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Multinational surveys for monitoring eHealth policy implementations – usefulness and pitfalls

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Abstract. Development of multinational variables for monitoring eHealth policy implementations is a complex task and requires multidisciplinary, knowledge-based international collaboration. Experts in an interdisciplinary workshop identified useful data and pitfalls for comparative variable development. The results are presented and discussed in this paper.

Keywords. Evaluation, implementation, national monitoring, indicators, methodology, eHealth policies.

Introduction

Most Nordic countries have developed policies for eHealth, and conduct regular monitoring activities on eHealth in order to be informed about distribution and usage. However, although healthcare systems and demographics are similar, there is no harmonisation between policy development, monitoring activities, data collection or contents for Nordic benchmarking and learning.

The Nordic eHealth Research Network (NeRN) is aiming at identifying similarities and differences in the Nordic national eHealth policies and surveys. More precisely, the purpose is: “to develop, test and assess a common set of indicators for monitoring eHealth availability, use, and impacts in the Nordic countries and Greenland, Faroe and Åland Islands, for use by national and international policy makers and scientific communities to support development of Nordic welfare” [1]. The network is collaborating with the OECD eHealth indicator work [2].

A robust, transparent indicator methodology to guide the work was developed with inspiration from environmental sciences [3] combining top-down and bottom-up indicator development. The methodology has been described by Hyppönen et.al.[4], and emphasizes involvement of different stakeholders, who will be impacted by the technologies to be implemented. To involve them, several workshops have been arranged. An expert workshop “Towards an International Minimum Dataset for Monitoring National Health Information System Implementations” was organized at

MIE 2011, where different participants provided viewpoints on main categories of data required at different stages of implementation [5]. The results of the workshop were reported as a paper at MIE 2012 [6]. The results were used to generate a long list of indicators, which was completed with results of an analysis of eHealth policies as well as existing measures used in the Nordic countries. These results were again mediated to eHealth experts in a workshop “Aligning National eHealth policy goals with indicators of eHealth policy effects. Challenges and opportunities” that took place in the Medinfo 2013 conference in Copenhagen. The objective of the workshop was twofold: first to introduce the audience to methods for and results of assessing the content of eHealth policy documents and existing measures, and secondly to share experiences when trying to accomplish this in a Nordic context, where monitoring data has previously been collected in different countries mainly with nationally designed surveys targeted to health care professionals and/or CIO’s of organizations.

Moreover, it was considered important to collect feedback and ideas from the audience.

1. Methods

The expert workshop at MedInfo 2013 was organized in three phases: first introductions to the topic and presentation of the experiences and results gained by NeRN, secondly a work group session and thirdly a presentation of the results from the discussions in the groups.

Phase 1, *introductions to the topic*, included a discussion of the current situation with monitoring in the Nordic countries. A faculty of Nordic eHealth researchers introduced the topics: Hannele Hyppönen from Finland presented methodology issues, Arild Faxvaag from Norway presented the eHealth policy analysis, Sabine Koch from Sweden discussed the development of a common set of indicators, Hannele Hyppönen talked about aligning data sets that already have been collected with the OECD model survey and Kristian Skauli from the Norwegian Ministry of Health discussed experiences with, and lessons learned from the interaction between researchers and policy makers in the domain of eHealth.

In phase 2, workshop participants were asked to form two groups, and were given the following questions to consider, first individually and then within the group:

- *What are the pitfalls when trying to develop a multinational survey for monitoring of policy implementations?*
- *How to ensure that the data is useful for policy makers?*

NeRN members moderated the discussions in the groups. The participants were asked to write keywords on post-it-notes. These were handed in to the moderator after the group work session. The duration of the group work was 20 minutes.

In phase 3, the moderators presented the results from the group discussions to all the participants of the workshop. Subsequently, the oral presentations and the post-it notes were transcribed and analyzed.

2. Results

17 international experts participated during the workshop, with an average of 8 in each group. The participants had different professional backgrounds (medicine, nursing, technology, social sciences). The group work produced 25 post-it notes with 63 statements of condensed comments to the two questions.

The following themes were identified as potential pitfalls when trying to develop a multinational survey for monitoring of policy implementations: 1) Stakeholders' interests, 2) Goals and foci over time, 3) Health culture, health system, health demography, and professional healthcare practices, 4) Professional qualifications, competences, and educational systems, 5) Data definition, data selection and data collection, and 6) Concepts, translations of concepts, cultural implications of concepts, wording, clarity and depth of questions, and joint terminology.

The following issues were regarded important to ensure that the data was useful to the policy makers: 1) Process transparency, 2) Research- and experience-based policy development, 3) Provision of data, 4) Collection of future needs of eHealth systems.

3. Discussion

3.1. Pitfalls

When dealing with the first question, the pitfalls when trying to develop a multinational survey for monitoring, the participants emphasized *differences* on various levels.

One of the pitfalls pointed out was that different stakeholders have different interests, which may also vary from country to country depending e.g on the maturity level of the eHealth systems and services. In general, the authorities have political, organizational and economic interests for implementing eHealth systems, healthcare professionals need systems that are usable in the everyday treatment of the patients. Furthermore, IT-developers are interested in the technological aspects of the systems whereas patients want their privacy to be maintained and to receive the best treatment. However, the needs and preferences of the stakeholders are not permanent. Goals and foci may change over time. The challenge for the policy makers is to find compromises between the diverging needs and preferences of the different stakeholders that are applicable over time. The challenge for survey developers is to define relevant indicators based on comprehensive data from all stakeholders.

Another identified pitfall in the development of multinational surveys was that socio-contextual aspects, such as health culture, health system, health demography and professional healthcare practices differ from nation to nation, and from region to region. Differences in the organization of the health provision and services, differences in the prevalence of diseases and differences in the conduct of healthcare (linked to for example availability of medical technology) are complex aspects to identify and compare. Monitoring activities must take into account the complexity embedded in these socio-contextual aspects.

The workshop participants also emphasized the fact that although healthcare professionals across nations may belong to the same professional affiliation does not mean they have corresponding qualifications. Professional competences and professional qualifications are not always equivalent across the nations. This depends on the requirements and the curricula of the educational systems, which, although loyal to the international standards, may not deliver equivalent education. The respondents of surveys may thus not have the same understanding of the problems raised in the questions.

Additionally, linguistic and semantic issues, such as variations in the use of concepts, translations of concepts, cultural implications of concepts, wording, clarity and depth of questions and lack of joint terminology, was discussed by the informants as issues that complicate the development of unified multinational surveys. Clarity of semantics and coherence across the national surveys was considered crucial for obtaining comparable data.

In overcoming the challenges described above, close multinational cooperation and attention must be paid to designing the surveys. Data from the different countries must be coherent and comparable, and this requires that data definition, data selection and data collection is synchronized. Moreover, an identification of the relevant stakeholders, and inclusion of their representatives in the policy and survey development was considered important for the transparency of the process and for the relevance and quality of the monitoring.

3.2. Useful data

Data must be useful to the national as well as international policy makers. The participants in the workshop touched upon the following issues when discussing the second question, how to ensure that the monitoring results are useful: process transparency, research- and experience-based policy development, provision of data, and focus on improvement.

The informants emphasized the importance of transparency in the process around monitoring policy implementations, so that all parties are informed and invited to give input. It was considered important to give the opportunity for asking questions and implementing potential changes. Involvement of the potential users and stakeholders in participating countries was considered imperative in all phases of the multinational indicator definition process. The informants suggested involving policy makers in the data definition and the data collection process to ensure that the information derived was relevant. Moreover, they suggested that interdisciplinary teamwork should be facilitated for in the process. A strong focus should be on the patients. Transparency also calls for public sharing of the methodology and results for continuous commenting.

The informants discussed that a way of ensuring the usefulness of data is providing the data that the policy makers want. One way of ensuring this is to operationalize eHealth policy goals to measurable variables. Another way is to collect different stakeholders' views on best features and development needs. It was also emphasized as important that the researchers and survey makers were included in the policy making process, to ensure that policy development would be knowledge-based. Confronting barriers and benefits from previous eHealth experiences (research and implementations) would inform the monitoring activity, but also help saving time and resources.

The provision of good, relevant data was considered crucial for the usefulness of the monitoring activity. The informants emphasized that log data should be exploited in monitoring activities to a greater extent than it is today. A discussion was raised about the availability of log data in the different countries, an issue that is dependent on political decisions.

4. Conclusion

Stakeholder involvement is an important way to avoid the pitfall of varying interests as well as differences in the way health care is organized. In the National eHealth Strategy Toolkit [7] concerning monitoring and evaluation, WHO supports the significance of stakeholder involvement, and emphasizes the importance of reviewing and confirming outcomes and outputs focus areas with prioritized stakeholders. WHO suggests that this also provides an opportunity to build stakeholders support, gather stakeholders input on indicators that could be used and communicate the expected outcomes relevant to stakeholders. However, the critical point may occur when the stakeholder's interests are conflicting. Which interests will be prioritized and what is at stake for whom? Studies on aspects concerning power relations, roles and rhetoric may contribute to insights about these questions. *Socio-contextual aspects*, such as health culture, health system, health demography, healthcare practices and professional qualifications, must be taken into consideration when developing surveys, since the point of departure in one country may differ significantly from another. WHO [7] suggests defining baseline measures and timeframes in order to identify the developmental steps. The Nordic countries are comparable, but have different organization and frequency of the monitoring activities. Diverging timeframes in monitoring activities influences the comparability of survey data across the Nordic countries. Focus on data provision, exchange and use tasks as guided by the OECD [8] is a way to overcome organizational differences. The monitoring activities, including survey development, should lead to improvement of existing practices, and the policy makers should be given hope of improvements. One way of ensuring improvement is to ask questions so that they suggest improvements. Close attention must be put on linguistic and semantic issues in the surveys, in order for the wording, concepts, terminologies and nomenclature to be accurate and in depth. This requires multidisciplinary research-based knowledge with involvement from relevant stakeholders.

The results from this workshop provide important input about the needs for the Nordic cooperation on strategy development and indicators for monitoring. The results will also be used to inform the OECD eHealth indicator work.

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