

SHARING AND USING HEALTH DATA – THE NORDIC REALITY!

HIMSS Nordic Workshop in Sitges
May 2018



REPORT

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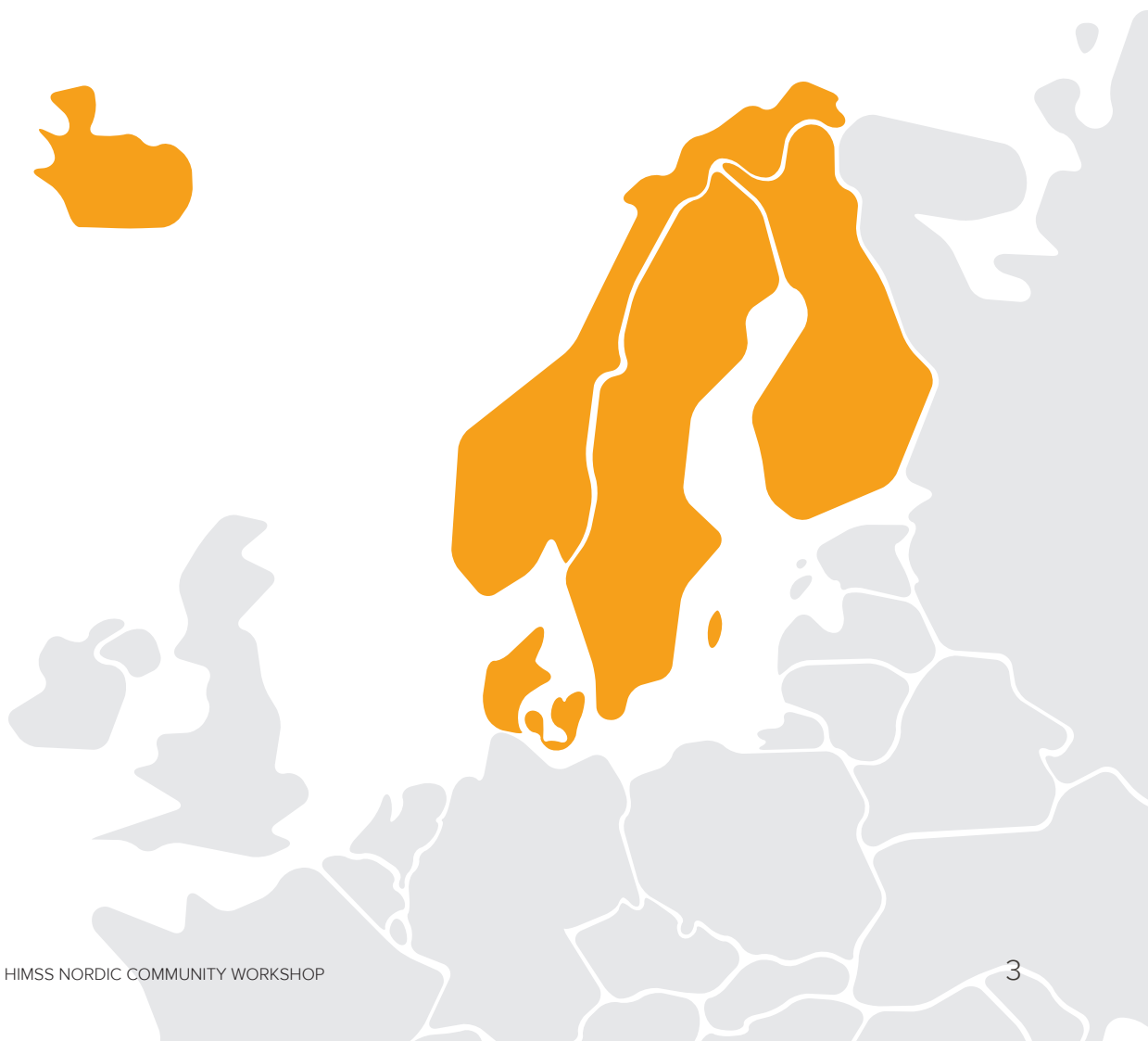


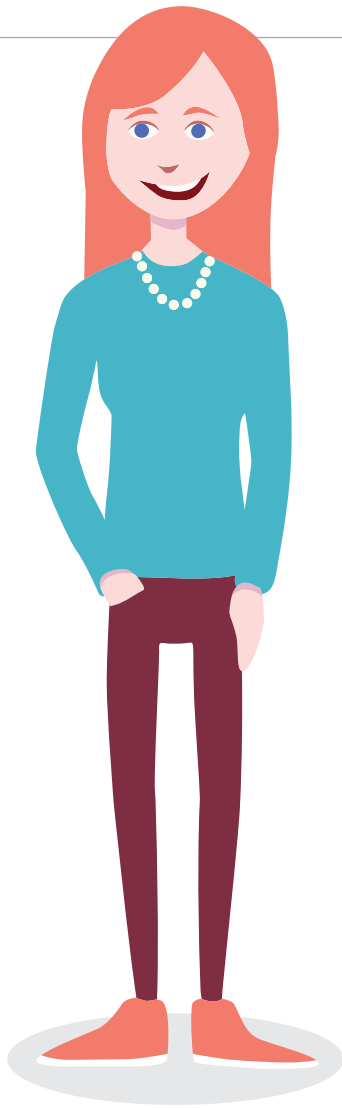
THE WORKSHOP

How do you eat an elephant? One bite at a time. The objective of the HIMSS Nordic Workshop in Sitges (May 2018) was to break down a big challenge into smaller bites. This workshop was a follow-up discussion from the Nordic Delegation panel in Las Vegas earlier in the year, during HIMSS18 (March 2018).

From the panel to the workshop, the expectation of the session was to move the conversation from the stage to roundtable discussions. Smaller groups then discussed the pain points and roadblocks, shared best practices, tackled the 'small bite' challenges together. Recommendations about what can be done next were also made. What are the next steps, how can we make things happen in our countries, what are the needs and how can we can support each other as a HIMSS Nordic Community.

To ensure the patient is always front of mind when discussing the road ahead in digital health, the fictional character, Julie, was used throughout the workshop as a use case for all the topics which were addressed.





About Julie

Julie is a 22 year old student from Odense, Denmark. She also has type 1 diabetes. While she is keen to live a normal student life, her condition needs continuous monitoring and regulation, and she often finds that she is misinformed about it. Julie needs to understand the opportunity of being an empowered patient and would like to access and gain an understanding of the latest diabetes-related technology. How can we help?

How can we support Julie when it comes to the following issues:

- how to use the existing data collected from her and how to connect it to the clinical outcome
- how to use the different data, genomic data, monitored data and other MyData and how to support her as a young patient
- as a Nordic community – how can we make this happen faster – what are the practical ways to make this happen – what are the most important steps to take – where we need the forums to cooperate

Objectives and desired outcomes

- Making the most of a very interactive session to explore all the stakeholders' perspectives, including decision-makers, experts, care providers – all represented around the same table
- Better understanding the rules of engagement – spoken or unspoken – when working with healthcare systems and implementing something new
- Identifying and working on the challenges, ideas and opportunities. How to genuinely transform a discussion into real implementation
- Providing guidelines and next steps for future collaborations between Nordic actors



ROUNDTABLE 1: Standards and Interoperability

Facilitator: Malin Helldin, Accenture

Case Julie:

Picture Julie travelling through the Nordic region. How can interoperability and joint standards make her life easier? Is there a vision around how we can support her with her interoperable data, enabling her to get easier and better service from the health system? Should the data move or should she carry everything on her USB stick?



NOTES

1. Identified Pain Point:

- Which standards should be used?
- The need to standardise legislation across borders
 - Who can access what information?
- Other standards than just clinical information needed:
 - Logs
 - Patient ID's
 - Language
- Who is accountable for Julie and the data and at what time?

2. Existing best practices

- Devices like implants, that store the information and can be connected to different systems. Note: the data stored is still just a small part of the data needed in a patient setting.

3. Future success scenarios

- We need common use cases
- What data should we start with?
- Vision: Semantic interoperability
- How can we enable physicians to use the data in further treatments, without the need of human interpretation which could possibly result in modification of the data.
- Julie will probably move across borders several times more in the upcoming years.
- Patient engagement
 - Politicians listening to real people

- Until we arrive at the vision of semantic interoperability, patients can play an important role in exchanging information manually.

4. Cooperation/Partnership opportunities

- We need a three fold cooperation on every level: the government/ directorate/ health agency level, the clinical level and the patient level

5. Next steps

- There are different work groups on more strategic/government level, but we need the tools to make it happen across all levels, with the help of HIMSS.
- Start by focusing on the big 5 behavior driven diseases: heart disease, stroke, cancer, atherosclerosis and diabetes. These often arise as a by-product of how people live and behave, tobacco use, diet, physical inactivity, and other personal behaviors being identified as the leading causes of death in the modern age.

6. HIMSS19, Orlando deliverables

- Less focus on pain points, which took up most of our time this time, and more focus on how to move forward.
- We agree on the vision, but how do we get there?
- What can be done along the way, step by step, to arrive at the vision?



ROUNDTABLE 2: Security and GDPR

Facilitator: Petter Ostbye, Sectra

Case Julie:

What legislative barriers do we have when Julie's data is moving across the borders? Where does her processed data end up? Can it be sold?



NOTES

The legislative and practical barriers we have when Julie's data is moving across the borders:

1. Who owns the data? Between the Nordic countries there is a variety of models as to who owns the data. Even though the patient is granted the basic ownership of all data, there is a mix of state, regions and private clinics managing the data on behalf of the patient, requiring models for authentication and authorisation that currently don't exist across the Nordic borders.

2. What information is needed and how is it structured? Standard sets of metadata for the different type of patient encounters have not been adopted in all countries, and language and semantics is an issue when interpreting the data that is generated and stored about the patient.

3. The political agenda in the countries must support the goal of creating a framework for sharing patient data across the Nordics.

4. Systems for information exchange needed to access or send the data. Datamodels and interoperability must be put in place. This is proven to be possible across countries: Finland and Estonia are exchanging e-prescriptions.

Based on this and based on the presentations from earlier in the Nordic Workshop, what options do we see?

The workshop agreed that the long-term future scenario is the ideal scenario where all obstacles are removed for the patient to

administrate (or autoshare) easy access to data to the relevant institutions/companies when needed.

The workshop at this table, however, focused on the short-term future scenario. This scenario is more realistic and will require some manual work done to overcome the current obstacles for each sharing of data.

Suggestion for a short-term future scenario:

- Like banks and brokers help us with stocks and shares, we can let brokers help the citizens (us) with the administrating and sharing of health data – across borders and across business. The Finnish concept idea of IHAN can be the basis for registering healthcare data and licensing the use of such data on behalf of the patient (us) for healthcare institutions and companies (healthcare and research).
- The GDPR regulations will help us get to this stage quicker than under the previous conditions. Healthcare providers who are producing data about us during patient encounters, are obliged to share the data with us as EU citizens if we request access to our data. The shared data can then be handed to an IHAN institution with an IHAN broker, who can enable the sharing of Julie's data across borders and across institutions and companies.
- In this way access to data will be based on patient consent with different limitations to the access based on what the patient/citizen is granting access to.
- The information banks that administrates IHAN should be required to have a «fair trade certificate» to ensure that data is being utilized in the patient/citizen's best interest (their own interest preferably).



ROUNDTABLE 3: Evaluating the quality and usage of data

Facilitator: Cathy Fuhrman, Hyland

Case Julie:

Julie is connected to many health system registries, produces her own monitored data and has a large digital footprint. Will this consumer data find a good use so that we can tap into these personal sources to support Julie's life?



NOTES

1. Identified Pain Points

- Each country has different data formats and languages
- Skepticism among the public that data will be appropriated by the private sector
- Treatment plans are locally implemented – not even shared regionally or within a country – let alone across countries
- Different reimbursement methods across countries drive different behaviour
- Culture change is the biggest hurdle

2. Future success scenarios

- Local, National & EU Governance
- Agreement upon direction from Nordic Health partnership

- Address digitisation inefficiencies
- Treatment could be online – teleconsult for mental health
- Ability to get physician referrals across countries
- Online patient journals
- Patient records on their phones so it is portable

3. Cooperation/Partnership opportunities

- EU must direct collaborations and Nordic Council of Ministers must adopt it in order to have the momentum required to change



ROUNDTABLE 4: Continued care data exchange

Facilitator: Harri Tatti, Cerner

Case Julie:

Julie travels across different Nordic countries and healthcare providers: how can we ensure the continuum of care? Do we have data to share about her history when moving between countries? How can we ensure that the data needed for the future “data supported” workflows is available?



NOTES

1. Identified Pain Points

- Lack of legal framework
- Who is controlling the sharing of the data?
- Who is willing to invest?
- What is the actual data set that should be shared?

2. Existing best-practices

- Not many best-practices between Nordic countries
- Estonian example: Finland and Estonia sharing medication information/prescriptions between the countries
- Imaging example in Germany, France, Belgium and Spain where the citizen can download their imaging data from a portal

3. Future success scenarios:

- Use case discovery existing
 - Leveraging the IHAN initiative drive by Sitra
- Create cancer network to share data between different countries

4. Cooperation/Partnership opportunities:

- Technology is rarely the barrier to forging public-private partnerships and apply the technology in practice
- The Nordic region is an excellent test laboratory to pilot use case models across the Nordics and expanding into Europe
- Nordic Council of Ministers should take a joint decision and request funding from the European Union



ROUNDTABLE 5:

Nordic data reality check – Where are we now, what is next?

Facilitator: Jan E Larsson, Cambio

Case

How can we make our “dream” of joint Nordic use of data and health information exchange happen? What is the reality about the interoperability of the Nordic Health Data?

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Making this dream happen is an ambitious project, but there is a Nordic health information exchange infrastructure in place (IHAN) and a Nordic Council of Ministers among which we aim to inspire political commitment in view of the opportunity for a global showcase. We have a coordination committee represented by the four countries and the industry working on identifying participants for the use-case: from the start-up community to providers to key decision makers.

Next

Centered around Julie's story and with the revolutionary IHAN as the back-bone for Health Information Exchange across the Nordic countries, the HIMSS Nordic Community will work on putting together the first Nordic Showcase at the HIMSS19 Global Conference in Orlando, United States. The showcase aims to highlight interoperability* and the value for the patient across the Nordic countries: Norway, Denmark, Finland and Sweden.

*this cross-country interoperability showcase is a demonstration of standards based interoperability. Not all participants need to be connected to another, but would be expected to discuss their work furthering interoperability and demonstrate their part toward achieving it fully. The Use Case is limited to 7-10 participants from both the public and private sector.

What is IHAN®?

(source: www.sitra.fi/en/topics/human-driven-data-economy)

Sitra's IHAN® project aims to build the foundation for a fair and functioning data economy. The main objectives are to create a method for data exchange and to set up European level rules and guidelines for ethical use of data.

The IHAN® system that transcends organisational and national boundaries and is linked by individual data could be adopted across the European Union and, in the longer term, on a global level.

The IHAN® system is built for the use of governments, and for standardising communities, companies and the ecosystems that connect them.

WHAT'S NEXT?

HIMSS19, Orlando

In February 2019, the HIMSS Nordic Community will gather in Orlando, Florida for a very special delegation edition. Not only will the community be featured in the HIMSS Interoperability Showcase pavilion for the first time ever, but the community is celebrating its 10th anniversary. We look forward to continue these discussions and take action in Orlando next year. See you there!

The HIMSS Interoperability Showcase™ is a pavilion on the HIMSS Global Conference exhibit floor that displays, in real time, the exchange and use of data through interoperability profiles and standards with products currently in the marketplace. Our demonstrations highlight the value of connected systems that ensure patients are receiving coordinated care regardless of circumstances. Organizations collaborate on a coordinated use case that demonstrates the standard based information exchange between partners.

Hosting a Nordic Interoperability showcase as part of this, is an unrivalled opportunity to demonstrate the value for the patient when cross-border cooperation and policy alignment in the Nordics is enabling the data (HIE) and health services flow from one Nordic Country to another. It will be the first international showcase featured at a HIMSS Global Conference.



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