

Nordic eHealth Indicators: Organisation of Research, First Results and Plan for the Future

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Abstract

eHealth indicator and benchmarking activities are rapidly increasing nationally and internationally. The work is rarely based on a transparent methodology for indicator definition. This article describes first results of testing an indicator methodology for defining eHealth indicators, which was reported at the Medical Informatics Europe conference in 2012. The core elements of the methodology are illustrated, demonstrating validation of each of them in the context of Nordic eHealth Indicator work. Validation proved the importance of conducting each of the steps of the methodology, with several scientific as well as practical outcomes. The article is based on a report to be published by the Nordic Council of Ministers [4].

Keywords:

Medical Informatics; Benchmarking, Quality Indicators, Health Care; Health Status Indicators; Benefits, Costs.

Introduction

Access to good quality care, equity, and solidarity are values shared across health care systems in Europe. All European Union health systems also aim at ensuring patient-centred healthcare provision, which is responsive to individual needs, while also making the systems financially sustainable. A shift in focus towards preventive measures is expected to reduce the burden of cost, due to avoiding the occurrence of disease and associated treatment costs [4].

To meet these goals and challenges more effectively, eHealth is envisioned as a key enabler. The most common aims for EU eHealth policies are reforming the health care system, improving its performance for more efficiency and quality of care, promoting quality of life and citizen centeredness in care, better data for management of the system and better communication among stakeholders [2].

Diffusion of eHealth rapidly increases the importance of monitoring the progress and impacts of eHealth policy implementations to learn from the initiatives. For this, adequate valid indicators are needed. However, to this date, there are no agreed upon common measures for monitoring eHealth, and a connection between existing measures and policy goals has remained obscure. The situation is similar in the whole European Union area: the eHealth ERA project surveyed the Euro-

pean Union Member States eHealth policies in 2006 (<http://www.ehealth-era.org/>). Only a few had detailed documents outlining concrete eHealth goals or their measures. An update to the report stated that this number had increased by 2011. The scope and procedures used for evaluation were very diverse, and a systematic comparison of approaches, techniques, and tools applied and specific applications or processes evaluated was not possible [3].

The pioneering status of the Nordic countries in eHealth implementations, and the fact that Nordic countries have similar health care systems, facilitate cross-country learning from eHealth implementations. Nordic collaboration in defining eHealth indicators further benefits from the fact that all countries already have national monitoring activities, whereby there is experience and an established network of actors to participate in such collaboration. Nordic countries also all participate in eHealth indicator work in the OECD-context, further increasing the need for internationally comparable data. For these reasons, the Nordic Council of Ministers eHealth group decided to establish a subgroup on eHealth research in the beginning of 2012. The main aim of the official network of research organisations within the Nordic countries was stated in the research network Mandate: "to develop, test and assess a common set of indicators for monitoring eHealth in the Nordic countries and Greenland, Faroe Islands and Aland for use by national and international policy makers and scientific communities to support development of Nordic welfare" [4].

Materials and Methods

A methodology for defining the key eHealth indicators had been presented in the Medical Informatics Europe-conference in Pisa in August 2012 [5]. It was taken as a starting point for the Nordic eHealth Indicator work. The methodology combines the expert-led top-down and community-led bottom-up way to define indicators. The top-down procedure is predominant in indicator work that focuses on defining measures with which to monitor implementation of policies and their impact on society level (e.g., economic growth, main aim also in European level eHealth indicator work). This approach is expert-led and predominantly science-based. Top-down methodology has been used in OECD and EU eHealth indicator work, but without clear connection to different stakeholders and their goals. The bottom-up methodology is used especially in fields

where the aim is to monitor or assess policy or strategy implementation and impacts on a micro level – e.g., in a local environment. In the bottom-up-methodology, indicators are tailored to the needs and resources of the end users or stakeholders, but still remain rooted firmly in the fundamental principles of the policy in question. The top-down and bottom-up indicator frameworks share four common phases, which were taken as the basis of the Nordic eHealth research network work plan:

1. Defining the context (human and environmental) for measurement with two primary components:
 - a) Identifying key stakeholders and
 - b) Defining the area or system that is relevant to the problem being studied.
2. Defining the goals. Top-down approaches rarely include this step formally, as the goals are pre-determined by funding agencies or government offices.
3. Defining methods for indicator selection and categorization. Indicators are often chosen qualitatively, by reviewing expert knowledge, peer-reviewed literature or existing indicator work.
4. Defining the data. This step tests the indicators by applying them. Data are collected, analyzed, reported and feedback is acquired from different user groups [5].

The second phase was tested by analysing the official eHealth policies/strategies issued by the Ministries of Health from the Nordic countries. Policies also defined the stakeholders from the first phase. The latest eHealth policy documents published in English, Swedish or Norwegian were used [6-9]. These documents covered a time span of 4 years between 2007 and 2010. Sentences and sections that contained statements about goals, stakeholders and measures were identified by reading and labelling with an appropriate code tag. As the coding took place, the code book developed. Documents that had been annotated before the code book was fully developed were read and coded a second time. Tagged statements were sorted and counted by use of the reporting functions in the hyperRESEARCH program. The annotations by coder B (with use of the code book developed by coder A) was used to revise the annotations done by coder A.

For the first phase – systems (services) definition – two data sources were used: the key functionalities as defined by OECD [10] for basis of their indicator work, and variables from the Nordic surveys, which national representatives for each country identified as the key surveys monitoring eHealth in their countries [11-16]. This was done to allow direct mapping of systems/functionalities measured by different Nordic eHealth survey variables against the data needs of the OECD. The OECD variables were used to generate a template that was filled in by each of the Nordic survey questions measuring availability and use of same functionalities. Open questions and needs for specification were listed and answers defined in the research network workshops (five workshops during 2012).

For phase 3 in the methodology, the first OECD indicators (availability and use) were selected to test the data collection. This was done to test OECD-defined draft indicators. In addition, eHealth availability and use are indicators, which are currently most comprehensively monitored in the Nordic countries. They also form a logic start in the indicator continuum, preceding measurements of effects on structures, processes and outcomes. For phase 4, data were collected from surveys, complemented from log data, to be analysed and reported.

Results

There were two key outcomes of the work conducted: 1) the strategic building and establishment of the Nordic eHealth research network, and 2) validation of the 4-phase indicator methodology, with Preliminary policy analysis results, and with Indicator analysis results with the first common Nordic eHealth indicators and suggested updates for the OECD indicator definitions.

Validation of the methodology would not have been possible without the strategic building and establishment of the Nordic eHealth Research Network as a subgroup of the Nordic Council of Ministers eHealth group, which consists of eHealth representatives of the Nordic Ministries. Researchers defining the indicators and collecting indicator data and policy makers, who are responsible for defining the national eHealth activities and need information on attainment of the goals set for these activities, worked in close collaboration. It was realized in form of frequent reporting of and comments to the progress, as well as joint meetings - three of the research group's five workshops were organized to coincide with the eHealth group meetings, with partially common agenda. Close collaboration was also established with the OECD eHealth indicator work, with participation of the leader of OECD indicator work to one of the meetings, and participation of members of the research network to the OECD Task forces.

Policy Analysis

The policy analysis was based on a sample of recent eHealth policy documents in the Nordic countries. The analysis revealed that all documents had more similarities than differences. All contained statements about improving quality, effectiveness and patient empowerment in healthcare services, about improving access to relevant health information, information security, privacy and secondary use. Effectiveness statements were most prominent in the Danish document. The Swedish document laid more emphasis on using ICT as a tool to instigate change in healthcare organizations. Improving the support for healthcare processes was most prominent in the Norwegian and Danish eHealth strategies. Sweden and Denmark laid emphasis on improving the usability of the systems, Finland on improving the IT-architecture [4].

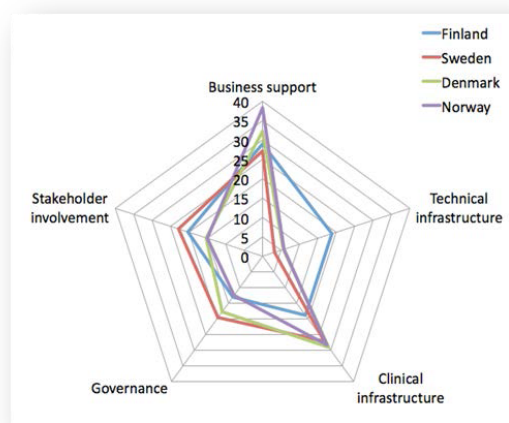


Figure 1- Strategic focus profiles in the eHealth policy documents [4]

All strategy documents described several measures to establish common IT services. Norway and Sweden focused most

commonly on clinicians, while patients were more prominent in the Swedish and Finnish documents. Plans for standardization were most prominent in Finland, Sweden and Norway. Figure 1 depicts variation in targets grouped into five dimensions. Business support relates to targets such as improving interoperability, process support, quality and efficiency. Technical infrastructure relates to the target of improving IT-system architecture. Clinical infrastructure relates to usability of, and access to systems and information, healthcare quality, supporting research and education and improving availability of healthcare data for secondary use. Governance relates to improving efficiency, making data available for leadership and management, information security and privacy. Stakeholder involvement relates to the mentioning of different stakeholders in the strategy documents (e.g. the patient, clinicians, leaders, policy makers, research institutions, IT-architects, Data inspectorate, IT-system vendors etc.) [4].

The Indicator Analysis

The indicator analysis was based on questions in the Nordic eHealth surveys, which were mapped against a list of OECD-compatible EHR, HIE and PHR indicators. Prior to comparing the actual measures of the surveys, the data sources were compared following the OECD definitions [10]. While the data collection is cross-sectional and sample-based, Swedish and Finnish availability surveys are comprehensive. All the surveys are national; the Finnish survey also covers Aaland, and the Danish survey also covers Greenland and Faroe Islands. Sweden and Denmark collect some data yearly; other surveys are conducted less frequently. Finland, Sweden and Norway survey CIO's of the organizations. All countries also survey workers. Worker surveys cover physicians in all countries, and also nurses and medical secretaries in countries other than Finland. Nobody surveys patients. Public sector and doctors' viewpoint are thus well represented in surveys. Finland and Denmark also survey private providers. Sweden and Norway have both electronic and paper surveys, Finland and Denmark only electronic. The response rates vary from 15% to 100% [4].

Table 1 - Availability, use (and usability) of OECD defined EHR, HIE, PHR and Telemedicine functionalities [10]

Indicator grouping	OECD January 2012 functionality description
EHR availability	Entry of core patient data electronically in a structured format -e.g. medication list
EHR availability	Electronic recording and use of detailed clinical care
EHR availability	Electronic provision of real-time information to clinician to optimize the quality of the order, request, or referral -e.g. medication dss
EHR availability	Electronic tracking system ensuring right medication-right patient-right time
EHR availability	Secure asynchronous electronic communication between patients and providers
EHR use	
EHR usability	
HIE availability	Placing of orders/requests/referrals -e.g. medication ordering
HIE use	Electronic receipt of results
PHR availability	Electronic appointment scheduling (patient electronically requests an appointment)
	Patient medication renewal
	Patient supplementation of data -e.g. medication list
	Viewing of own clinical data -e.g. own medication list
PHR use	
Telemedicine availability	% of Communities with Telemedicine Solutions
Telemedicine use	Per Capita Count of Clinical Telemedicine Events
	Per Capita Count of Patients Enrolled in Telehomocare

	(also called home monitoring)
	Per Capita Count of Health Professionals Participating in Distance Education
	Per Capita Count of Health Care Professionals That Use Telemedicine to Provide Care to Patients
Telemedicine benefits	Avoided Patient Travel to Healthcare Appointments/Services

Some of the countries focus on indicators based on eHealth systems, some on key functionalities of these systems. Some of the surveys are based on a practical consensus method to define key indicators; others have used a more theoretically grounded approach for defining the key variables. The background (demographic) data collected varied.

The OECD-defined electronic health record (EHR), health information exchange (HIE), personal health record (PHR) and Telemedicine functionalities for availability and use (Table 1) were used to generate a template in which national representatives filled in variables from national surveys.

The mapping showed that there were several clarifications needed to the functionality descriptions - e.g., “data provision” vs. “generation” vs. “data entry” vs. “ordering” vs. “data viewing”. The functionalities needed to reflect clinician’s data handling tasks of “entering data”, “sending or transmitting data” and “viewing data”. Most of the “entry” functionalities were already saturated in the Nordic countries. “Viewing” functionalities required several specifications to reflect comprehensiveness, completeness and accuracy of the data available to be viewed. It was concluded that without these specifications the indicator data reflecting a particular functionality would not be comparable between countries. Three functionalities were identified (Table 2) for which specifications were made and data collection and reporting were tested.

Table 2 – Nordic definitions to the selected three functionalities

Indicator group	Nordic research network specifications to functionalities
EHR availability	Entry of core patient data electronically in a structured format - e.g. medication list. Suggestion: to separate entry and viewing. Entry saturated. Suggested survey question for viewing (of the medication list): Does your electronic system allow you to perform the following functions electronically: 1) list medications of an individual patient? Yes/No How comprehensive is the list geographically (organizational/regional/national/international) How comprehensive is the list institutionally (public/private/ambulatory/hospital) How accurate is the list (prescribed/dispensed/OTC/taken) How complete is the list (electronic/paper/phone/fax)
HIE availability	Placing of orders/ requests/ referrals – e.g. medication ordering. Suggestion: to separate entry and transmission. Entry (Generating) of orders saturated. Suggested survey question for transmission (of the medication order, i.e. prescription): Does your electronic system allow you to 1) Send a prescription electronically to the pharmacy? Yes/No a) What is the degree of integration? (separate system/ integrated to EHR) b) At which level can it be dispensed? (specific pharmacy/regional pharmacies/nationally/ internationally) c) What codes are used for medication?
PHR availability	Electronic appointment scheduling. Suggested survey question: Is it possible for clients to book appointments electronically with your organization? YES/ NO a) Which options are there for booking? Choose-book (web access)/ accept-book (e.g. SMS access) b) For which services is the booking possible? (Laboratory, dental health, maternity care, imaging...) c) What is the scope of user access? (Local/ regional/ national portal)

Thus, the analysis conducted by the network provided specifications to the OECD draft eHealth indicators and questions/

variables with which to measure them to provide comparable results. Specifications to metadata included fitting the functionality descriptions to the clinical tasks of entering, sending and viewing patient data. Also institutional and geographic levels of comprehensiveness of the data or functionality were specified, as well as completeness and accuracy of the data provided by the functionality. Among other specifications were level of integration of the functionality, security and structuring of the data. Pilot data from existing sources for the three defined functionalities were collected, showing extent of comparability of current data.

Conclusions

The strategic establishment of the Nordic eHealth Research Network and close collaboration between researchers and policy makers proved fruitful for both parties. For researchers, it helped ground the indicator work to practices for which indicators are being developed. For policy makers, it gave insight into indicator work and provided means for establishing attainment of policy implementation for steering of the implementation, as well as means for structured identification of short and long term policy modification needs. Collaboration of the Nordic eHealth research network and OECD eHealth Indicator task forces continues to be essential – it paves the way to inclusion of international variables for national monitoring, which is a cost-effective way to provide data needed internationally as well as for Nordic benchmarking. For national data collection it is essential not to become dependent of surveys that are conducted with different content, definitions, ambitions, goals and clients, which makes them useless for national monitoring of development over the time.

The Indicator Methodology Validation proved extremely fruitful, providing several conclusions. A generic conclusion is that the four steps should be included in all indicator work. Conclusions for validation of different phases of Methodology implementation were:

Phase 1: Defining the systems and functionalities in adequate detail is a prerequisite to providing internationally comparable data. Functionalities need to reflect clinical tasks of data entry, sending and viewing. Defining the stakeholders (done in the policy analysis) is essential; their viewpoint needs to be reflected in the indicator work. At present, data are collected from organisations and doctors relatively comprehensively in the Nordic countries, but not from patients. Existing indicator work does not go into adequate detail in defining either of these contextual elements.

Phase 2: Analysis of existing goals of eHealth policies is essential to ground the indicator work on the activities defined in the eHealth policies. Existing indicator work does not define the goals (or variation in national eHealth policy goals) in adequate detail to define key measures for monitoring them. The documents selected for content analysis represented latest versions of eHealth strategy documents provided by ministries, and represent a snapshot from the time they were published. Each country's eHealth policy document reflects and builds upon achievements from the past, i.e., have a history. The results cannot therefore express the level of evolution of the policies, the current importance of the goals, the level of advancement at each country or the effectiveness of the policies [4], and policy updates should be analyzed to monitor changes in these aspects.

Phase 3: The EFMI and IMIA-defined grouping of eHealth research foci [17] forms a robust conceptual framework for grouping of eHealth indicators. A conceptual analysis should be conducted to map it with other frameworks used in grouping of eHealth indicators, such as e.g. the WHO-ITU National

eHealth Strategy Toolkit. This is a future research challenge proposed for the scientific community

Phase 4: For validity, data comparability is essential, and it can only be achieved if systems and services are defined in detailed enough manner to make comparison possible. For data reliability, each indicator needs to be accompanied with the source. Log data, and to an exceeding degree, timely register data, can provide a reliable alternative to some survey data. For indicators which rely on user experience (e.g., use, usability), users themselves rather than indirect source is preferable.

Future work includes generating and rating a list of common Nordic indicators by defining the key EHR, HIE and PHR functionalities beyond the three presented in this article and indicators associated with them (beyond availability and use), such as productivity and eventually also health outcomes. Feedback from stakeholders for prioritizing them will be collected. Close collaboration in implementing indicators in national monitoring activities is ensured by the fact that the Nordic eHealth research group consists of organisations collecting the national monitoring data. This ensures development of surveys to provide comparable data. Close collaboration with the eHealth policy makers provides a link to exploiting the results also in evidence based eHealth management.

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