programme (HEAP) was to deepen healthcare providers’ competence in information technology as a way of increasing customers’ inclusion in the service system. Therefore, it was important to find out what customer inclusion means, and how it has been implemented in social and healthcare services. Another important thing was to find out what kind of development needs have been detected so far, and how these challenges can be overcome in a service system undergoing digitisation.

Several terms are used for service users in social and healthcare services (customer, client, patient, consumer and individual). Other terms include party, agency, stakeholder and citizen. All these concepts open perspectives for customer inclusion. The words consumer and customer are related to the marketing-based perspective in the services, whereas the term patient involves being treated or being ill (Leemann and Hämäläinen 2016).

Inclusion has been described as a phenomenon, a comprehensive concept and a framework. Therefore, it has been defined in a variety of ways. In Finnish discussions about inclusion, references are often made to Raivio and Karjalainen’s (2013) definition of well-being, where inclusion is based on Erik Allartd’s (1976) three dimensions (having, acting, belonging), i.e. an adequate income and well-being, functional capacity and integration into the community. Isola et al. (2017) emphasise action as part of inclusion in addition to the above-mentioned three dimensions. Inclusion involves belonging to an entity, where people have access to a variety of resources, which provide well-being, and to interactive relationships, which increase the meaningfulness of living. Inclusion involves having an opportunity to influence one’s own life, and to make the most of opportunities, services and other common matters. Inclusion is manifested in: 1) inclusion in one’s own life; 2) inclusion in social processes; 3) inclusion in local welfare (Isola et al. 2017; Koivisto et al. 2018).

Inclusion can be divided into knowledge, planning, action and decision inclusion depending on how the individual can participate in the decision-making process (Rouvinen-Wilenius et al. 2011). In social and healthcare services, inclusion means that the customer can participate in decision-making and is able to affect care and service processes in some way. Participation refers to being part of situations defined by others and mainly on their conditions. Involvement means that the customers are involved in different situations in planning, commenting on and influencing things and events, which affect them at different levels from their own care or individual service to the service structure in society (Kettunen and Kivinen 2012; Leemann and Hämäläinen 2016; Isola et al. 2017; Koivisto et al. 2018).

This article defines customer inclusion as the customer's active participation in the planning, production, development and assessment of services. Inclusion involves interaction with professionals in a way that makes it possible for the customer to affect the service process (Kettunen and Kivinen 2012; Linnanmäki 2017). The implementation of customer inclusion in social and healthcare services was considered with the help of a graduated classification with four classes. In this classification, customer inclusion increases gradually from the customer's feedback to the customer's role as a manager of services. First, the customer is an informer, for example by giving feedback. In this case, inclusion is false inclusion, and the customer is only participating. The second class is a basic level of customer inclusion, where the customer is involved as a customer in the service. The third class represents a high level of inclusion where the customer influences, helping to develop services and improve quality, for instance. The fourth class is the highest level of inclusion, where the customer manages and defines the service framework (Leemann and Hämäläinen 2016.) The classification includes knowledge, planning, action, decision-making and evaluation inclusion.

> *Inclusion was implemented by providing the customers with an opportunity to participate in their own treatment.*

To draw up a survey on customer inclusion, publications on social services and healthcare were searched for in the Medic database and by using the search engines of electronic publications. The studies selected for the survey described the implementation of customer inclusion in mental health and substance abuse work and services in the Finnish social and healthcare system from the workers' perspective (Laitila and Pietilä 2012; Perälä 2014) and from the parents' perspective in child healthcare clinics (Mäkinen and Hakulinen 2016). Perälä et al. (2014) describe inclusion in substance abuse services and Rytkönen et al. (2016) adolescents' experiences of basic services. The insight of experts by experience was studied in Hipp et al. (2016) and the experiences of an advisory group of patients on developing the services of an organisation in Lindfors et al. (2017). One of the studies is a quantitative inquiry (Mäkinen and Hakulinen 2016) and four are qualitative interview researches (Hipp et al. 2016; Laitila and Pietilä 2012; Lindfors et al. 2017; Rytkönen et al. 2016) and one a triangular study with a quantitative survey and qualitative interview data (Perälä et al. 2014).

Customer inclusion at different levels

According to Laitila and Pietilä (2012), professionals suggest that currently mental health and substance abuse customers' inclusion is only false inclusion and inadequate. Inclusion was implemented by providing the customers with an opportunity to participate in their own treatment, to participate in available activities or to give feedback to the unit. The workers thought that the customers' participation is important and their opinions should be taken into consideration, in particular when new functions and services are developed. According to Rytkönen et al. (2016), customers' inclusion varies, and they identified four levels of customer inclusion: inviting, enabling, prohibiting and excluding. The level of customer inclusion was affected in particular by the atmosphere, interaction and services (Table 1).

TABLE 1.
The levels of customer inclusion in the basic services in social services and healthcare (Rytkönen et al. 2016)

INVITING	ENABLING	PROHIBITING	EXCLUDING
Caring atmosphere	**Comfortable atmosphere**	**Uncomfortable atmosphere**	**Cold atmosphere**
Confidential Open Warm Safe	Positive Relaxed Welcoming	Awkward Stiff Busy	Oppressive Unprotected Distressing
Encouraging interaction	**Enabling interaction**	**Disregarding interaction**	**Discouraging interaction**
Encouraging Respecting the customer's rights Equal Close	Being heard and understood Ability to affect one's own care	Disregarding the customer Inflexible workers Problem-centred speech	Blaming Doubting Dominating
Meaningful service experience	**The customers believe the service has fulfilled their needs**	**Mechanical service experience**	**The customer feels threatened by the service**
The customer is taken seriously and gets help The customer is encouraged to participate	Reliance in the professional Service offers differ Supports trust in services	Work orientation based on performance produces distrust in the service	Frustrating Feeling betrayed Makes a challenging situation even more challenging

The atmosphere of inviting inclusion is caring, interaction is encouraging and it makes the experience of the service meaningful. A comfortable atmosphere creates inclusion and enables interaction, and the customers feel that the service has fulfilled their needs. Inclusion is prohibited by an uncomfortable atmosphere and interaction that disregards the customers. The service is felt to be mechanical. The level where the customer is excluded is related to a cold atmosphere and discouraging interaction. The service is felt to threatening. (Table 1).

As a result, the feeling of being truly understood is closely connected with the experience of inclusion. According to Mäkinen and Hakulinen (2016), 80% of parents felt that they were equal with the professionals in the discussions. One fifth of the respondents felt that their opinions were not equivalent with the professionals. Another fifth of the respondents felt that they did not get adequate information on relationship issues or on where they can get help. The majority of families had good experiences, and they felt that they were included. In particular, those parents who prepared themselves together for the health check-up in the child healthcare clinic experienced stronger inclusion.

Despite problems, parents who had experienced substance abuse problems felt that they were included, and they were able to cope in everyday activities. According to Perälä et al. (2014), the threshold for asking for help had been very high for many parents. Even when they had asked for help, it was difficult to get it. The professionals' knowledge of substance abuse was not adequate or the professionals had resorted to hard actions and disregarded the parents. It was also hard to get information from service providers.

The workers thought that working as companions with the families worked well, and companionship was connected with the parents' inclusion. Difficult situations arose, when help was provided for the parents and families, and they created challenges for substance abuse units. In most substance abuse units, multidisciplinary teams dealt with the children's and families' problems and the experiences were rather positive. In most cases, common practices were agreed on together with the workers of child protection, other social workers and the school. Expert teams were often used to support co-operation between these different agencies. However, co-operation did not work very well between healthcare services and substance abuse units (Perälä et al. 2014).

Group activities promoting customer inclusion

According to the studies, customer inclusion was considered important. In other words, customers should have the chance to participate in the development of services, practices and quality. The interviewed members of advisory patient groups (Lindfors et al. 2017) and groups of experience experts (Hipp et al. 2016) thought their groups functioned in a good and target-oriented way, and they appreciated being members of the group. Networking inside the group and the chance to influence the services and functions promoted inclusion in both models. Inclusion was enhanced by encouragement and equal co-operation with the professionals, by showing appreciation to the experts and members of patient groups as well as to the members' personal abilities to function. Both groups emphasised good organisation of functions, clear goals and adequate time for meetings.

However, there were also development needs and challenges. If professionals belittle and question patient activities and experience experts, they weaken inclusion. Hospital staff and organisations should be aware of the functions and groups that promote customer inclusion. The groups need feedback on their work and visibility in the organisation. Structural changes should be made, and attitudes should become more positive towards customer inclusion (Hipp et al. 2016; Lindfors et al. 2017).

Core factors of customer inclusion

Significant factors in customers' experiences of customer inclusion consist of being understood and respected. As a result, customer inclusion requires a positive attitude and encountering skills from the workers. The most important skills include consideration of the customer's needs, listening to the customer's experiences, encouragement, care and respect. Investing in inclusion encounters improves the customer's reliance on the service and the experience of being helped (Laitila and Pietilä 2012; Perälä et al. 2014; Rytkönen at al. 2016; Mäkinen and Hakulinen 2016).

As a result, work settings should promote inclusion activities, i.e. a positive atmosphere in encounters, listening and being heard, as well as encouraging interaction (Rytkönen et al. 2016). It is also important to develop the measures and measurement of customer inclusion, so its quality can be improved in digitised social services and healthcare in the future (Mäkinen and Hakulinen 2016).

Discussion

According to the research findings, customer inclusion was mainly implemented as participation in care and services, as receiving information and giving feedback. In other words, customer inclusion was carried out at the first or second level (Leemann and Hämäläinen 2016). There were also problems with getting information and with encounters in these first two, more basic, levels of inclusion (Perälä et al. 2014; Mäkinen and Hakulinen 2016). The third level of customer inclusion is the level, where the customer can participate in planning and in developing quality (Leemann and Hämäläinen 2016), was strived for with the help of experience experts and advisory patient groups. According to the professionals, it is especially important to take the customers' opinions into consideration and involve them when new functions and services are developed (Laitila and Pietilä 2012). However, the results show that this level of inclusion was not reached. Unfortunately, the hospital staff were not always even aware of the groups and their aims and functions. In addition, by questioning and belittling the customers' opinions, patient membership activities and experience expertise, the hospital organisation and its staff weakened inclusion (Hipp et al. 2016; Lindfors et al. 2017).

However, initial results were obtained from inclusion at the third and fourth levels. They are shown in Table 1 in the descriptions of enabling and inviting inclusion by Rytkönen et al. (2016). In situations which enable inclusion the customers are taken into consideration, their experiences are listened to and they are encouraged. The staff show consideration and respect the customer. Investing in inclusive encounters improves the customer's reliance on the service and the experience of being helped.

At times, it is necessary for the professional to shed the role of a professional.

In promoting inclusion, three things need to be developed: individual and co-operation factors, organisational factors and social factors. The results of this survey show that the factors involved in customer inclusion consist of: 1) the functions and resources of organisations; 2) workers' actions and attitudes; 3) customers' motivation and skills; and 4) division of power and dynamics of power.

The results also show that the general opinion of the work community towards inclusion has a significant bearing on how inclusion succeeds in a care unit (Kettunen and Kivinen 2012; Linnanmäki 2017). The staff at all levels of the organisation seem to be sceptical about customer inclusion. If customers only give feedback and participate in care or services, they are not genuinely involved, since they are not part of the planning, evaluation and decision-making processes (Leemann and Hämäläinen 2016).

Customer inclusion requires new competences, attitudes and co-operation from the professionals. At times, it is necessary for the professional to shed the role of a professional. This can open up new insights into how to create common understanding. In fact, customers and patients have a range of experience and competence that the service providers do not have (Kettunen and Kivinen 2012). The promotion of customer inclusion involves new training, management and new kinds of communication, since changes in actions are not self-evident (Linnanmäki 2017). On the other hand, even professionals need to be heard and common discussions are needed. Kettunen and Kivinen (2012) suggest coaching for healthcare units so they can develop new ways of acting, which enable inclusion. Changes in functions mean that the customer's expertise is accepted, and the organisation is arranged in a way that enables and allows inclusion (Leemann and Hämäläinen 2016). Real changes can be made by developing healthcare services together, but experience knowledge has to be accepted by the decision-makers at the organisation and by those who make decisions on service production (Linnanmäki 2017).

Conclusions

Increasing inclusion was highlighted in Sipilä's government programme (2015) and in the aims of the ongoing social welfare and healthcare reform. The aim of the government's project, entitled Customer-Driven Services, is to combine the functions in social services and healthcare into customer-driven entities, with which digital, flexible and bureaucracy-reducing services can be provided and which make the customers more independent. Meeting customers and service users in a digitising environment creates both challenges and possibilities for customer inclusion. Demands are placed in particular on case management, welfare coaching, the user-friendliness of applications and the implementation of the collected data in the patient's care. The aim of the Health Analytics Programme (HEAP) is to meet the training needs resulting from the professionals' competence challenges. In addition to competences in analytics and analysing, training focuses on finding user-friendly services and solutions, which support the customer's inclusion and its implementation.

5.2 References

Allardt E. (1976), *Hyvinvoinnin ulottuvuuksia (Dimensions of Well-Being)* WSOY, Porvoo.

Hallitusohjelma (2015), *Ratkaisujen Suomi (Finland of Solutions; Government Programme 2015),* Hallituksen julkaisusarja, October 2015. Available at: http://valtioneuvosto.fi, accessed 15 Sept 2018).

Hipp K., Kangasniemi M., Vaajoki A. and Kuosmanen L. (2016), *"Kokemusasiantuntijan osallisuus mielenterveyspalvelujen kehittämisessä" (The inclusion of experts by experience in developing mental health services),* Hoitotiede 28 (4); 286-297.

Kettunen T. and Kivinen T. (2012), *"Osallisuus hoitotyön kehittämisen suunnannäyttäjänä" (Inclusion as a Vanguard of Development in Healthcare),* Tutkiva Hoitotyö 10 (4); 40-42.

Koivisto J., Isola A-M and Lyytikäinen M. (2018), *"Osallisuus kuuluu kaikille. Innokylän innovaatiokatsaus" (Inclusion belongs to everybody).* Available at: www.julkari.fi/bitstream/handle/10024/136074/URN_ISBN_978-952-343-077-8.pdf?sequence=1, accessed 15 September 2018.

Laitila M. and Pietilä A-M. (2012), *"Työntekijöiden käsityksiä asiakkaan osallisuudesta mielenterveys- ja päihdetyössä" (Professionals' insights into the customer's inclusion in mental health and substance abuse work),* Tutkiva Hoitotyö 10 (1); 22-31.

Leemann L. and Hämäläinen M-L. (2016), *"Asiakasosallisuus, sosiaalinen osallisuus ja matalan kynnyksen palvelut. Pohdintaa käsitteiden sisällöstä" (Customer inclusion, social inclusion and low-threshold services. Discussion on the content of concepts),* Yhteiskuntapolitiikka 81 (5), 586-594.

Lindfors S., Joronen K., Roine-Mentula K., Koponen R. and Rantanen A. (2017), *"Asiakasjäsenten kokemuksia erikoissairaanhoidon neuvoa antavasta potilasryhmästä" (Customer members' experiences of an advisory patient group in specialist nursing care),* Tutkiva Hoitotyö 15 (2); 14-21.

Linnanmäki E. (2017), *"Asiakkaan ääni kuuluviin sote-palveluissa" (The customer's voice must be heard in social services and healthcare),* Duodecim 133(18);1623-5.

Mäkinen A. and Hakulinen T. (2016), *"Vanhempien osallisuus lastenneuvolan laajassa terveystarkastuksessa" (Parents' inclusion in a comprehensive check-up of children in a child healthcare clinic),* Tutkiva Hoitotyö 14 (4); 21-30.

Perälä M-L., Kanste O., Halme N., Pitkänen T., Kuussaari K., Partanen A. and Nykänen S. (2014), *"Vanhempi päihdepalveluissa – tuki, osallisuus ja yhteistoiminta" (The parent in substance abuse services – support, inclusion and co-operation).* Available at: www.julkari.fi/bitstream/handle/10024/116150/URN_ISBN_978-952-302-214-0.pdf?sequence=1&isAllowed=y, accessed 17 September 2018.

Raivio H. and Karjalainen J. (2013), *"Osallisuus ei ole keino tai väline, palvelut ovat! Osallisuuden rakentuminen 2010 –luvun tavoite- ja toimintaohjelmissa", (Inclusion is not a means or tool, services are). In Era T. (ed.) Osallisuus -oikeutta vai pakkoa (Inclusion – a right or obligation?),* Jyväskylän ammattikorkeakoulun julkaisuja 156, 12-34, Jyväskylän ammattikorkeakoulu.

Rouvinen-Wilenius P., Aalto-Kallio M., Koskinen-Ollonqvist P. and Nikula T. (2011), *Osa2. "Osallisuus osana tasa-arvoa" (Inclusion as part of equality).* In Rouvinen-Wilenius P. and Koskinen-Ollonqvist P. (ed.), *"Tasa-arvo ja osallisuus väylä terveyteen. Järjestöt suunnannäyttäjinä" (Equality and Inclusion as Ways to Health. Associations as Vanguards),* Terveyden edistämisen keskus julkaisuja 9/2011 TEKRY Helsinki, pp. 49–66. Available at: www.soste.fi/media/pdf/julkaisut/tasa-arvo_ja_osallisuus_2012.pdf, accessed 17 September 2018.

Rytkönen M., Kaunisto M and Pietilä A-M. (2016), *"Nuorten osallisuuden toteutumisen tasot sosiaali- ja terveydenhuollon peruspalveluissa" (The levels of adolescents' inclusion in the basic services of social and healthcare),* Tutkiva Hoitotyö 14 (4); 31-38.

5.3

Health coaching – challenges to widespread incorporation within healthcare

KYLE MULHOLLAND, RESEARCHER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES

There appears to be a growing burden on the existing healthcare system, with several factors contributing to this global problem. Increased lifespans and the growing number of ageing individuals have seen an associated rise in the number of non-communicable diseases (NCDs), or chronic pathologies. Unfortunately, the existing healthcare system appears to be lacking the necessary resources to combat this growing problem. The limited number of healthcare professionals, combined with this increased patient load, means patients are having less and less contact time with healthcare professionals. This is also an area of considerable concern, as research is increasingly highlighting the benefits of patient education, behavioural change practices and empowerment in managing chronic conditions. These chronic pathology management strategies typically require spending a significant amount of time with patients, to ensure successful translation of knowledge and skills.

Accordingly, the ageing population increasingly stretched resources and associated healthcare costs are a huge concern. To combat this challenge, we need to develop and implement systems that provide alternative treatment options, promote efficiency and reduce costs. The recent emergence of Health Coaching (HC) professionals may help to alleviate this problem. Considering the relative infancy of this new profession, there are a number of challenges to ensuring successful incorporation of HC into the current healthcare system. This paper presents some of these key challenges.

Health coaching

Health coaches are healthcare professionals "trained in behaviour change theory, motivational strategies, and communication techniques, which are used to assist patients to develop intrinsic motivation and obtain skills to create sustainable change for improved health and wellbeing" (Wolever et al. 2013). Their role is to support patients, operating as skilled partners in the management of the patient's healthcare.

Engaging people in keeping themselves well is an essential component of reducing ill health and the demand for health services (more activated patients experience 8-21% lower healthcare costs) (Hibbard and Gilburt 2014). Although research suggests that people want to be more involved in their care, this does not typically happen in practice. There are potentially numerous contributing factors, including reduced time availability of healthcare professionals, low levels of patient activation (25-40% of the population have low levels of activation), lack of patient education, reliance on the healthcare system to manage conditions, etc. HC aims to empower patients, helping them to become experts in their own health. Considering only 3.2% of patients with long-term conditions report involvement in developing their own care and support plan, there is huge potential for HC to foster patient engagement (Mathers and Paynton 2016).

Considering the relative infancy of this new profession, there are a number of challenges to ensuring successful incorporation of HC into the current healthcare system. These challenges are multifactorial, including but not limited to the following:

- roles and responsibilities (of both the HC and patient);
- whether HC should be a stand-alone profession or incorporated into existing healthcare professional duties;
- training requirements;
- mechanisms for the delivery of HC services (face to face, online, group, etc.)
- associated research and ensuring evidence-based practices;
- evaluation of HC outcomes.

Should health coaching be incorporated into existing healthcare professional roles?

Challenges to the widespread adoption of health coaching

Defining roles, responsibilities and intervention characteristics

HC may be delivered by a range of individuals, with provision not limited to healthcare professionals. Individuals who have experienced similar long-term health conditions (and associated HC training) may also be appropriate for the delivery of HC interventions. As such, there currently does not appear to be conclusive evidence to suggest that one type of coach is more effective than others (“Does health coaching work?” 2014).

There are also challenges to identifying the most suitable patient groups for the delivery of HC interventions. To date, the most commonly studied areas relate to: body weight (or BMI), systolic blood pressure (SBP), low-density lipoproteins (LDL), haemoglobin A1C, health risk appraisal (HRA), pain, psychological factors, exercise behaviours and nutrition behaviours (Sforzo et al. 2014). For these most commonly studied areas, HC has typically demonstrated positive outcomes. Overall, it appears that HC may be most effective for people who are highly motivated to change (from the outset) and who have the most severe conditions or unhealthy lifestyles.

Specifically identifying the characteristics of HC interventions represents an additional challenge. Consensus regarding ideal intervention characteristics is lacking, possibly due to the broad nature of HC and its potential areas of application (HC interventions may be applied to numerous potential pathologies, potentially requiring differing approaches). Table 1 identifies some potential delivery characteristics for HC interventions.

Placement of health coaching within the healthcare system

Considering growing challenges, such as reduced availability and contact time (between patients and healthcare professionals), the following question can be raised: Should HC be incorporated into existing healthcare professional roles, or delivered as a stand-alone intervention/profession?

There are numerous potential barriers associated with incorporating HC roles into existing healthcare professional duties. The most apparent relates to the lack of available resources. In addition to time availability, there are potential resource limitations relating to funding and supporting associated training. In addition, the potential shift in healthcare professional roles may not be seen as a priority. Due to the relative infancy of HC, evidence supporting the efficacy of interventions is limited. This can make it difficult to justify the necessity of incorporating HC interventions into existing healthcare methodologies. Additionally, as with any innovation, perceptions (from both a healthcare professional and bureaucratic perspective) may create a fear of change.

Should HC be delivered as part of a separate profession, care should be exercised to ensure any interventions incorporate

TABLE 1.
Potential HC characteristics

Characteristic		**Potential intervention options**
What?	Is HC delivered as a stand-alone intervention or as part of an integrated intervention?	Component of broader intervention Stand-alone intervention
How?	How is the intervention delivered?	In person Online (including smartphone applications) By phone
Duration	Over what period of time is the intervention delivered?	Single session Intensive intervention period (a few days/weeks) Longer periods (over several months, or even years)
Sessions	How many HC sessions are needed?	Single session Several sessions Periodic sessions (no defined amount)
How often?	How often is the intervention delivered?	Daily Weekly Monthly Yearly
Ratio	How many individuals are participating in the intervention?	One-on-one sessions Group setting

communication with the multidisciplinary healthcare team. This is particularly important for more complex, long-term conditions, involving an array of healthcare professionals. Questions also arise regarding how this new profession is placed within the existing system, where funding comes from, who regulates the profession, etc.

Training requirements and ensuring evidence-based practice

With the growing prevalence of HC programmes, it is currently difficult to determine the expertise and quality of coaches. Many studies investigating the efficacy of HC identify a vast range of training lengths and intensities (if at all). Coaching-specific training can range from less than two hours to close to two years, with a median between six and 40 hours (Wolever et al. 2013). Without agreed-upon standards for the training and practice of HC, the public and healthcare professionals are confused about what to expect from coaches and how they complement other professions.

This lack of definition regarding minimum training requirements also creates challenges to interpreting research. To ensure evidence-based practices are employed in the delivery of HC interventions, associated clinical research is necessary. Unfortunately, there appear to be several factors influencing the quality of existing research. As previously identified, difficulties arise when attempting to clearly define what constitutes HC and studies have used this or similar terms to represent widely varying interventions. When interpreting research, it is important to consider the exact HC methods, providers, duration, frequency, etc. Additionally, most studies fail to compare HC with other alternatives; or employ HC as a stand-alone intervention (rather than part of an integrated healthcare strategy). When interpreting research, it is also important to remember that HC is a prime example of an intervention based on human communication and not easily controlled in a laboratory setting. This also creates difficulties when attempting to quantify research outcomes. Many studies are not data-based, however emerging tools such as the Patient Activation Measure (PAM) facilitate the design and evaluation of HC interventions that are valid, reliable and data-based (Hibbard, Stockard, Mahoney and Tusler 2004).

Conclusions

Although research investigating the efficacy of HC interventions should be interpreted with caution, HC appears to have a positive influence on patient outcomes. In particular, HC has demonstrated positive effects for individuals who have long-term, severe conditions or unhealthy lifestyles. Accordingly, HC offers the potential to alleviate some of the healthcare system burden associated with NCDs and an ageing population. Nevertheless, several challenges need to be overcome before there is a widespread incorporation of HC professionals (applying evidence-based intervention strategies) within the existing healthcare system. This paper has highlighted some of these key challenges.

5.3 References

"Does health coaching work? A summary of key themes from a rapid review of empirical evidence" (2014). Retrieved from: https://eoeleadership.hee.nhs.uk/sites/default/files/Does%20health%20coaching%20work%20-%20a%20review%20of%20empirical%20evidence_0.pdf#overlaycontext=Listen_and_read_about_health_coaching.

Hibbard J. and Gilburt H. (2014), *Supporting people to manage their health. An introduction to patient activation, The King's Fund, London.*

Hibbard J. H., Stockard J., Mahoney E. R. and Tusler M. (2004), *"Development of the Patient Activation Measure (PAM): conceptualising and measuring activation in patients and consumers"*, Health services research, 39(4p1), 1005-1026.

Mathers N. and Paynton D. (2016), *"Rhetoric and reality in person-centred care: introducing the House of Care framework"*.

Sforzo G. A., Kaye M. P., Todorova I., Harenberg S., Costello K., Cobus-Kuo L. and Moore, M. (2017), *"Compendium of the Health and Wellness Coaching Literature"*, American Journal of Lifestyle Medicine, 1559827617708562.

Wolever R. Q., Simmons L. A., Sforzo G. A., Dill D., Kaye M., Bechard E. M. and Yang N. (2013), *"A systematic review of the literature on health and wellness coaching: defining a key behavioral intervention in healthcare"*, Global advances in health and medicine, 2(4), 38-57.

5.4

Designing individually tailored health promotion programmes for people with disabilities

KATI KARINHARJU, SENIOR LECTURER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES, PORI, FINLAND

RIIKKA TUPALA, RESEARCHER, SATAKUNTA UNIVERSITY OF APPLIED SCIENCES, PORI, FINLAND

Over one billion people in the world have some form of disability and nearly 200 million of them are experiencing considerable difficulties in their health and functioning (World Health Organization 2011). People with disabilities can gain similar benefits from health promotion programmes as individuals without a disability (Rimmer et al. 2010). However, to be successful, health promotion programmes for people with disabilities need to be individually tailored, taking into consideration the complexity of one's personal disability as well as environmental resources. This article focuses on the client-centred health promotion programme for people with disabilities, using physical activity promotion as an example. Physical inactivity is a global health risk that not only leads to disease and early death, but also imposes a major burden on the economy. In terms of physical activity, adults with disability are not meeting basic physical activity recommendations and in the years ahead, considering the prevalence of disability is on the rise, this inactivity among people with disabilities will be an even greater concern (Rimmer et al. 2010; World Health Organization 2016). Therefore, there is a need for effective physical activity interventions for people with disabilities. In order to promote physical activity among people with disabilities, objective and accessible methods are needed. This paper also presents an example of a novel physical activity monitor that has been purposefully created to measure physical activity for people using wheelchairs.

Health promotion for people with disabilities

Health promotion is the process of enabling people to increase their health and control over their health. The purpose of health promotion is to positively influence individuals' health behaviour, ensuring they are achieving sufficient behaviour for health by adopting new daily activities and maintaining a new healthier lifestyle (Marcus and Forsyth 2009). It has been shown that different sections of the population (whether those classified on the basis of gender, socio-economic status, age or ethnicity) respond differently to the same intervention (Fertman, Allensworth and Auld 2017). Therefore, the better a health promotion programme matches with individual characteristics, the more likely the programme will succeed. However, people with disabilities are a very heterogeneous group and among the individual characteristics, disability and impairment themselves might have broad influences on individuals' capacity to participate and implement the planned health promotion programme. Previous health promotion programmes for people with disabilities have primarily been conducted in fixed facilities, such as hospital-based or outpatient-based facilities (Clanchy, Tweedy and Trost 2016). As an alternative, individually tailored health promotion programmes have been created, where the goal is to work with the individual at their own living community by reorienting their life to promote a healthier lifestyle. The aim of these individually tailored, community-based intervention programmes is to enhance natural support systems within the participant's home and community environment, where the programme needs to be flexible enough to accommodate changes in their life circumstances and routines (Marcus and Forsyth 2009). Individually tailored, community-based programmes are determined to be most cost-effective when compared to structured fixed-facility programs (Clanchy et al. 2016).

Wheeleri enables people using walkers and wheelchairs to monitor the distance and speed they are travelling.

Example of a client-centred health promotion programme

Adapted physical activity promotion intervention has been demonstrated to successfully increase physical activity adoption in adults with brain impairment (Clanchy et al. 2016). This programme combines psychological theories of motivation and behaviour change, and each programme is individually tailored, based on the client's stage of motivational readiness (Prohaska and Di Clemente 1989). The programme aims to help participants create a physically active lifestyle by finding activities in their home and nearby community that are: 1) effective for improving their health; 2) safe, by taking into consideration the client's health condition and functioning; 3) enjoyable, as the activities selected will be the choice of the participant; and 4) sustainable, meaning the programme is utilising client's existing resources (e.g. access, time and money), so that they will be able to maintain the new healthy lifestyle at the conclusion of the intervention.

Using welfare technology in health promotion programmes for people with disabilities

In addition to individually tailored health promotion programmes, the methods and monitors to assess the benefits of the programme also need to be designed from the user perspective. Methods of user-oriented designing, like the Design for Somebody, Design for All and Universal Design frameworks give guidelines to meet the user's needs (Finn and Loane 2016; Aragall, Neumann and Sagramola 2013). Among the field of welfare technology, the devices to promote physical activity and to objectively evaluate physical activity programmes for people with disabilities are limited. There is an abundance of physical activity devices available to the ambulant population (Bravata et al. 2007), but these monitors may not be accessible or accurate measures for people with disabilities (Conger et al. 2015). Especially among people using assistive aids like wheelchairs, the movements for daily mobility are very different to the movements required for locomotion in able-bodied populations.

Satakunta University of Applied Sciences (SAMK) and the electronic company Siru Innovations created a welfare technology device called Wheeleri, that is purposefully designed for customer and research use, to measure physical activity for people using walkers and wheelchairs. Wheeleri enables people using walkers and wheelchairs to monitor the distance and speed they are travelling. In the ambulant population, self-monitoring daily distances with a physical activity monitor has been shown to be an effective method for increasing physical activity. It has also been found that greater wheeled distances by people using wheelchairs improves their wheelchair manoeuvring skills and, in turn, can improve their quality of life. From the customer use point of view, Wheeleri also offers an objective health promotion tool for clinicians and research purposes and it can be used to evaluate the efficacy and health benefits of health promotion programmes.

Conclusion

In conclusion, to be able to create safe, effective, enjoyable and sustainable health promotion programmes for people with disabilities, the intervention needs to be individually tailored and take into consideration not only the characteristics related to disability and impairment, but also the personal and environmental factors (World Health Organization 2018). By creating feasible and accurate technology for people with disabilities, it is possible to evaluate the efficacy of health promotion programmes, while also enabling individuals to use the technology to monitor their behaviour and improve their own health.

5.4 References

Aragall F., Neumann P. and Sagramola S. (2013), *Design for All in progress, from theory to practice,* EuCAN – European Concept for Accessibility Network, c/o Info-Handicap, Luxembourg.

Bravata D. M. et al. (2007), *"Using Pedometers to Increase Physical Activity and Improve Health: A Systematic Review"* JAMA, 2007; 298(19): 2296-304.

Clanchy K. M., Tweedy S. M. and Trost S. G. (2016), *"Evaluation of a Physical Activity Intervention for Adults with Brain Impairment"*, Neurorehabilitation and Neural Repair, 30(9), 854-865. doi:10.1177/1545968316632059.

Conger S. A., Scott S. N., Fitzhugh E. C., Thompson D. L. and Bassett D. R. (2015), *"Validity of Physical Activity Monitors for Estimating Energy Expenditure During Wheelchair Propulsion"*, Journal of Physical Activity & Health, 12(11), 1520-1526. doi:10.1123/jpah.2014-0376.

Fertman C. I., Allensworth D. D. and Auld, M. E. (2017), *"What are health promotion programs?"*, in Fertman C. I. and Allensworth D. D. (eds) (2017), Health promotion programs: from theory to practice, second edition, Society for Public Health Education, San Francisco, 3-27.

Finn E. and Loane J. (2016), *"Approaches to Smart Technology Deployment in Care"*, in Merilampi S. and Sirkka A. (eds) (2016), "Smart eHealth and eCare Technology. What is that? In Introduction to Smart eHealth and eCare Technologies", Chapman and Hall/CRC, 31-61.

Marcus B. H. and Forsyth L. (eds) (2009), *Motivating people to be physically active,* second edition, Human Kinetics, Champaign, IL.

Prochaska J. O. and DiClemente C.C. (2005), *"The transtheoretical approach"*, in Norcross J. C. and Goldfried M. R., Handbook of psychotherapy integration (Oxford series in clinical psychology; second edition), Oxford University Press, Oxford/New York, pp. 147-171.

Rimmer H. J., Chen A. M-D., McCubbin A. J., Drum A. C. and Peterson A. J. (2010), *"Exercise Intervention Research on Persons with Disabilities: What We Know and Where We Need to Go"*, American Journal of Physical Medicine & Rehabilitation, 89(3), 249-263. doi:10.1097/PHM.0b013e3181c9fa9d.

World Health Organization (2011), World report on disability: www.who.int/disabilities/world_report/2011/report.pdf, accessed 5 October 2018.

World Health Organization (2018), *"What is Moderate-intensity and Vigorous-intensity Physical Activity?"*: https://www.who.int/dietphysicalactivity/physical_activity_intensity/en/, accessed 3 October 2018.

Annex 1

THE EVOLUTION OF THE CONTENT OF HEALTH ANALYTICS EDUCATION IN THE HEAP PROJECT

1) The Content of the International HEAP Pilot Programme (2017–2018):

1. **eHealth and telemedicine 10 cr**
    - Digitalisation and Smart Services
    - Health 1.0 → Health 4.0
2. **Decision Support Systems & Tools 10 cr**
    - a. Knowledge basis of Decision Support Systems (DSS) in Healthcare
    - b. Decision Support Technologies in Clinical Decision Support Systems (CDS)
3. **Client Involvement & Smart Services 5 cr**
    - a. Customer Involvement in Healthcare and Social Services
    - b. Self-care Services
    - c. Coaching in health and wellbeing
4. **Service Design & Case Management 5 cr**
    - Introduction to Service Design
    - Methods and Tools to Generate Customer-centred Services
    - Customer-centred Case Management
5. **Piloting Data Analytics in Health Services 20 cr**
    - Implementation of Data Analytics
    - Innovation & Change Management
    - Research in Management & Knowledge Management

2) The Content of the Proposed Specialised Education Programme Generated in the HEAP Project:

MODULE 1. e-Health and digital services in healthcare and social services 10 cr
Smart technologies in healthcare and social services 3 cr
Digital services in healthcare and social services 7 cr

MODULE 2. Alternative studies:

Data Analytics 10 cr	**Smart Customer Coaching and Case Management 10 cr**
PART I Data Analytics and Information Systems in Healthcare and social servicse 5 cr	PART I Customer Involvement and Smart Services 5 cr
PART II Data Analytics and Decision Support Technologies 5 cr	PART II Data Analytics in Designing Customer-centred Services 5 cr

MODULE 3. Implementation of Data Analytics in Healthcare and Social services 10 cr
Applying Data Analytics in Customer-centred Services 10 cr (development project)

SITRA STUDIES 141
Sitra Studies is a publication series which
focuses on the conclusions and outcomes
of Sitra's future-oriented work.

SITRA.FI
Itämerenkatu 11–13
PL 160
00181 Helsinki
P. +358 294 619 991
@SitraFund