

Collaborative efforts are needed to ensure proper knowledge dissemination of telemedicine projects

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ABSTRACT

INTRODUCTION: Telemedicine is often seen as the solution to the challenge of providing health care for an increasing number of people with chronic conditions. Projects are often organised locally and based on the involvement of stakeholders with a wide range of backgrounds. It can be challenging to ensure that projects are based on previous experience and that they do not repeat previous studies. To better understand these challenges and current practice, we examined telemedicine projects funded in the 2008-2010 period to explore where, how and to what extent results from the projects were documented and disseminated.

MATERIAL AND METHODS: Public and private funds were contacted for information about telemedicine studies focusing on people residing in their homes. After an initial screening of titles and abstracts, 19 projects were identified. The managers of the projects were contacted and information about project results and dissemination were obtained.

RESULTS: More than half of all projects were disseminated to professionals as well as to the public and used two-way communication. However, it was generally difficult to obtain an overview of the projects due to dynamic changes in names and scopes.

CONCLUSION: We propose that the funding authorities require designs comprising proper evaluation models that will subsequently allow the investigators to publish their findings. Furthermore, a dissemination plan comprising both peers and other professions should be made mandatory. The investigators should ensure proper documentation and dissemination of changes both during and after the projects in order to ensure transparency, and national or international organisations should establish a database with relevant data fields.

FUNDING: not relevant.

TRIAL REGISTRATION: not relevant.

Worldwide it is recognised that one of the major challenges in health-care provision is the increasing number of people with chronic conditions combined with a low number of active people in the workforce. If nothing is done to counter this trend, the result will be increasing costs, and chronic conditions will take up a greater share of the available capacity of health professionals [1-3]. One response to this challenge is telemedicine, where it

is anticipated that the development of new methods and technologies that support the treatment of patients from a distance and independently of time will lead to self-directed, self-managing and empowered people which will, in turn, decrease the need of manpower and reduce costs [3-5].

Unfortunately, many telemedicine pilot studies and local projects run for a limited period of time, they only include few patients and are often not well planned with respect to evaluation and documentation. This may result in limited or no knowledge dissemination, which will cause the projects to be repeated rather than becoming part of an incremental development [2]. Although Denmark has strategies and plans for the development and implementation of regional and especially national IT solutions at scale, it is still necessary – due to the nature of the health-care services – to develop and test local add-ons and to evaluate or investigate how the technologies may be implemented for optimal outcomes. This is important to be able to rapidly respond to the user's new needs and requests.

When projects are initiated, they often involve small companies, many entrepreneurs and local administrations, as telehealth and telecare are seen as areas suitable for public/private partnerships that can trigger growth in the health IT industry [6].

It is essential in these partnerships that the innovation and implementation build on the experiences and results of previous projects. Often, these partners do not have the resources or knowledge to make extensive research to identify sources they may learn from. Also, when they conclude the projects, the stakeholders do not necessarily have any incentives to document or report their experiences.

Traditionally, the involved medical doctors will tend to ask for evidence and clinical outcomes, other health professionals will focus on workflows and the ensuing impact on the patient's behaviour, and the involved companies will consider issues such as technology and documentation of quality, safety and privacy issues. The involved stakeholders will often refer to different sources of documentation and have different ways of disseminating their findings, and prior knowledge and evidence may therefore not be taken into consideration when new projects are established.

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 TABLE 1

Number of funds and other sources used to identify telemedicine projects in Denmark 2008-2010. Sources are divided into public and private funds^a, websites and additional resources: vaekstguiden.dk, an overview published by The Danish Society for Clinical Telemedicine [7], and MedCom – the Danish National Health Data Net. For each source, the numbers of included and excluded projects are given.

	Included	Excluded ^b	
		different scope	not coinciding with study time period
<i>Private funds</i>			
The Novo Nordisk Foundation	3	4	
The Obel Family Foundation	1		
The Lundbeck Foundation			
The VELUX FOUNDATION			
TrygFonden Foundation		2	
The Villum Foundation			
The Rockwool Foundation			
<i>Public funds</i>			
The ABT Fund/The Danish Public Welfare Technology Fund	7	21	2
“Kronikerpuljerne”	4		
The Fund for Better Working Environment and Labour Retention		1	
The Business Innovation Fund/The Market Development Fund		5	2
The Danish Council for Technology and Innovation			
The Danish Council for Strategic Research			
“Vaekstfonden”			
The Danish National Advanced Technology Foundation			
<i>Supplementary</i>			
MedCom	1	1	
Vaekstguiden.dk			
Danish Society for Clinical Telemedicine	3	7	3
Total	19	41	7

a) A total of 17 funds were addressed, but 4 of these funds proved to be 2 funds that have changed names over time resulting in a total of 15 fund entries.

b) Projects were excluded either because they were not executed within the study period or because their scope was different to that of the present study, i.e. projects not including patients residing in their home.

To be able to propose new effective ways to disseminate knowledge about results and experiences from Danish telemedicine projects, we have investigated how telemedicine projects are currently documented and disseminated to learn from best practice and to identify any obstacles.

MATERIAL AND METHODS

In this project, telemedicine is defined according to the WHO 1998 [5] as: “Time, place and space-independent digitally supported health services delivered over distance with the potential to create measurable health benefits or value”.

The scope of the study was limited to projects that can be considered a part of a treatment course that takes place in the patient’s own home. Furthermore, the intervention should serve the goal of reducing hospital admissions and readmissions. The 2008-2010 period was selected to optimise the likelihood that the projects would have been completed and evaluated by now.

In the period March-April 2013, 17 funds were identified as possible donors. The administrators of the funds were contacted by email in which we explained the purpose of the study and requested information about any donations. If the fund’s website contained a database of donations, this was used to identify relevant projects. If there was a discrepancy between the results from the data search and the mail correspondence, the fund was approached again to clear up any doubts.

In parallel, we also sought information from additional sources (Table 1) and to ensure that our project list would be as complete as possible, we contacted one of the key persons behind the Danish eHealth Observatory, Professor Christian Nøhr, Aalborg University, Denmark, who could not contribute with additional projects.

In the initial screening, the titles of the projects were used to determine if they were within the scope of this study. If a title was not concise, we read the project description and in a few cases we contacted the principal investigator (PI) to clarify any doubts.

In all, 67 projects were identified. Due to the study criteria, 48 were excluded, which resulted in a total of 19 included projects. The PIs of the 19 projects were contacted to obtain documentation and information about dissemination activities. Nine of the PIs responded with various materials including reports and links, and in a few cases additional information was obtained by email for clarification.

In addition, a thorough internet search was made in the autumn of 2013 to obtain information about the ten projects that did not respond directly, and to ensure that all information from the nine respondents was up to date. Keywords from the title, names of project participants and descriptions were used.

Documentation was grouped as either publications in peer-reviewed journals, reports written by the project group or as third-part reference to the results of the projects, e.g. evaluation reports or in publications referring to unpublished results from the projects. The dissemination activities were grouped into references to the project description on the internet, dissemination of results to peers and dissemination of results to the public; and the last two were further divided into either one-way communication such as websites or interactive communication, e.g. presentations at conferences, workshops or seminars. Results are given as numbers with percentages in brackets.

Trial registration: not relevant.

RESULTS

It was difficult to establish the number and type of projects as several public foundations and government

agencies have changed their names over the years, and also many of the projects have changed their title. Some titles were changed because the projects had received funding from a foundation. Other name changes occurred as a consequence of changes in the project, e.g. when pilot projects or demonstrators were later converted into large-scale studies.

Only ten of the 19 projects (51%) were documented by the investigators either through publication of project data in a peer-reviewed journal, $n = 4$, publication of a written report, $n = 1$ or indirectly in third-part publications, $n = 5$, e.g. in evaluation reports or in publications referring to unpublished results from the projects. The four (21%) projects published in a peer-review journal were all designed as randomised control trials (RCTs), whereas one RCT and the 14 projects designed otherwise, e.g. as feasibility or exploratory projects, were not published in a peer-reviewed journal. Often, these types of projects are conceived as pilots or proofs of concepts preceding larger studies.

Dissemination of the projects – in addition to the information that could be gathered from the research funds' webpages – was accessible on the internet for 18 of the 19 projects. Fourteen (74%) of the projects disseminated results to peers such as health professionals. Twelve (63%) of the projects disseminated results in an interactive form such as workshops, seminars or lectures at national and international events. Six (32%) of the projects also disseminated results to the public through websites and social media, but not in a form that resulted in direct physical interaction.

One excellent model of documentation and communication is the following case. Activities included 117 items related to a PhD project. The PI has presented results both nationally and internationally. Documentation of the results includes abstracts, scientific publications and a PhD thesis, and the results were disseminated by news media such as television, radio and newspapers and interactively at lectures, conferences and workshops.

DISCUSSION

This study was designed to describe how telemedicine projects are documented and disseminated. We aimed to identify all projects from a given period by identifying donations to the projects from private and public funds. During the process, we found that not only can projects be difficult to find, but also that in several cases the public funds that provided their funding have changed their names and organisational affiliation during this rather limited period of less than six years (2008-2013). However, it was possible to create a map of funded projects in collaboration with the funds.

The identified projects varied with respect to documentation. Only a few of the projects were published in



Telemedicine often involves patients residing in their home. Here, a patient in the Epital COPD project monitors himself at home.

peer-reviewed journals and only half of the projects were documented in publications. The lack of publications may be due to the employed project designs, as RCTs would have been easier to publish. However, it may also be due to the project group's lack of experience with the drafting of articles or with lacking organisational incentives to publish. However, if new projects are to be based on previous experiences, it is mandatory that the funds or organisations that finance the projects include criteria regarding proper designs, sufficient resources and academic competencies in order to ensure a valid and proper documentation. This can be done by requiring applications that conform to well-established models such as the West Midland Model [8] or the Model for Assessment of Telemedicine (MAST) [9].

Such requirements may increase the number of published articles in international journals, published reports or monographs. A proper design and sound data handling of both qualitative and quantitative data will also facilitate the dissemination to peers and therefore ensure an impact on future studies. This is in accordance with the West Midland Model for telemedicine projects in which the final step is the preparation of a knowledge sharing plan [2, 8]. As only half of the identified projects actually succeeded in documenting their results in written form, the financing bodies should therefore consider introducing a dissemination plan as a project requirement and possibly even making the full funding dependent on the dissemination activities performed.

However, not all ideas can be aggregated to full projects. Innovation and maturation programs are necessary in the development phase of cases where full research protocols are not feasible. These projects may be designed as proof-of concepts or pilot studies. In the planning phase, it is essential that the project management considers how to document the results. Often this kind of studies can be documented in methodology articles [10] or published as reports with an ISBN no.

The nature of many of the identified projects was almost organic as they included merging and convergence between projects and involved participants, which

resulted in a change of project titles or collaborators. These dynamic changes make it difficult to track progression and achievements over time and to distinguish evolving and changing projects from any new projects that repeat the same ideas. We need to differentiate between these, as it is important to learn from the processes and experiences made by the changing projects during their transitions.

Regardless of whether a project ends abruptly, changes its objective, merges with others or produces outcomes or not, it is essential that the processes and the results are properly documented and disseminated. Therefore, investigators have an obligation to ensure a proper documentation through all steps of their projects from design to evaluation. Currently, this can be done through various websites such as clinicaltrials.gov and institutional sites.

However, although we have these instruments, they do not offer an easy and accessible way to find the projects for those who are planning new projects and are not familiar with the Danish telemedicine environment. This has already been identified as an issue at the national level, and thanks to the new Danish action plan for telemedicine, a registry of all telemedicine projects has been available from the end of 2013 [11, 12]. An esteemed and recognised national database with a minimum of standardised and required information and a possibility of filling in additional optional fields which could be structured according to the seven domains of the MAST [9] covering health, technological, socio-economic and organisational issues and allowing PIs to easily update their project information is a desirable – but currently missing – tool for project planners as well as industrial partners. This registry may be the tool by which proper documentation can be disseminated and may also serve as a supplement to articles published to uncover important data suitable for business cases. Furthermore, the registry may prove instrumental in capturing and making transparent the organic dynamics of the projects.

Based on the observations in this study, we recommended which fields such a database should include and who should fill them in. First of all, the database should be managed cooperatively by funds and projects. The project owners should create a record in the registry when they write a proposal, and if the project achieves funding, the involved funds should ensure that a record exists and they should update any entries with the specific conditions and information relating to their donation, e.g. budget, milestones, evaluation, and plans for documentation and dissemination. Regular updates made by the project owners allowing for progression to be captured in the database can then be ensured through automatic reminders.

The entries added by the project owner should include any registrations of the project, e.g. with clinicaltrials.gov, the National Ethical Committee or the national data agency. When results are obtained, these should be reported by links to reports, articles and other communication channels, and, when relevant, also by adding information about the impact factors of the journals publishing the scientific papers based on the projects' findings.

If the project is reorganised or needs to be concluded earlier than planned, this should be reported in a field with links to associated projects, and a short form should be available to document any experiences and to state the reason for the deviation from the original plans.

These recommendations will ensure transparency and facilitate incremental learning from both concluded and on-going projects for public and private actors in the health-care sector.

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