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Updated Mapping of Telemedicine Projects in Denmark

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Abstract. Telemedicine is suffering from pilotitis. Only few initiatives manage to scale up to make significant impact. It is challenging to obtain good indicators for dissemination and use, and it is, therefore, difficult to provide evidence that telemedicine projects fulfill the prophecies of reducing cost, improving quality of care and providing equitable access to health care services. The telemedicine mapping project seeks to provide a national contemporary overview of telemedicine initiatives in Denmark. The project is introduced, challenges in keeping the database behind the map updated are presented and attempts to promote rapid update are discussed.

Keywords. Telemedicine, dissemination, benchmarking

1. Introduction

Telemedicine, telehealth, telecare, eHealth and mHealth seem to be used interchangeably in the literature [1]. The technology behind any of these terms has often been referred to as the solution that will reduce the cost of health care, improve quality and provide equitable access to health care services [2]. However, it has proven very difficult to establish evidence that these prophecies really come true. Firstly, the majority of telemedicine projects has not been able to sustain and scale up to a level where real measures could be obtained – something that is often referred to as pilotitis [3]. Secondly, it is difficult to obtain valid and reliable outcome measures. It is relatively simple to count how many systems that exist and where they are implemented, but dissemination and availability quantities do not indicate how much it is in use, by whom, and what the outcome of the use is [4]. A recent review study of methodologies used to evaluate telemedicine service initiatives in hospital facilities identified only 137 telemedicine services and found that either telemedicine service implementation is still not a part of mainstream clinical services, or it is not being reported in the peer-reviewed literature. Furthermore, the study stated that the depth and the quality of information was variable across studies, reducing the generalisability [5]. Other review studies support this conclusion [6,7].

Review studies of telemedicine initiatives resemble cross-sectional studies. Although they cover literature published over a period in retrospect, they rarely have a time dimension in their analysis. Telemedicine is a fast-paced technology-driven area where innovative concepts and new application areas are launched frequently. This calls for a longitudinal monitoring of telemedicine projects on a large scale.

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MedCom has since 2013 mapped telemedicine projects in Denmark in a single database. The objective of the database is to annually collect and publish an overview of the diffusion of telemedicine in health care and provide a status for each project as a first step to systematise the wealth of telemedicine experience. For each telemedicine project, the database contains data in the following categories:

- Master data (title, aim, volume, etc.)
- Involved actors (managers, users, etc.)
- Disease area
- Activities (consultation, diagnostics, screening, monitoring, shared care, etc.)
- Relation to specific trajectory programs
- Applied technologies (hardware, software, specific integration to other systems)

The inclusion criteria of the database has been the WHO definition of telemedicine: “The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities”[8]. The database contains data on 430 projects (2017), which have been collected among telemedicine initiatives in the 5 regions and the 98 municipalities in Denmark.

The use of mapping data and recording of mapping data are linked together. Data must be valid, reliable and updated to be used, and data must be used to motivate people to deliver valid, reliable and updated data. As delivering input to the telemedicine database and keeping it updated has been (and still is) voluntary, a lot of effort has been put into the strategy for collecting valid, reliable and updated data to ensure that the data is actually useful. This paper presents the strategy for collecting valid, reliable and updated data about the telemedicine projects’ status, aim, volume, disease area, who the users are, what, where and why it is used, etc. The update for 2017 is completed and the 2018 update is in progress. The experiences and lessons learned from these updates will be presented and discussed.

2. Methods and material

The experience is that the combination of a working group (WG) and the use of autogenerated emails contribute to the collection of valid and reliable data to the telemedicine database.

Telemedicine initiatives are often local and only known to the health professionals involved in the projects. Therefore, the WG plays a central role in promoting the database, identifying sources and facilitating the data collection. The advantage of the WG is that it comprises local representatives who i) know what is going on in their respective geographical areas, and ii) have connections to those who do. The WG consists of:

- Representatives from the five regions, which represent the Danish hospitals;
- Representatives from municipalities, which represents homecare;
- Data consultants, i.e. consultants who guide Danish GPs in the use of IT.

Once a year, a coordinated effort between MedCom and the WG is made to collect new data and to update existing data in the database. Until 2016, the procedure has been as
follows: An email template was sent to the WG members. They could either adjust the email to their local context and forward it to contacts at hospitals, municipalities etc., who then entered/updated data directly in the database, or the WG member collected data from their contacts and entered it into the database themselves. Hence, the task of collecting and updating data was decentralised as much as possible to ensure identification of all local telemedicine initiatives. Despite the advantages, the procedure was quite extensive and time consuming for the representatives of the WG, since the task included forwarding the message and/or contacting the contact persons for the initiatives, or the individual who originally recorded the initiative in the database. In addition, contacts might have changed jobs and/or job function causing the procedure to be even more time consuming. To overcome these challenges, a package of autogenerated emails was launched in 2017, including an email to a person behind every initiative once a year to remind them of the database and their task of ensuring the validity of the data recorded. The email is, thus, targeted directly to those qualified to update the initiative and outdated contact info is discovered and corrected, all contributing to a less time-consuming collection of valid data. In the autogenerated email the receiver finds a list of all initiatives to which that person is registered as contact or editor. To ease the access, the list contains direct links to the editor site of the specific initiative. In addition, the email contains 1) a description of the objective of the database and the data elements that might have changed, e.g. project finishing date; 2) link to a guide for recording and updating the initiatives; 3) support info, i.e. contact info and links to the representatives in the WG.

The package of autogenerated emails also includes: i) An email sent to the contact person at the time when he or she is recorded as a contact in an initiative. The email contains guidance on how to register as a user of the database, in case he or she is not already registered, and a direct link to the recorded initiative. Hence the contact can react in case of disagreement on recorded data; and ii) an email that is sent to the editors of an initiative, which is close to the recorded finishing date.

Despite the increased focus on the data collection process, including the autogenerated emails, additional fields to be filled in and efforts to increase correct recording of initiatives, the WG undertakes once a year the specific task of cleaning-up, i.e. to identify duplicates and initiatives with missing information.

3. Results

An interactive map (see Figure 1) has been developed to provide a common overview and, thus, create a basis for disseminating knowledge and collaboration across regional boundaries and sectors. The map provides easy access to knowledge about telemedicine experiences within the Danish health sector. Clicking on one of the dots in one of the municipalities will perform a search for telemedicine initiatives in that municipality and display them in a table. Further search criteria can be added to specify the results.

By October 2017, the telemedicine map contains 430 registered initiatives. The 2018 update is in progress. The number of registered initiatives has increased over the years as shown in Table 1.
Table 1. Registered initiatives from 2013 to 2017

<table>
<thead>
<tr>
<th>Year</th>
<th>2013</th>
<th>2014</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>289</td>
<td>345</td>
<td>402</td>
<td>430</td>
<td>Not yet available</td>
</tr>
</tbody>
</table>

It is known that the telemedicine map does not cover the totality of telemedicine initiatives in Denmark. Initiatives may exist in regions and municipalities that have not been registered because of lacking awareness of the existence of the map.

Furthermore, several initiatives are still incomplete, despite an effort to fulfil these initiatives in 2017. This has consequences for data validity.

Figure 1. Screen dump of the interactive map of telemedicine initiatives in Denmark (https://telemedicinsk-landkort.dk).

The distribution of the number of pilot projects and initiatives in operation has shifted over time. Figure 2 shows that the number of initiatives in operation exceeds the number of pilot projects in 2016 and 2017.

Figure 2. Registered initiatives in operation and in pilot project state.

The telemedicine map is intended for decision-makers, project leaders and clinicians. It is available to the public and everyone can set up a telemedicine initiative on the map. It is accomplished by registering as a user.
It is known that decision makers, project leaders, journalists and students are using the telemedicine map, but no data is available on how much it is used by clinicians.

4. Discussion and conclusion

Even though several strategies have been implemented to ensure the collection of valid and updated data, several challenges remain:

Inclusion criteria for initiative recording are not clear-cut. Different standpoints exist to whether initiatives such as video conferencing and use of telephone qualify as telemedicine. The ambiguity arises because activities – at some point – become standard use and might not be considered as telemedicine. Awareness is given to the fact that the question is up for discussion and might be reflected in diverse recording behavior.

Incompleteness of data remains a challenge. Initiatives may exist in regions, municipalities and general practices that have not been recorded due to either unawareness of the existence of the database or lack of motivation to do so, as recording is voluntary. The latter being strongly related to active use of data. Both factors are highlighting the important role of promoting the database and its usability.

Data is not validated or reviewed by MedCom or any other part before publication. The consequence is that incorrect recording of data is not necessarily discovered and corrected, challenging data validity. However, validation procedures are time-consuming and risk becoming a bottleneck. When an initiative is recorded, an email is sent to the contact of the initiative. This contact person is not necessarily the same as the one who recorded the initiative, and in such a case, it is possible that the contact person reacts to errors or misinformation, which will improve the validity of the data.

To monitor the use of the telemedicine database, Google Analytics tracking has been set up. At this moment, only limited use data has been generated but it will onwards be used to evaluate the use of the telemedicine database in terms of e.g. website traffic. However, even though data can be used to understand several perspectives of telemedicine initiatives, Google Analytics will not reveal how data are used. The telemedicine database contains several structured fields and can provide information about e.g. the distribution of the initiatives according to their status (pilot project, being disseminated, in operation, terminated), in which health care sector the initiatives are “located”, number of cross-sectoral initiatives, which technologies are used etc., and – if downloaded once a year – comparison over time. This information is valuable for researchers, decision makers, policy makers, and the central administration. All initiatives have a contact person who can provide further information about the initiative by email or phone, and some initiatives link to evaluation reports, enabling knowledge sharing.

Pilotitis is hard to overcome, and the database itself will not achieve this. However, by visualising how many telemedicine activities are ongoing or have been terminated (and why), the database has the potential to bring projects and people together, minimising the number of actors initiating a similar pilot project and/or not taking advantage of experiences already gained elsewhere. Under the assumption that the data is used actively, it could result in less pilotitis and increased focus on scalable initiatives. This will qualify further research of positive, negative and/or unintended consequences of telemedicine. The above underlines the need for continued focus on the usability of the general data retrieval as well as the data entry processes related to the quality of the telemedicine database.
References