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Chain of TRUST

Understanding patients' and health professionals' perspective on **Telehealth** and building confidence and acceptance

(Grant Agreement N° 2009 11 13)

Interim Report of Chain of Trust findings

Forewords

Dear Reader,

We are delighted to share with you the most relevant findings of the Chain of Trust project "Understanding patients' and health professionals' perspective on telehealth and building confidence and acceptance".

Chain of Trust is a two-year project that kicked off in January 2011 with the objective of assessing the perspective of the main end users of telehealth services across the EU to see whether and how views have evolved since the initial deployment of telehealth and what barriers there still are to building confidence in and acceptance of this innovative type of services. You can learn more about this project at www.chainoftrust.eu.

This report presents the findings of the activities implemented by the Chain of Trust Consortium, between February 2011 and February 2012. These activities consisted of a Literature Review, an Online Survey, six joint National Workshops, undertaken in order to gather information on the specific views and perceptions on benefits and concerns among patients and health professionals with regard to telehealth services, and four European Focus Groups meant to develop evidence-based policy recommendations to be carried forward at both European and national level.

This is the first public deliverable produced by the Chain of Trust Consortium in order to start disseminating the findings of the project. This document will also serve as a reference for the preparation of six National Roundtables that will be implemented in autumn 2012 in Greece, Latvia, Poland, Portugal, the Netherland, and Norway with a view to raising awareness among national stakeholders on the project findings and policy recommendations and promote the integration of users' perspective into their national telehealth strategies and programmes.

The final results of the project, including the outcomes of the six National Roundtables, will be presented in the final project publication that will be issued in December 2012 and the final project Conference taking place in Brussels, in late January 2013.

With best wishes,

The Chain of Trust Consortium

European Patients' Forum (EPF) – project coordinator, Standing Committee of European Doctors (CPME), European Federation of Nurses Associations (EFN), Pharmaceutical Group of the European Union (PGEU), Norwegian Centre for Integrated Care and Telemedicine (NST), The Latvian Umbrella Body of Disability Organisations (SUSTENTO).

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1. The Chain of Trust project

1.1 Premises of the project: Why Chain of Trust?

Despite wide acknowledgment of the potential benefit of telehealth services, the use of telehealth remains limited and with wide disparities across and within Member States. Different factors contribute to this ranging from the lack of evidence-based information on benefits to lack of legal clarity in areas such as privacy, licensing and liability, from technical issues and lack of support in implementation to market fragmentation. Poor awareness of and confidence from patients and health professionals also need to be added to the list as they continue to pose major barriers to telehealth adoption in Europe.

Although a major pre-condition for large-scale deployment of telehealth, user confidence and acceptance is often side-lined in discussions around telehealth, and more generally eHealth, strategies and policies. Even though all this has started to change as more and more stakeholders are increasingly acknowledging that user acceptance in this area cannot be taken for granted, there remains a lot to be done in order to promote the paradigm shift in the place and role users have in the design and deployment of telehealth services.

The "Chain of Trust" project was launched in order to bridge this gap by assessing the perspective of the main end users of telehealth services across the EU based on the assumption that health services should be patient-centred and enable health professionals to deliver high-quality care. Knowing the needs of end users is therefore crucial.

To this end the Chain of Trust focuses on the perspective of patients, doctors, and nurses, and at a more secondary level on pharmacists, since for these stakeholders telehealth is still at a speculative stage.

Through a sustainable partnership between their leading representative EU umbrella organisations, all target groups identified for this project have the opportunity to voice their views through various activities focused on gathering qualitative information, that reflect the diversity of users and driven by a participatory approach.

Collaborating partners representing leading umbrella organisations of health managers, hospitals, and carers, and an Advisory Board composed of the leading e-Health networks at EU level, will ensure extensive dissemination and outreach to relevant target groups to raise awareness, and create synergies between the project and broader e-Health developments at EU level.

An End User Interest Group composed of individuals from a broad cross section of the patient and health professional community guarantees on an on-going basis feedback on the projects processes and outcomes, thus forming one pillar of the project evaluation. This group also provides an important opportunity to explore how the outcomes of the project are relevant and can be replicated in patient and health professionals' communities that are not directly represented within the project Consortium.

1.2 Objectives and methodology

The paramount objective of the "Chain of Trust" project is to advance the empowerment of patients, and health professionals across the EU in their understanding and effective use of telehealth services in an effort to actively contribute to the vision of high quality, patient-centred, equitable healthcare for all EU patients. Through a series of focused and well defined actions the project will also

significantly strengthen trust and raise awareness among all key stakeholders.

In order to achieve this goal two specific objectives have been defined:

- **Objective 1:** To improve available knowledge of the specific views – needs and perceptions of the added value and concerns - among patients and health professionals with regard to telehealth services.
- **Objective 2:** To increase awareness and understanding of users' perspective on telehealth amongst patients' and health professionals' organisations and health authorities at European and Member State level.

Accordingly, the project has been structured around two main components: a first component dedicated to gathering knowledge on users' perspective on telehealth which is meant to deliver on the first objective, and a second component focused on awareness-raising of such knowledge contributing to the second objective.

At the time of writing, the project has completed all activities relating to the knowledge gathering component, which comprises a mix of quantitative and qualitative methods and approaches to assess the views of patients and health professionals on telehealth. These include: a) a **literature review** on telehealth looking at state-of-the-art knowledge and understanding of users' perspectives and exploring communication approaches and tools used to raise awareness of telehealth; b) an **online survey** conducted with all target groups; c) **six Joint National Workshops** with all target groups aimed at validating and complementing the information collected through two aforementioned activities, and; d) **four European-level Focus Groups** with the four main target groups - patients, doctors, nurses, and pharmacists, designed to develop evidence-based policy recommendations.

These four activities are the main sources that have been used to inform the content of this report. The methodology and main outputs of individual activities are presented in the paragraph 1.3.

In relation to the second component, the project is using a variety of activities to raise awareness of knowledge collected to ultimately build better understanding and trust.

The most important are:

- **Six National Roundtables** will be held in the same countries of the workshops. The audience will be broadened to ensure that all relevant telehealth stakeholders participate. **Press conferences** will be attached to also draw the attention of media on project results and for wide dissemination at national level
- Build synergies with other telehealth events and projects (European and national) by doing **presentations, workshops** and other joint activities making use of dissemination channels of the various Consortium partners
- A **final conference** gathering representatives of the EC, the Council, MEPs, Governmental officials, WHO, OECD, the Assembly of the Regions, representatives of policy units and think thanks
- A **Documentary** presenting the main views of target groups by documenting project events and activities
- **A Final Report** on the findings obtained through these different approaches: the findings will also be peer reviewed and published. The project will formulate recommendations targeted to European Institutions, authorities at MS level, health professionals associations and patient organisations.

1.3 Expected outcomes of the project

Through the survey, national workshops, and European focus groups the project will deliver a unique and unprecedented assessment of the views, needs, benefits and barriers related to telehealth from the perspective of patients and health professionals. The assessment will show differences and similarities between the national and the European context as well as between patients and health professionals already using telehealth services versus those that have not used the services. With regard to patients, the project will also look into socio-demographic data like gender, education, age, economic situation, etc.

Through the national roundtables, the documentary, the final conference, and other activities intended to share the assessment findings and related recommendations the project will increase the knowledge and understanding of the specific perspective of health professionals and patients amongst various stakeholders.

Moreover, the findings and the recommendations will constitute a unique tool to inform policies and decision-making at various levels: in primis the European Commission, Member States health authorities, European Parliament, World Health Organisations, OECD, Council of Europe, regions and their European umbrella organisations, patient organisations, and health professionals' associations.

2. Purpose of this report and methodology used

This document presents an overview of the main findings collected since the project started its work in January 2011 according to following structure:

- Contribution of Chain of Trust towards advancing knowledge of users' perspective on telehealth
- Main benefits of telehealth from a user perspective
- Main barriers of telehealth from a user perspective

Recommendations made during the four European Focus Groups have been linked to relevant project findings throughout the document.

This report will serve as the backbone of the final project publication which is expected to be published in late 2012 to be presented at the project's final conference scheduled to take place in late January 2013.

2.1 Methods used to collect the information presented

At the time of writing the "Chain of Trust" project, has successfully completed the activities planned for the first phase of the project aimed at gathering knowledge on patients' and health professionals' perspective on telehealth.

2.1.1 Baseline assessment: the Literature Review

During the first quarter of 2011 the Chain of Trust consortium conducted a literature review with the objective of understanding patients' and health professionals' views, needs and barriers regarding telehealth as expressed in the scientific and grey literature and gathering information as to communication approaches and tools used to raise awareness of telehealth and communicate it to the end users.

The analysis of the 168 total literature sources investigated provided an overview of the state of the art of knowledge on users' perspectives on telehealth and highlighted a number of under-researched areas and knowledge gaps requiring further investigation.

2.1.2 Moving beyond the state of the art: Online Survey

The results of the literature review set the ground for the design and implementation of an online survey targeting the four user groups identified for this project (patients, doctors, nurses, and pharmacists).

The purpose of the online survey was to collect additional information on patients' and health professionals' perceptions and experience of telehealth in order to validate and complement the findings of the literature review. The online survey was made up of two questionnaires, one for patients and one for health professionals, both users and non-users of telehealth services.

It had been running from early June to late July 2011 and was available in 13 languages – English, French, German, Polish, Norwegian, Latvian, Greek, Portuguese, Dutch, Spanish, Italian, Romanian, and Lithuanian. A total number of 6704 responses were received (1646 from patients and 5058 from the three health professional groups) – which is well above the 4000 responses target the Consortium had set out for this activity at the beginning of the project. The survey gathered responses from across 30 European countries (all EU countries plus Norway, Iceland, and

Lichtenstein).

The data from the online survey was collected and coded for the further analysis. First, an exploratory analysis of data frequencies was made by groups of respondents and all questions as variable. The understanding of the raw data was then captured through the exploration of the demographic data including general frequency tables and cross table analysis. The second phase went beyond frequency and cross tables by performing a cluster analysis. Findings were then compared with evidence from the literature and used to shape the discussions within the six National Workshops and the four European focus groups.

2.1.3 Validating the findings: the Chain of Trust National Workshops

The online survey was followed up by the implementation of six Joint National Workshops organised in six European countries, namely Greece, Latvia, the Netherlands, Norway, Poland, and Portugal.

These workshops were implemented between October and December 2011 with the objective of validating and complementing by means of a qualitative approach the information collected through the previous two activities. Each workshop was delivered as a mix of plenary sessions and parallel focus groups one for each of the main four end-user groups targeted by this project.

Globally, 240 participants attended the Chain of Trust national workshops split up evenly among the four user groups. Although some participants did not have any experience or even knowledge of telehealth, their views were particularly important to consolidating the initial project findings. The diversity of participants enabled the Consortium to capture the diversity of perspectives of all four end-user groups among both users and non-users of telehealth.

2.1.4 Making recommendations: the European Focus Groups

The European focus groups, one with patients, one with doctors, one with nurses, and one with pharmacists, were the last set of activities designed to contribute to the knowledge gathering component of the project.

These focus groups were implemented in Brussels in January-February 2012, with the following two purposes: a) to further complement and validate the information collected through the previous activities, i.e. the literature review, online survey, and national workshops; b) to translate project's findings on users' perspective on telehealth into a set of recommendations to be taken forward in the activities scheduled for the second phase of the project.

Overall 42 participants attended the Chain of Trust European focus groups.

3. The contribution of Chain of Trust to better understanding users' perspective on telehealth

Telehealth refers to the delivery of healthcare across a distance, using information and telecommunications technology and specially adapted equipment. It allows health professionals to diagnose, treat, care, assess and monitor patients without requiring both individuals to be physically in the same location[1].

Telehealth is commonly touted as a means to improve access to high quality of care, while helping contain costs by making healthcare delivery more efficient. Despite all these claimed benefits there is very little knowledge and evidence about how these are perceived by those who are or will ultimately be using telehealth services, i.e. the patients and their informal caregivers as well as the various health professional groups (doctors, nurses, and pharmacists).

So far no assessment of this type has been done at EU level and there is clearly a gap to be filled to ensure that telehealth services effectively meet the needs of their intended users.

Three years ago when we started putting together a proposal for a project focused on exploring the perception of patients and health professionals on telehealth, we identified a number of key user-related questions we wanted our project to answer. These questions were as follows: What do users know about telehealth? Where do they find information? Do they use telehealth services? If yes, what is the benefit and what would they like to improve? If not, what are the barriers? What role does trust play in their using or not using telehealth services?

Surprisingly enough, twenty years after the dawn of telehealth services these apparently straightforward questions were in fact still left pretty much unanswered as it was confirmed by the findings of the literature review we conducted on this topic in early 2011.

At this stage of the project, having implemented already four out of five sets of activities designed to gather information on the issues above, we are already in the position to assess how much progress we have made in answering these questions.

The objective of this chapter is therefore to present the key messages of the Chain of Trust project in relation to each of the questions identified at the beginning of the project. The ensuing chapters will then expand more on the various user-related issues tackled throughout the project.

3.1 Assessing some initial learning

3.1.1 What do users know about telehealth and where do they find information?

One of the most noteworthy findings of this project is that there is still a widespread lack of understanding of telehealth among the user population, especially the patients. Even in countries were eHealth and telehealth are rapidly becoming a reality a lack of awareness of the existence and

[1] Telehealth should not be confused with eHealth, which according to the definition used by the World Health Organisation, refers more generally to the use of electronic communication and information technology in the health sector, with telehealth being a subset of it encompassing the use of ICT in relation to the preventative, promotional and curative processes. Telehealth is in turn an expansion of the term telemedicine, which focuses more narrowly on the curative aspect.

availability of telehealth services has been identified, especially among patients.

In an attempt to identify the causes of this poor understanding, patients who participated in the six joint National Workshops pointed to the lack of targeted user-friendly communication and information on this type of services, especially in terms of benefits these can deliver to people with chronic conditions requiring long-term care. Likewise, although we documented an ever-growing interest in telehealth among the patient population, there is still very little involvement of patient organisations in this area.

Chain of Trust also tells us that health professionals do play a major role in informing patients and citizens at large about telehealth services available and the benefits these can bring to them. One every two patients who declared having some knowledge of telehealth reported he/she had received this information from a health professional. This finding emphasises once more the key role health professional's acceptance will play in the years to come in fostering the wide up-take of these services among patients.

Health professionals are in general more aware of telehealth as well as of how these types of services could eventually improve the way they provide healthcare to their patients. There is, however, a general consensus among the health professional population targeted that advancements in telehealth have largely been driven by technology and manufactures instead of the needs of end users, and this has often resulted in mismatches between the final products/services and the real needs of health professionals, a feeling which patients also share.

Similarly, health professionals believe that there is a need for a more extensive transparent dialogue between all actors, the patients, professionals, informal carers, industry, and policy makers in order to promote a more user-centred approach in telehealth.

On the basis of the foregoing the Chain of Trust Consortium would like to make the following recommendations:

Recommendations

- Awareness campaigns on telehealth benefits should be organised at MS and EU-level targeting both patients and health professionals;
- The adoption of an EU harmonised set of definitions would promote a clear understanding of the various terms used in the field of e-Health such as "telemedicine", "telehealth", "telecare", etc. and their sometimes differing connotations with regard to healthcare delivery;
- Telehealth services must embrace end users' needs. To that end, services must be co-designed with patients and health professionals to take into account their needs, preferences, as well as limitations;
- Health professionals must be supported by the healthcare management to be able to effectively integrate telehealth in their delivery of care on one hand and to properly inform and support their patients on the other, especially in the context of chronic disease management. Integration of telehealth in institutional strategies; organisational changes; provision of technical facilities and education are the necessary preconditions for this.

3.1.2 Do they use telehealth services?

As expected, the large majority of patients and health professionals reached out throughout project's implementation consists of individuals who have either very little experience of telehealth - having taken part to some pilot programmes – or no experience at all with this type of services.

By way of example, only 14% of patients who responded to the survey knew of the existence of

telehealth services in their region. If we look at the share of respondents that had or was still using telehealth services at that time, this figure goes down to only 6%.

A key lesson we learned so far is that both user groups, i.e. patients and health professionals are in general quite willing to use telehealth, but we can say with a high degree of confidence that there will be many more if patients and health professionals were more aware of the opportunities presented by telehealth.

As a general remark, we can therefore argue that there is a lot more to be done in order to better communicate telehealth to the various end user groups. While there are still some barriers to adoption which would require actions be taken at either policy, regulatory, or technical level, many others could be simply overcome through better tailoring information on telehealth to different users through the use of appropriate language and communication channels and explain to them what telehealth actually stands for, what the benefits are, which the risks, and how to avoid them.

The online survey revealed that while 92% of patients are quite keen to play a more active role in managing their own condition - which is a fundamental element inherent in all telehealth services, hence an essential precondition for acceptability of these type of services - only 60% of those who have never used telehealth would be willing to actually do so in the short-medium future. Interestingly, less than 50%, however, thinks they have the necessary skillset required to be able to handle the additional responsibilities arising from the adoption of telehealth.

Turning our attention to health professionals, the Chain of Trust online survey tells us that 70% of health professionals, all three groups considered, who have never used telehealth before would be willing to use it in the short-medium future, but only one every five professionals (i.e. 20%) reported that the management in their workplace actually promotes the use of telehealth. Moreover, only 29% believe that their patients would be in the position to use telehealth services safely.

This of course does not mean that health professionals do not want to involve more the patients in the care process, nor do they think all major responsibilities for the low uptake of telehealth lie with the lack of interest in this type of services on the side of health managers. As confirmed by the European focus groups these figures should be appraised as indicative of some concerns within the health professionals community that telehealth, if not implemented properly and unless coupled with ad-hoc education and training for professionals, health literacy programmes and user support facilities for patients, could become detrimental to patient safety and undermine the trust-based relationship between patients and health professionals. Failing to take measures to ensure health professionals are fully confident in patients' ability to use telehealth safely could ultimately lead to poor acceptability of this type of services, thus lower adoption.

On the other hand, these findings are also quite indicative of the need to generate interest in the opportunities of telehealth among health managers and favouring the dialogue between the latter and health professionals regarding the introduction of telehealth in the workplace.

The Chain of Trust also found out that there is a great interest among both patients and health professionals in being involved in decisions on introducing telehealth as well as in designing, testing and deploying telehealth. User involvement is perceived by both user groups as crucial to ensuring acceptance in the long term and maintaining trust among different end-user groups. We also discovered that patients are becoming more and more willing to play a more empowered role in healthcare. This should ultimately facilitate patient acceptance, since, as well known, patient's active participation in the care process is an increasingly vital feature in telehealth.

It goes without saying that all these elements present a window of opportunity that should be fully exploited by policy makers in shaping eHealth and telehealth policies at all levels, as well as by manufacturers and health organisations when designing and deploying telehealth applications and

services.

Based on these findings, the Chain of Trust Consortium recommends:

Recommendations

- eHealth and telehealth related knowledge and skills should be included as an optional subject in the health professionals curricula and be part of Continuing Professional Development according to the different professional needs;
- Patients must be provided with education and training related to a specific service to empower them with the skillset required by the new ways of communication and interaction arising from the use of telehealth;
- Informal care givers have to be provided to access to training and support systems to be able to uptake the changes in care entailed by the introduction of telehealth;
- Institutions responsible for eHealth and telehealth strategies and action plans should engage end users as well as other stakeholders in an effective and transparent process of dialogue and collaboration throughout the entire cycle from development to implementation of telehealth services.

3.1.3 If yes, what are the benefits and what would they like to improve?

The usefulness and advantages of telehealth are acknowledged by all four groups of end users. Even though, as expected, users tend to have slightly more positive attitudes towards telehealth especially in the way they perceive benefits, there is no large difference in the perception of telehealth between users and non-users, and perhaps even more importantly, between the patients and health professionals as well as between the three health professional groups themselves. There are of course some disparities among user groups in perceiving benefits and risks of telehealth, but these patterns are less marked than we were expecting.

Our literature review told us that health professionals tend in general to have positive perceptions on telehealth in so far as these services enable them to have a more continued therapeutic relationship with patients and increase the quality of healthcare they provide. Despite this, the review remarked that perceived benefits of telehealth for health professionals *vis-à-vis* conventional services tend to be less significant than patients' perceived benefits, for health professionals would benefit far less from patients' reduced travel, easier schedule, and improved quality of life. One interesting study observed in that respect that while patients' lives can change significantly with telehealth, it is possible for health professionals to see only changes in routine[2].

Looking at the results of the online survey and the national workshops we can argue that only to a certain extent does the latter statement hold true for we found out that health professionals, regardless of whether they actually use telehealth, do not seem to be narrowly looking at telehealth just as a process of technology diffusion in healthcare. Instead they regard it as something with the potential to change for the better the delivery of care and enable the active participation of patients in their own care, which is perceived by health professionals as a desirable outcome of telehealth.

Among the major benefits of telehealth acknowledged by all user groups there are:

[2] Whitten P, Love B. Patient and Provider Satisfaction with the Use of Telemedicine: Overview and Rationale for Cautious Enthusiasm. J. Postgrad. Med. 2005;51(4):294-300

- Improving quality of healthcare through more personalised, efficient, patient-centric, and responsive health services
- Improving access to healthcare for patients living in underserved areas, and to a lesser extent, for socio-economically disadvantaged patients
- Fostering patient adherence to treatment and care because of the higher involvement of patients in the disease management process, and hence more awareness of the importance to adhere, as well as thanks to more frequent contacts with health professionals allowed by telehealth
- Helping patients and health professionals stay more regularly in touch, which is a fundamental condition for maintaining trust.

All these issues are further elaborated and discussed in Paragraph 4.4.1 Common benefits to patients and health professionals.

Patients also regard telehealth as a good solution to help them overcome some of the barriers they regularly face when seeking healthcare, especially in scheduling appointments, and travelling to healthcare facilities. For the very same reason there is large consensus among the patients who took part in the Chain of Trust activities that telehealth can lead to economic benefits for them, which can be measured in either less money spent on healthcare, less travel, days off work because of less face-to-face visits, or a combination of the three.

While acknowledging the potential for reducing health inequalities, patients also believe that there is a need to pay thorough attention to current socio-economic, gender, and health literacy inequalities and avoid that only better-off patients may ultimately benefit from the introduction of telehealth services. If we fail to do so they think chances are that existing inequalities would persist or even be exacerbated by large scale introduction of telehealth.

Likewise, patients believe telehealth does have great potential for favouring genuine patient empowerment, through the improvement of their knowledge of the condition and higher participation in the care process. Improved health status and quality of life as well as reduced anxiety because of a feeling of being more in control of the disease and the reassurance to know somebody is regularly keeping a check on him/her are other key benefits patients tend to associate to the use of telehealth.

All these issues are further elaborated and discussed in Paragraph 4.4.2 Benefits to patients.

A major specific benefit for health professionals is the perceived potential of telehealth to improve the cooperation with other colleagues. Because patients are usually in contact with different health professionals working in different settings, the possibility to coordinate this care is a major benefit health professionals expect of telehealth. Coordinating such care is, however, challenging as it takes effort to maintain efficient communication across different health organisations. For the very same reason health professionals are also very concerned that interoperability issues, if not addressed right from the onset, could water down the benefits of telehealth in terms of fostering remote collaboration and health information exchange.

A more detailed presentation of health professionals-specific benefits is provided in Paragraph 4.4.3 Benefits to health professionals.

Our findings suggest that to ensure acceptance and adoption, telehealth needs to be integrated in mainstream healthcare services as a complement and not as a replacement of conventional services. A dramatic reduction in physical meetings is as a matter of fact not an option for the high majority of patients and health professionals. Maintaining a minimum level of face-to-face contacts is crucial to sustaining trust-based relationships between health professionals and patients. Accordingly,

telehealth is perceived by users as largely beneficial when it helps eliminate unnecessary use of conventional healthcare services.

This latter element is indeed at the very core of the Chain of Trust Consortium's main concerns. In that respect the project told us that we are perhaps facing one more communication barrier. There are patients as well as health professionals who perceive telehealth as "the new thing" that would inevitably replace the "old" face-to-face-based way of delivering healthcare. This line of reasoning is obviously misleading since telehealth will never entirely replace face-to-face visits, and shall not be presented as such. Instead we should insist on the value telehealth adds to current healthcare services in so far as it enables more integrated care pathways in which face-to-face contacts between patients and health professionals are complemented by regular remote monitoring and exchange of information.

To foster acceptance it is also very crucial to tailor telehealth to patients' and health professionals' needs and preferences and involve the patients in defining the right mix of face-to-face and telehealth-mediated visits.

Similarly, training is crucial in ensuring health professionals are appropriately equipped to use telehealth and as such, it is a key driver of acceptance. Health professionals who have received ad-hoc training on telehealth generally believe that telehealth services and applications are not difficult to use, while this tends not to be the case for those who did not receive any training. Interestingly, our online survey revealed that only a small group of health professionals was convinced that they had enough education and training in using telehealth services. Among the non-users, a big proportion felt they did not have sufficient training, stressing the importance of integrating telehealth at all levels of education as well as throughout the Continuing Professional Development (CPD). As mentioned elsewhere in this document, this needs to relate to the technology, but also and perhaps more importantly, to the new interaction and ways of communication between patients and professionals arising from the use of telehealth, as well as new roles and responsibilities.

Based on these findings, the consortium recommends:

Recommendations

- To build and maintain trust in teleahealth it is necessary to keep face to face consultations between health professionals and patients and seek agreement in defining the right mix of face-to-face and telehealth-mediated visits;
- An incentive system should be put in place to favour the use and application of services promoting user-centred outcomes. This should apply to different levels: policy-making, eHealth action plans; funding and procurement;
- Member States have to exploit the opportunities offered by telehealth in order to fill the gap between patients and citizens' needs for services and their accessibility and quality;
- The implementation of telehealth should go hand in hand with the set-up of community-based care and support systems for patients and their informal caregivers. This is to ensure a balance between their more active role in self-management and the risk of telehealth adding burden and responsibilities they are not able to take;
- Telehealth must be used to better support, optimise and complement the delivery of healthcare in a more efficient way; facilitating coordination along the healthcare process and between different sectors (social and healthcare) involved and by fostering inter-professional communication and teamwork.

3.1.4 If not, what are the barriers?

The Chain of Trust project found out that there are still some major issues which need to be addressed sooner rather than later in order to foster user acceptance of telehealth, especially among the more sceptic. Patients and health professionals who have never used telehealth services tend to see more barriers to telehealth adoption.

There is sufficient evidence, however, suggesting that many of these barriers are not insurmountable and that progress is being made in overcoming these obstacles. Many of the barriers commonly associated with the usability of telehealth services and applications can be for instance addressed though more effective training, while others, such as the level of privacy and perceived intrusiveness of telehealth in patients' life can be offset if telehealth delivers other benefits.

A clear example of this is provided by an interesting finding of our online survey telling us that almost one every five patients (18%) non-user of telehealth and one every four (24%) among users believes that telehealth involves too much responsibility for the patient. A key lesson learned here is that unless we pay thorough attention to patient needs and health literacy requirements chances are this perceived fear of ending up with too many responsibilities could easily become a major barrier to telehealth adoption.

Another important conclusion that can be drawn on the basis of the evidence gathered is that users, especially patients, are quite keen to accept compromises on what would otherwise be regarded as a barrier to telehealth adoption in exchange of other benefits.

For a patient such benefits could be either improved health or better quality of life, more independence, or even the rewarding feeling of being more involved and in control of his/her care. Perception of such benefits may of course be different from one individual to the other and may be perceived differently even throughout time, requiring, therefore, a careful assessment of individual needs when integrating telehealth into existing chronic disease management programmes.

Turning to health professionals, Chain of Trust shows us that there still are some major barriers to adoption, some of which are country-specific, which need to be addressed through appropriate regulatory action or other measures, and thus more difficult to overcome. Issues like licence - such as whether a health professional is actually entitled to provide healthcare remotely or in a country where they do not have a practicing license - confidentiality of patient data in electronic data exchange, malpractice liability, and reimbursement schemes for telehealth – were mentioned in all six national workshops by the various representatives of the three groups of health professionals.

The issue at stake here is that although telehealth has been growing and expanding especially over the last ten years, the legal and regulatory environment has visibly lagged behind. It is not surprising, therefore, that health professionals singled out legal and ethical issues associated with telehealth as some of the most important issues still hampering its large-scale adoption across European countries and even within individual countries.

By contrast other barriers to adoption, such as resistance to change rather than distress related to the perceived impersonality of telehealth-mediated communication, could be solved if telehealth helps reducing the workload of health professionals, releasing them from administrative tasks to allow them to spend more time focusing on their patients, improve their overall efficiency and boosting their satisfaction.

From a user-point of view technology is not the real issue at stake. While it is true that lack of familiarity with the technology and IT equipment in general, and "technology-related anxiety" can have a significantly negative impact on attitude and intention to use telehealth, especially for the

low IT-literate component of end-users, many technology-related concerns could be resolved through user-friendly services and tools, integration of user requirements, proper support at workplaces, and effective IT and health literacy programmes.

Likewise, fear of possible threats to data confidentiality and integrity due to access of unauthorised people were still mentioned as barriers to telehealth adoption by non-users of telehealth who participated in the national workshops. Surprisingly enough, this contrasted with the findings of our online survey which registered low concerns across all user groups about data confidentiality. By contrast, users of telehealth did not report any major issues with data confidentiality, showing that many concerns relating to security are eliminated with usage as soon as the user is reassured that effective measures to protect confidentiality and integrity are in place.

More important to fostering acceptance is ensuring that telehealth does not affect negatively the patient–health professional relationship, it does not undermine mutual trust, delivers real benefits to users, and ensures at least the same standards of patient safety *vis-à-vis* conventional-only healthcare. All user groups studied by this project do not have a clear opinion as to whether and how telehealth could change communication between patients and health professionals. While there is large consensus on the fact that telehealth could allow more frequent contacts between patients and health professionals, which is perceived as a positive element, there are concerns regarding the impersonality of telehealth-mediated consultations and difficulties in capturing patients' emotional status during such consultations.

Similarly, although we are not in the position to draw any definitive conclusions on whether users find telehealth at least as safe as conventional practice, we can say without a shadow of a doubt that decisions as to whether adopt telehealth will depend to a great extent to the perceived effects of telehealth on patient safety.

All this suggests that it is crucial that we carefully assess the impact of telehealth on patient-health professional communication, and more broadly, on the relationship between the various end user groups. Despite being perceived as somehow "impersonal", telehealth, if implemented properly and seamlessly integrated in mainstream healthcare delivery, should not affect negatively the relationship between patients and healthcare professional. By contrast it has the potential to sustain this relationship by enabling more regular contacts between patients and health professionals.

This brings us back to the issue of training and education for health professionals and patients. Education materials should be developed to support health professionals through the paradigm shifts and cultural changes that are required for integrated care models which needs to include all the skillset required to be able to comfortably communicate remotely, making sure patients, especially the older and ill ones, are fully confident performing all necessary tasks implied by the use of telehealth under the remote supervision of health professionals to ensure the highest standards of safety.

Based on these findings, the CoT Consortiums recommends:

Recommendations

- European and national strategies on eHealth and telehealth must take into account the need to clarify new roles, responsibilities, data protection and security, liability and reimbursement schemes in order to provide a clear framework for a wider implementation of telehealth;
- The EU should favour the creation of synergies between different telehalth and eHealth initiatives to avoid duplication and promote sharing of good practices that proved to be secure, safe and cost-effective while incentivising innovation and competitiveness;
- National strategies on eHealth and telehealth must be long term and not jeopardised by political changes;

- The EU should support Member States in providing the required infrastructure for telehealth by promoting the use of EU funding; particularly the EU Structural and Cohesion Funds.

3.1.5 What role trust plays in their using or not using telehealth services?

There is no doubt that a key pre-condition for adopting telehealth is that both patients and professionals must trust the technology to be safe and effective. Building confidence in telehealth is, however, not just about having trust in the technology itself, but also, and perhaps even more importantly in other users.

Trust has traditionally been considered a foundation of effective health professional–patient relationships. Without trust patients may well not access healthcare services at all, let alone disclose all relevant information which is needed for health professionals to make informed decisions. One of the most noteworthy finding of the Chain of Trust project is that trust does play a key role in shaping patients and health professionals' decisions regarding whether to adopt and use telehealth.

Chain of Trust revealed that too often studies have looked at telehealth as a mere technological innovation in healthcare and have narrowly looked at the relationship between users and technology to identify barriers to acceptance. Elements such as human interaction, changing relationship between patients and health professionals have been largely side-lined, if not entirely neglected, while there is sufficient evidence from this project suggesting that these factors are actually crucial to building confidence and trust.

It could be argued that the shift towards more integrated care with the addition to telehealth as a complement to more conventional services and the changing role of patient from passive receiver to an active user who participates in decision-making is leading to greater inter-dependence between patients and health professionals.

The introduction of telehealth does, therefore, not lessen the need for trust in healthcare, but it actually demands more trust. Telehealth is about delivering healthcare services at a distance. This distance does not diminish the importance of the human dimension, but it actually makes it even more important since the reduction in physical contacts requires greater levels of mutual trust among different users. Patients need to trust health professionals, and at the same time health professionals need to trust and have confidence in their patients' ability to safely use telehealth. Focusing on the changing interaction between different user groups at the two "ending" of telehealth will thus be key in promoting the large uptake of telehealth.

It is not surprising therefore that many patients will only use telehealth if they know already the health professionals that will be involved in the remote monitoring of the patient, suggesting that a previously-established trust-based relationship is a major *conditio sine qua non* behind patient's adoption of telehealth. For the very same reason it is very important, when it comes to benefits for patients, that there is transparency on how telehealth solutions will benefit a patient more than traditional solutions and the balance benefit-risk should also be clear to the patient.

We have learned through this project that patient's decision regarding whether to use telehealth is very often based on information they receive on these services from health professionals. Trusting health professionals is therefore largely conducive to building trust in the telehealth service. On the other hand, effective, safe use of telehealth requires a trust-based partnership between patients and health care professionals, calling upon all of us to pay extra attention to the trust dimension in considerations regarding the introduction of telehealth.

4. Detailed overview of Chain of Trust's findings

This chapter explores in more detail the various findings of the Chain of Trust project. It emphasises the difference between the findings of the literature review carried out at the start of the project and the information collected through the various quantitative and qualitative activities used by the Consortium to gather such information which are described in Paragraph 2.1 Methods used to collect the information presented.

Green boxes are used throughout the chapter to highlight project's key findings.

Areas where definitive conclusions cannot be drawn are emphasised.

4.1 Exploring Chain of Trust's general findings

4.1.1 Perceptions on telehealth are very similar across user groups

Key finding

There are no great differences in the perception of telehealth between users and non-users as well as across different user groups.

An interesting conclusion that can be drawn on the findings of Chain of Trust is that there is no large difference in the perception of benefits and risks of telehealth between users and non-users of telehealth. Likewise, no major differences in terms of perception exist between patients and health professionals as well as across the three health professional groups studied in this project, i.e. doctors, nurses, and pharmacists.

Different perceptions have been found in relation to some of the topics associated to the use of telehealth, in which case these are highlighted in the respective paragraphs, but these patterns are less marked than we were expecting.

Overall users tend to have slightly more positive attitudes towards telehealth especially in the way they perceive benefits. A clear example of this is the different perception of the relationship between the use of telehealth and improvement in patient's health status between patient users and non-users. While only 17% of patients who responded to our survey believe that the use of telehealth would lead to significant health improvement, the number of patient users who actually believe so is between two and three times higher (43%). The same pattern was found among health professionals, although this group of users is overall slightly more positive *vis-à-vis* the link between telehealth and improvement in patient's health status.

4.1.2 Lack of awareness of the existence and availability of telehealth services

Key finding

Despite major development in the telehealth area, awareness of the existence and availability of these types of services is still quite low among the various groups of end users, especially the patients.

Knowledge collected by the Chain of Trust Consortium in the period February 2011 – February 2012 revealed that only a small percentage of patients are actually aware of the existence and/or availability of telehealth services. This could be due to various factors such as the limited deployment of telehealth in many parts of Europe and the lack of appropriate information strategies

on availability of such services.

As far as health professionals are concerned, a larger proportion is aware of telehealth services available. Most health professionals defined themselves as familiar with telehealth stating that their awareness of the services does not necessarily entail previous usage. The services that health professionals use more often are analysis of clinical data, remote monitoring of vital signs, as well as health promotion and educational support. Similarly, the large majority of patients and health professionals involved in the various knowledge-gathering activities consists of individuals who have either very little experience of telehealth - having taken part to some pilot programmes – or no experience at all with this type of services.

The situation described above indicates that additional effort is needed to raise awareness of telehealth services in order to meaningfully engage users and support implementation, especially among the patients. The issue was largely discussed within the six national workshops as well as in the European focus group with patient representatives where patients pointed to the lack of targeted layman-friendly communication and information on this type of services their benefits and potential risks as some of the major outstanding barriers to patients' understanding and involvement in telehealth.

All user groups also emphasised that in order to foster large scale implementation and adoption awareness of benefits of telehealth is crucial not only to patients, but equally importantly for health managers, Chief Medical Officers, Chief Nursing Officers, hospital directors, as well as politicians, as actors who are ultimately in the position to make decisions regarding the implementation of telehealth services.

Recommendations

- In order to steer the general attitude towards telehealth in a more positive direction, the Chain of Trust Consortium recommends the organisation of awareness campaigns on telehealth at EU level targeting patients and health professionals to raise the information they have on the benefits and possibilities offered by telehealth.
- In addition, health professionals must be supported within their workplace to make the best use of telehealth support and to foster their role as key players in disseminating and informing patients and citizens at large about telehealth.

4.1.3 The key role of health professionals in informing the public about telehealth services

Key finding

Health professionals play a key role in informing patients and citizens at large about telehealth as well as about benefits these services can bring to them.

When asked about the source of information about telehealth services, half of the patients who responded to the online survey replied that they had obtained this information from a healthcare professional, while the remaining half declared having received this information from the media (local, press, TV, Internet).

In this sense, health professionals play a central role in informing the patients and more generally the public about telehealth services available. The engagement of health professionals in dissemination of information, especially on potential benefits of telehealth services need to be fully exploited and reinforced.

The lack of information about telehealth services has been identified by the Consortium as one of

the major outstanding barriers preventing larger scale uptake of telehealth services.

4.1.4 Patients are willing to be more empowered actors in care process

Key finding

Patients are more and more willing to be involved in the care process and take on additional responsibilities for managing their condition as required by telehealth. Yet there is a non-neglectable group of patients who think they lack the necessary skillset required to be able to handle these responsibilities.

Being ready to take greater responsibility for their own care is in most cases a fundamental pre-condition for patients to use telehealth services.

The Chain of Trust online survey told us that more than nine every ten patients (92%) would like to play a more prominent role in the care process. Only half of the patient respondents reported however they would be confident handling the additional responsibilities presented by the use of telehealth in terms of self-management of the health condition.

However, 18% of patients who are non-users of telehealth believe that telehealth would involve too much responsibility on the patients' shoulders, clearly pointing to the latter as an element that, if not addressed, is likely to represent a barrier to their adoption. Interestingly, and quite unexpectedly, this figure rises up to 24% among patients who declared they were using telehealth.

This shows that one every four patients using telehealth is either not confident he/she is equipped enough with the knowledge and skillset required for telehealth usage, or is simply not comfortable handling the responsibilities telehealth involves. The foregoing stresses once more the importance of ensuring that telehealth is effectively coupled with adequate e-Health literacy programmes for patients to accompany the patient throughout the empowering process.

This also calls upon service developers and health organisations to undertake user requirements assessment when designing and evaluating telehealth services and applications, as well as to health professionals to carefully assess patient capabilities, needs, and limitations before deciding whether telehealth is the right option for a patient and if so adjust the services accordingly.

4.1.5 Patients and health professionals are willing to use telehealth

Key finding

The vast majority of patients and health professionals who took part in the project's activities believe that telehealth adds value to conventional healthcare services and are, therefore, willing to use it the short to medium term.

The literature review undertaken at the beginning of the project did not provide a definitive answer as to whether the various user groups think of or perceive telehealth as an added value to more conventional ways of delivering healthcare services.

Information collected through the other activities of the Chain of Trust project revealed that both user groups perceive, to a large extent, telehealth as something positive, that, if implemented properly, could bring a lot of benefits to patients, health professionals, as well as to healthcare systems as a whole.

The project also told us that both patients and health professionals are quite willing to either start using or continue to use telehealth services. This is quite indicative of a very positive perception of telehealth across the various user groups. We can however say with a high degree of confidence that

there will be many more if there were more effective strategies in place to better communicate opportunities presented by telehealth to its intended users and involve them in the design and deployment of telehealth services.

As far as health professionals are concerned, while only 7% respondents to the online survey declared they would rather not use telehealth, only a minority of health professionals (25%) thought telehealth would actually fulfil their professional and work place needs, contrasting with what was actually found in the literature. A possible explanation could be that there are perhaps other factors contributing to health professionals' acceptance of telehealth that offset this perception of telehealth not fulfilling their professional needs. Results of some national workshops highlighted for instance that telehealth should be first and foremost considered for its potential to increase quality of healthcare and patient safety rather than just a way to save time in healthcare. The fact that telehealth could make patients more satisfied with healthcare services they use could by itself contribute considerably to strengthening acceptance of telehealth among professionals, thereby explaining to a certain extent these contrasting findings.

Having said this, the fact that both patients and health professionals feel very much positive about using telehealth presents a window of opportunity health organisations and policy makers should fully exploit.

4.1.6 Telehealth as a complement and not a replacement of conventional care

Key finding

Patients and health professionals are ready to accept telehealth as long as this complements and does not replace traditional face-to-face healthcare services.

Both quantitative and qualitative findings are quite unanimous conveying that patients and health professionals think that telehealth is a valid complement to conventional healthcare services, but it shall not fully replace face-to-face contacts. This largely confirms the findings of the literature review and highlights the importance of keeping a minimum of face-to-face contacts between patients and health professionals as a key pre-condition for maintaining mutual trust among users when introducing and using telehealth.

On the basis of the outcomes of the activities implemented thus far we can comfortably say that both patients and health professionals believe that telehealth services, if properly implemented, can be very helpful in avoiding the unnecessary use of conventional health services. In order, however, not to undermine mutual trust and foster user acceptance of telehealth, patients, health professionals, as well as informal caregivers should jointly define the minimum level of face to face contacts to be maintained after the introduction of telehealth.

This is in line with a patient-centred model of care whereby health services are designed around the needs of the patient and not the other way round.

4.1.7 Change in health professionals' routine

Key finding

Health professionals will accept a change in routine - inherent in the introduction of telehealth - as long as it enables them to perform their tasks more quickly, more accurately and that their overall efficiency is increased.

According to the literature review, organisational aspects represent one of the most significant obstacles for telehealth acceptance among health professionals. Telehealth always entails a change

in routine and it is not clear whether this really corresponds to what health professionals actually want. The literature emphasised that change often implies that something is not working optimally and this contrasts with some professionals' feeling that they are already providing the best care to their patients, which could explain why various studies reported that health professionals resist to the adoption of telehealth more than the patients.

The literature review suggests that health professionals would accept change in routine resulting from the introduction of telehealth services as long as it enables them to perform their tasks more quickly, more accurately and that their overall efficiency is increased. For instance, due to increasing service capacity and enabling patients to manage their own care, telehealth can ease the burden on national health systems' resources. Moreover, telehealth services avoid the need to travel to specialist centres enabling health professionals to be consulted remotely to avoid unnecessary referrals and travel, and offer support to clinical and educational networks to reduce professional isolation, share best practices and support continuing professional development. Specific types of services like video-conferencing could also allow the clinical staff on the transport team, and in the critical care units, the opportunity to view the patient and advise the local team. Rather than putting patients and health professionals at a distance, all examples pointed in the opposite direction: it made them feel closer to one another.

Furthermore, from the nurses' perspective, the use of ICT could reduce stress because of decreased travelling time and home visits. One of the studies also pointed out to the improvement of quality of life of pharmacists due to elimination of certain manual work.

As discussed further down in this document, health professionals do have, however, some concerns regarding the impact of the telehealth on their workload (Please refer to Paragraph 4.5.3.3. Increased workload)

Recommendation

- The implementation of telehealth services must be accompanied by supporting organisational changes, equipment availability and education from the management side. Beyond the willingness of health professionals and patients to use telehealth, it is of utmost importance that the management opts for these services and incorporate sufficient technical facilities for health professionals to provide a good delivery of care. Three major components, namely technical facilities of the workplace, encouragement from the management and trainings provided on telehealth must be promoted.

4.2 Questioning some common beliefs

One of the objectives of the Chain of Trust project was to look into the various issues that, at least in the European-level discourse on telehealth, are commonly referred to as representing the major barriers to the adoption of this type of services by patients and health professionals. These issues range from the lack of familiarity with IT equipment generating technology-related concerns especially among the elderly to threats to patient's privacy and confidentiality.

Interestingly, this project found out that from a user-point of view the above mentioned "would-be" barriers to user acceptance of telehealth may not necessarily be the real issue at stake. As discussed in Paragraph 3.5.1 What role trust plays in their using or not using telehealth services?, people have traditionally looked at telehealth as a mere technological innovation in healthcare and have narrowly looked at the relationship between users and technology to identify barriers to acceptance. Elements such as human interaction, changing relationship between patients and health professionals have been largely side-lined, while there is sufficient evidence from this project suggesting that these factors are actually crucial to building confidence and trust.

In the light of the foregoing this paragraph describes and discusses how issues such as familiarity with technology, privacy, and confidentiality are actually perceived by the users we have involved in our project trying to draw some conclusions as to how these aspects should be looked at in future developments in the telehealth area.

4.2.1 Revisiting user's beliefs on privacy and confidentiality

Key finding

Concerns about threats to privacy and data confidentiality, which are commonly regarded as major barriers to telehealth adoption, are overestimated.

One of the major topics investigated throughout the project is the perception of patients and health professionals in relation to a number of ethical issues arising from the adoption of telehealth services, such as privacy and confidentiality. These elements are commonly regarded as major barriers to telehealth adoption among users, as confirmed by the findings of the literature review.

For the purpose of this project we have used the word "privacy" to refer to the right of an individual to be free from external interference. The continuous monitoring nature inherent in many telehealth services may prove to be an infringement of patients' rights to privacy. When it comes to telehealth the notion of privacy is therefore often associated with the concept of intrusiveness. Confidentiality was used as an extension of the concept of privacy. It refers to data (some identifiable information about a person) and to agreements about how data are to be handled in keeping with subjects' interest in controlling the access of others to information about themselves. As health data are considered under the EU legislation as constituting a particularly sensitive category of data, the issue of confidentiality is particularly relevant in telehealth.

The literature identified 'privacy' and 'confidentiality' within the list of the main barriers for the adoption of telehealth especially from the patients' perspective. However, conclusions of the literature review revealed that patients are willing to compromise on certain "soft" aspects of their privacy, notably aspects such as the capacity to be physically alone with limited external interference – which tend to be affected by highly intrusive services such as some telehealth services– if telehealth would prove to yield other benefits. In addition older patients were more willing to "trade" certain aspects of privacy in exchange of other telehealth benefits like, for instance, increased independence.

Recommendations

- In order to preserve privacy and confidentiality the Consortium recommends measures to be taken at the EU-level and reinforced in Member States. Particularly, the current EC proposal for a data protection regulation should take into account the evolving telehealth deployment and services environment to ensure that new issues are addressed properly.
- It is also recommended that appropriate and understandable information on security provisions and procedures should accompany telehealth services so as to increase the trust of users.

Key finding

Unless perceived as unnecessary burden, intrusiveness of telehealth does not represent a barrier to adoption for patients, especially if this is offset by other benefits (e.g. improved quality of life, independence, reduction of unnecessary visits with health professionals)

The online survey and the national workshops confirmed that the intrusiveness of telehealth does not represent an obstacle to patients' adoption of this type of services. Having a camera in the apartment or having to deal with tele-homecare related duties, such as frequent or untimely measurements and remote consultations, do not in principle represent major issues for patients, especially if all this is offset by other types of benefits and unless this alleged intrusiveness is perceived as an unnecessary burden. This conclusion is also largely shared by health professionals.

The survey also revealed that only 13% of patients think telehealth would not fit into their daily lives, indicating that any burdens that may be placed on the patient by telehealth-related duties are offset by the possibility to stay in their home environment and enjoy independence as suggested by some of the patients who participated in the national workshops. It goes without saying that all this can also bring about benefits to family members and informal carers looking after the patient.

The online survey tells us that only according to a minority of users can telehealth have negative implications for patients' privacy. Less than half of the patient users and one third of non-users said they would be willing to compromise on certain aspects of their privacy in favour of using telehealth. Patients who use or have used telehealth services tend to be less concerned about the possible negative implications of telehealth for their privacy. This could be explained by the fact that, having some experience of telehealth they are more aware of the advantages of telehealth and are, therefore, more willing to "trade" a quota of their privacy in exchange of other benefits.

Key finding

Health professionals do not regard confidentiality as a major issue in telehealth. The same conclusion, albeit to a lesser extent, holds true for patients.

When it comes to confidentiality the situation is less clear. Whereas from the point of view of health professionals confidentiality is not a major issues in telehealth, there remain some open issues *vis-à-vis* what the patient take is on this crucial issue.

While the online survey revealed that only 18% of patients believe telehealth could put at risks confidentiality of personal health data, security-related issues re-emerged quite blatantly in five out of six national workshops (only in Norway was the issue less prominent in the discussions) especially in relation to the risk that unauthorised people may have access to their health information. In that respect not only health professionals were mentioned, but also insurers and employers and the adverse social consequences of such unauthorised access, e.g. stigmatisation, social discrimination, etc. Potential misuse of information was also mentioned, like for instance passing it on to pharma or researchers (secondary use of health data).

There is at the same time a non-neglectable group of patients who attaches less importance to confidentiality and risks of inappropriate disclosure of sensitive health information. This group of people usually consists of patients who expect huge benefits of telehealth and such benefits outweight the risk of any damage that may be caused by inappropriate disclosure of personal health-related information to unauthorised people.

As a general principle, patients who use or have used telehealth services tend to be far less concerned about security and possible negative implications of telehealth for the confidentiality of their data. Once again, we can confidently conclude that confidentiality-related issues do not represent insurmountable barriers to adoption in so far as effective security procedures are put in place and patients are reassured all measures have been implemented to protect their data from unauthorised access.

Turning to health professionals, the literature review highlighted some concerns regarding the lack of clarity of data protection legislation and the risk of being sanctioned and thus facing legal consequences such as a claim for negligence, breach of contract or breach of confidence. The

literature also showed that unauthorised access may be a concern for health professionals for it may affect integrity and authenticity of patient data. These issues re-emerged in the various national workshops, but there is a general feeling among professionals that, although there may always be a risk that unauthorised users could access information, all security-related issues in telehealth can be effectively addressed just as they were dealt with in other ICT-intensive services.

Although the concerns expressed are numerous, most patients and health professionals think that too strict data protection and security systems should not hinder the transfer and sharing of health information and ultimately the health service. Patients are in general quite in favour of making their health data available to those who are involved in the therapeutic process, but emphasised the crucial role trust plays when it comes to ensuring confidentiality.

Closely related to that, the issue of 'patient's consent' could be unreasonably burdensome in some cases, as has been specifically acknowledged by physicians. However the latter group was clear saying that patients must give their consent for their data to be made available on shared electronic data bases.

As regards confidentiality, and in line with the above, a properly secured system for electronic storage and transfer of information could ultimately be even safer than current paper-based system, as acknowledged by the nurses in particular.

Last but not least appropriate and understandable information on security provisions and procedures should be provided alongside the introduction of telehealth services so as to increase trust across all end users.

Recommendations

- Data protection and security systems should not hinder the transfer and sharing of health information and ultimately the health service. They need to ensure however that consent and processing modalities respond to the expectations of both patients and health professionals.

4.2.2 Lack of familiarity with technology is not the real barrier

Key finding

Lack of familiarity with the technology and IT equipment in general can have a negative impact on attitude and intention to use telehealth. Technology does not however represent a major barrier to adoption since many technology-related concerns could be resolved through more user-friendly services and tools, integration of user requirements and effective education and training, and health literacy programmes.

One of the most common barriers to user acceptance of telehealth is a perceived lack of necessary knowledge and skills required to be able to effectively and safely use telehealth. Studies that investigated the introduction of telehealth into home care nurses highlighted a certain lack of confidence of nurses in their ability of use the technology and performing home care tasks. Some studies reviewed by the Consortium suggest that patients are not always comfortable using telehealth due to their perceived lack of skills to use these services. However, there were studies suggesting otherwise as well.

Notwithstanding this, there is enough evidence showing that "technology-related anxiety", which is referred to as a negative psychological reaction to technology, has a significant negative impact on attitude and intention to use telehealth, especially for the patients. Competence and confidence in using telehealth do represent key variables influencing acceptance of a telehealth service. Users' abilities to adapt to new technologies and become familiar with its operations vary considerably.

As discussed in paragraph 4.1.4 as far as patients are concerned the element of confidence should also be understood to encompass all the additional responsibilities and more generally the new role a patient needs to take on when adopting telehealth to support chronic disease management.

As discussed a bit further down in this paragraph, education, training and user support facilities are crucial to address the abovementioned issues and concerns relating to confidence. Some users might need intensive education and training, while some others might not, while some users with functional or age-related limitations may not be able to achieve sufficient competence and confidence levels, so telehealth may simply not be an option for them. Patients with declining health and/or rapidly deteriorating physical and cognitive capabilities also require specific attention and their competence and confidence levels should be regularly re-assessed, as emphasised by the patient representatives who attended the European focus group.

The results of the online survey revealed that the large majority of patients who are using telehealth services indicated in the survey the telehealth services are easy to use. In addition, we explored the relationship between patients' opinion on 'easy to use telehealth' and whether they have received any sort of training on telehealth. Those patients who received training in telehealth thought telehealth was easy to use (more than half of them) while those who did not received any training found it more difficult.

This suggests that many of the barriers associated with the usability of telehealth services and applications can be overcome though effective training. The online survey also tells us many perceived barriers relating to technology disappear after a certain period of usage, especially if user requirements are effectively integrated in service design and implementation. Interestingly, while only 37% of the non-users, all four groups considered, believe that telehealth is easy to use, twice as many (72%) users actually reported so. This element was already identified in the literature, although many studies reporting these findings referred to small-scale pilot programmes where users usually receive a lot of additional support in using applications.

On the other hand, self-confidence is known of being something that can be increased over time. Having said that, from a user-point of view, technology does not seem to be the real issue at stake. While it is true that lack of familiarity with the technology and IT equipment in general, and "technology-related anxiety" can have a significantly negative impact on attitude and intention to use telehealth, especially for the low IT-literate component of end-users, many technology-related concerns could be resolved through user-friendly services and tools, integration of user requirements and effective education and training, and health literacy programmes.

Key finding

Although patients and health professionals may have concerns about their ability to use and interact with telehealth services, the more/better the training, the easier is to use the telehealth services.

Lack of appropriate education and training, both within their academic curricula and training provided to them during the working period as part of the Continuing Professional Development (CPD) is perceived as having potentially negative impacts on health professionals' perception of their ability to integrate telehealth in the clinical workflow while ensuring efficiency and patient safety.

The importance of integrating telehealth training into Continuing Professional Development for health professionals was mentioned in all national workshops as well as in the European focus groups with the three health professional groups. Looking at the results of the online survey a big proportion felt they did not have sufficient training to be able to use telehealth, thereby confirming the literature review findings.

When looking at the relationship between whether health professionals followed any training on telehealth and whether telehealth was easy to use, those who received education and training in the

past three years indicated that those applications are not difficult to use. The data indicated a clear relationship between health professionals finding telehealth easy to use and whether they received any training in the past.

It goes without saying that more education and training on telehealth need to be offered for health professionals at all levels of education (graduate and CPD), as health professionals perceive a clear lack of CPD programmes on telehealth. Furthermore, significant association was observed between gender of health professionals and whether they feel adequately trained to use telehealth tools. Male health professionals and non-users more often feel adequately trained, which also highlight the need to take a gender perspective when offering opportunities for CPD.

Turning to patients, there is a clear link between patient involvement in decisions concerning the integration of telehealth into chronic disease management, the education and training provided and the use of telehealth services. The patients who consider telehealth applications difficult to use, are among the ones who have not received any training on using these services. This highlights once more the need to put more effort into training for all users, which shall include paying thorough attention to patients' health literacy requirements.

Further to the need to address different ways of training, the patients group call on manufacturers to take the 'usability framework' (machines that are easy to use) into account when designing telehealth tools. Nurses explicitly pointed to the need to be involved in the design and deployment of telehealth emphasising the importance of ensuring that applications are simple, user-friendly, and aligned to real user needs.

Patients have also emphasised that usability should be considered as something that can evolve. As many chronic conditions worsen over time, needs and capabilities of patients usually change much more quickly than that of people without a chronic condition. Therefore, needs and capabilities of patients using telehealth have to be regularly re-assessed, while, telehealth services and applications need to be sufficiently flexible to account for these changes.

Recommendations

- In order to increase the confidence of patients and health professionals in using telehealth services, manufacturers shall make telehealth applications easy to use by employing a user-centred approach. End users should be active leaders in integrating their expertise into the design of telehealth applications and ensuring they are fit for purpose.
- Telehealth services need to be affordable, useful, user-friendly, and must be designed to support the daily practice and usage. In light of an on-going assessment, telehealth services should be adapted to the evolving needs of patients and evolving technology.

4.3 Key drivers of telehealth acceptance: a user-centred approach

In the previous paragraph we have seen that from a user-point of view some of the issues that are traditionally considered as main outstanding barriers to telehealth adoption may not necessarily be the real issues at stake.

On the basis of the results of the Chain of Trust project it can be argued that there are other elements shaping user acceptance of telehealth that needs to be thoroughly looked at by policy makers, health authorities, industry, as well as patient and healthcare professional organisations themselves.

Chain of Trusts tells us in that respect that more important to fostering acceptance among users is ensuring that telehealth does not affect negatively the patient–health professional relationship, it

does not undermine mutual trust, delivers real benefits to users *vis-à-vis* conventional-only healthcare, and, most importantly, does not reduce patient safety.

Let us then have a more detailed look at these issues.

Key finding

Patients and health professionals attach a lot of importance to the way telehealth affects the patient-health professional relationship. Yet there are no definitive conclusions regarding how telehealth could change this relationship, especially as far as non-users of telehealth are concerned.

The impact of telehealth on patient-professionals relationship and communication was identified as a major issue by the Chain of Trust Consortium through the literature review. This is in fact one of the underlying elements of trust and acceptance, and as such it lies at the very heart of the Chain of Trust's key concerns.

As discussed elsewhere in this document, trust is largely regarded as the cornerstone of effective health professional-patient relationships. As such it does play a key role in shaping patients and health professionals' decisions regarding whether to adopt and use telehealth. If the shift towards more integrated patient-centred care enabled by the introduction of telehealth requires greater inter-dependence between patients and health professionals, the distance factor inherent in telehealth does not diminish the importance of the human dimension, but it actually makes it even more important since the reduction in physical contacts requires greater levels of mutual trust among different users.

Knowledge collected through the activities implemented thus far tells us that while users attach a lot of importance to trust and the possible implications for patient - health professional relationship resulting from the use of telehealth, we are not in the position of drawing any definitive conclusions regarding how telehealth could actually affect this relationship, especially among the non-user population.

The online survey included a set of questions aimed at assessing how patients perceive the impact of telehealth on the communication and relationship with health professionals, both in terms of frequency and quality of contacts. Frequency-wise users have no doubt telehealth does allow more regular contacts between patients and health professionals, which is perceived as a desirable outcome. 61% of the patients believe that telehealth helps staying more in touch with their health professionals (75% of users), while 58% of health professionals agreed with this statement (68% of users).

Looking at the quality side of the patient-health professional relationship 20% of the respondents using telehealth services believe that telehealth affects negatively the communication between them and health professionals. This figure rises up to 38% among non-users. By contrast, 47% of users disagreed with this statement against only 20% of the non-users. Consequently, it can be concluded that while the majority of telehealth users believe that telehealth does not have in principle a negative impact on their communication with their health professionals, this feeling is not shared among the non-user population, who does have concerns on this issue.

As discussed further down in the document there is a component within both patients and health professionals who does not have concerns relating to the potential impersonality of telehealth-mediated communication and the difficulty health professionals may encounter capturing the emotional status of patients when using telehealth, which in turn could also affect negatively the relationship between the patient and health professionals, most users say.

All this confirms to some extent the findings of the literature review. While some studies reported positive impact on the patient – health professional relationship following the introduction of

telehealth, especially in terms of promoting patient-centred communication, others revealed that patients felt that telehealth had affected negatively this relationship as it resulted in health professionals adopting a more paternalistic approach towards the patient.

A key conclusion that can be drawn on these findings is that to ensure acceptability and adoption it is crucial we carefully assess the impact of telehealth on patient-health professional relationship and communication at all stages, during the design, piloting, assessment, and deployment phase.

As mentioned elsewhere in this document, it is also crucial health professionals receive effective support at the work place, which shall include ad-hoc training not only relating to the technology, but also and perhaps more importantly, to the new interaction and ways of communication between patients and health professionals arising from the use of telehealth.

Moreover, as explicitly emphasised by the participants to the Dutch national workshop, in order not to undermine patient-professional relationship, the choice of the right communication form should always be the result of a custom-made decision made after adequate information and in consultation between patient and professionals.

Recommendation

- The Consortium recommends that telehealth is used when there is a clear added value to complement conventional healthcare and provided that the patient-health professional relationship is not undermined by the introduction of telehealth to the services.

Key finding

To accept telehealth patients and health professionals wants it to be user-centric as opposed to technology-driven.

There is a general consensus among the health professionals that advancements in telehealth have largely been driven by technology and manufactures instead of the need of end users, and this has often resulted in mismatches between the final product/services and the real needs of health professionals.

This feeling, which is also shared to a large extent by patients, particularly emerged out of the national workshops and the European focus groups where it was emphasised that one of the risks associated with introducing telehealth is that these services may ultimately not meet the needs of health professionals and patients as end-users are too often not properly and timely involved in the design and deployment of telehealth.

Key finding

Perception of benefits is key in shaping individuals' decisions regarding whether to adopt telehealth (different individuals have different needs and priorities, thus different perceptions of benefits).

Another important conclusion that can be drawn on evidence gathered through the Chain of Trust project is that one of the principal factors weighing in favour of willingness to use telehealth is the perception of benefits flowing from the adoption of this type of services *vis-à-vis* conventional-only services.

The literature told us that perceptions of benefits very much depend on people's expectations of telehealth. Although exploring individuals' expectations was beyond the remit of this project, we can argue that these very much depend on many factors, such as socio-economic status, gender, age, health conditions, and many others. Thus, while for some patients acceptance of telehealth could be driven by the possibility to improve his/her health status as well as better quality of life, for others it could be simply linked to the rewarding feeling of being more involved and in control of his/her

care.

Likewise while for some health professionals acceptance could be primarily associated to improved effectiveness and efficiency in delivering care, for others it can be driven by the increased professional satisfaction, an element which according to the literature is the keystone for adopting telehealth practice.

Recommendation

A quality control system to check the quality and patient-centeredness of telehealth services through using patient-centred outcomes as indicators should be developed.

Key finding

Health professionals and patients will accept telehealth services only in so far as and as long as they have at least the same safe and reliability standards as conventional health services.

A major conclusion that can be drawn on the results of the Chain of Trust activities is that unless coupled with safety and reliability standards, any other benefits flowing from telehealth will not by themselves contribute to health professionals' acceptance of this type of services.

Patient safety is a major concern for health professionals. Accordingly, decisions regarding whether to adopt and use telehealth will consequently be strongly influenced by the way health professionals perceive safety associated to telehealth *vis-à-vis* conventional-only practice.

The introduction of telehealth is generally regarded as being conducive to higher patient safety for it enables health professionals to acquire information on their patients on a much more regular basis. Undoubtedly, the sooner information is known about a patient's evolving condition, the earlier can health professionals act upon warning signs, thus the better and safer the patient will be in the treatment process.

The literature review indicated, however, that while there are some studies showing a positive correlation between telehealth and patient safety, there is still very little evidence on patient safety in telehealth. This seems to be due to different factors, such as the lack of scientific evidence, but also, and perhaps even more importantly, to the lack of understanding about the emerging safety issues associated with telehealth. An interesting paper reviewed by the Consortium highlighted in that respect that safety issues associated with telehealth are far more complex than in conventional care, and include not only apprehension about malfunctioning equipment which could occur in relation to any medical device, but also concerns regarding potential adverse effects on patient management decisions through delayed, inaccurate, or missing information, misunderstood advice, or inaccurate findings due to patient or health professional error[3].

It came as no surprise, therefore, that the Chain of Trust online survey and the national workshops singled out safety and reliability-related issues among the main remaining barriers to telehealth acceptance, particularly for health professionals. Patients are also concerned about safety and reliability, especially with regard to accountability and legal responsibility in case of errors that may occur during telehealth interventions.

According to the online survey half of patient users think that telehealth is as safe as face-to-face

[3] Schlachta-Fairchild L, Elfrink V, Deickman A. Patient Safety, Telenursing, and Telehealth. In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 48.

services, while non-users tend to think that patient safety is reduced when using telehealth. Views among health professionals are not that different with only half of the health professionals who use/have used telehealth indicating that telehealth is as safe as conventional face-to-face healthcare services, while only 30% of non-users indicated telehealth would be as safe as traditional healthcare services.

Only partially were these findings actually confirmed by the outcomes of the national workshops and European focus groups. The feeling that telehealth is at least as safe as to face-to-face health services was shared by the slight majority of health professionals and patients who participated in the aforementioned activities. There were some participants who emphasised that if implemented properly telehealth could actually bring about improvements in terms of patient safety. An interesting example came from the area of telepharmacy, according to which, the possibility presented by telehealth to pharmacists to have prescriptions reviewed more carefully by pharmacists increases patient safety and the quality of service provided.

Although in the light of the foregoing it is not possible to draw definitive conclusions as to whether patients and health professionals find telehealth at least as safe as conventional practice, a key message here is that a decisions as to whether adopt telehealth will depend to a great extent to the perceived effects of telehealth on patient safety.

Recommendations

- EU funding must support and foster the collaboration of health professionals through the development of networks and guidelines of evidenced based healthcare in order to promote successful, efficient, safe and proven practices on telehealth.
- To ensure maximum effectiveness, safety and reliability of telehealth, the role of informal carers has to be fully acknowledged since they are an integral part of most patients' lives. Informal carers should have the same rights as patients to access training and support mechanisms to manage the additional responsibilities and tasks when looking after patients who use telehealth services. Telehelath should however not add burden on their shoulders.

4.4 Main benefits of telehealth

As discussed in Chapter 3 usefulness and advantages of telehealth are acknowledged by all four groups of end users considered by this project, with no large variations in the perception of telehealth across user groups. We nonetheless remarked some disparities in perceiving benefits as well as risks associated with telehealth, but these patterns are less marked than we were expecting.

A major element we retained from the literature was that perceived benefits of telehealth for health professionals *vis-à-vis* conventional services tend to be less significant than benefits for patients, for it is possible for them to see only changes in routine whereas the patient could see immediate benefits such as more personalised treatment and care plans, better quality of life and reduced travel.

Looking at the results of the various activities implemented between 2011 and 2012 we can affirm that this statement proved to be only partially true. We found out that health professionals, regardless of whether they actually use telehealth, do not seem to be narrowly looking at telehealth just as a process of technology inclusion in healthcare, but as a way of changing the delivery of care, one in which not only the patient, but also professionals themselves can enjoy many benefits.

The objective of this paragraph is therefore to present the main benefits of telehealth as perceived by users. To that end the paragraph starts out by presenting and discussing benefits on which we found large consensus across the four user groups and will conclude with an overview of patient-

and health professional-specific benefits.

4.4.1 Common benefits to patients and health professionals

4.4.1.1 Improving quality of healthcare

Key finding

Most of the health professionals and patients believe that the use of telehealth services can increase the quality of care delivered to the patients.

One of the benefits of telehealth identified by the Consortium is the contribution to better quality of care. Some studies assessed by the project indicate that nurses have general positive perceptions when using telehealth services because they appreciate the fact that it can improve the therapeutic relationship with patients and this contributes towards providing better quality healthcare to the patient.

Similar to the nurses' views, the majority of physicians and pharmacists think that telehealth increases the quality of the health services in particular in relation to availability. Furthermore, the majority of health professionals believe that telehealth is a valid complement to support conventional healthcare services.

Ensuring high quality of healthcare services is the key driver for health professionals. As such the impact of telehealth on the quality of their services is a major element behind their willingness to take up telehealth services.

As regards the patients, majority of the telehealth users indicated that telehealth helps to increase the quality of health services; half of non-users also agreed with this statement.

Recommendation

- Telehealth must be used to better support, optimise and complement the delivery of healthcare in a more efficient way; facilitating coordination along the healthcare process and between different sectors (social and healthcare) involved and by fostering inter-professional communication and teamwork.

4.4.1.2 Improving access to healthcare

Key finding

Patients and health professionals believe that telehealth can in principle lead to greater access to healthcare, particularly for patients living in underserved areas, and to a lesser extent for disadvantaged low-income patients.

Access to healthcare was assessed by the Consortium in relation to two main aspects: a) geographical, i.e. whether patients and health professionals think that telehealth can improve access to healthcare for people living in underserved areas, and; b) socio-economical, i.e. whether patients think that telehealth can improve access to healthcare for disadvantaged groups of people.

Patients tend to think that telehealth carries the potential for improving the quality as well as access to healthcare for patients living in underserved areas, and to a lesser extent, for socio-economically disadvantaged patients. These findings seem to suggest that overall patients think that telehealth can led to a reduction of health inequalities enabling patients to access healthcare service remotely and could lead to more affordable and sustainable healthcare.

The latter conclusion should be appraised carefully as only to a little extent did we manage through

the survey and national workshops to capture the views of patients belonging to lower socio-economic groups. The issue of access and affordability of care for low-income patients was raised in some national workshops were it was highlighted that since low-income as well as old people hardly have access to broadband there might be a risk that the better-off only could ultimately benefit from telehealth. The national workshop in the Netherlands concluded in that respect that if we fail to ensure wide accessibility and affordability of telehealth to include disadvantages and vulnerable patient groups chances are that health inequalities can be eventually exacerbated with the introduction of telehealth on a large scale.

As regards health professionals, most of them believe that telehealth carries the potential for improving access to healthcare, at least geographically; this assumption is believed particularly true for patients in underserved areas.

Recommendations

- Member States have to exploit the opportunities offered by telehealth in order to fill the gap between patients and citizens' needs for services and their accessibility and quality

- Telehealth should serve with priority the needs ofthe most vulnerable patients. These could be patients living in underserved areas (e.g. geographical distance to conventional healthcare), those with age-related needs (very young or very old) or condition-related issues, persons or families having to manage multiple diseases or conditions.

4.4.1.3 Improving patient adherence to treatments

Key finding

Telehealth is regarded by both patients and health professionals as having the potential to increase patients' adherence to treatment, care and appropriate lifestyle recommendations.

Among the benefits of telehealth identified by the Consortium there is the improvement of patients' adherence to treatments, care, and appropriate education for health recommendations.

Looking at the online survey results, the majority of the patients-users think that the addition of telehealth improves their adherence to treatment and care, while the non-users of the patient sample agreed with this statement in half of the cases. The findings are very indicative of the importance of adherence among patients. Patients seem to think that thanks to their more active involvement in decisions concerning their health inherent in many telehealth services, patients are more aware of the importance of adhering to treatments, thus they are more willing to actually do so.

When asked about whether telehealth improves patient adherence, similar to the patients' view, more than half of the health professionals responded positively.

In the light of these findings, we can conclude that since patient adherence is amongst healthcare providers' primary concerns they would be in principle more willing to accept telehealth if this leads to strengthened adherence among patients. Regular follow up by health professionals enabled by the integration of telehealth in chronic disease management is thought to be conducive to better adherence.

4.4.2 Benefits to patients

Apart from benefits that both patients and health professionals share, we have identified some additional ones, this time specific to the point of view of the patients. These are presented and

discussed below.

4.4.2.1 Telehealth and patient empowerment

Key finding

Patients believe that the use of telehealth is conducive to increased patient empowerment. In particular, patients think telehealth helps the patient improve the knowledge of the conditions, and facilitate his/her involvement in the care process in partnership with health professionals.

An aspect that is often overlooked by many studies on users' perspective on telehealth is whether the patients think that telehealth could help them improve knowledge of their health condition and, likewise, whether health professionals, in turn, think that this is the case and that is something that should be regarded as a desirable outcome of telehealth.

Increasing knowledge on one's health condition is a pre-requisite for patient empowerment. Although it is an important aspect, only a few studies have explored the issue of whether the patients are willing to play a more active role in the management of their condition and whether they think that telehealth can enable them to do so.

Some studies reviewed by the Consortium confirmed that patients are in principle willing to play a more active role in managing their condition and that telehealth is a suitable tool to promote it. Other studies, however, arrived to different conclusions highlighting that the perceived acceptance by patients of taking on greater self-management role varied and in general reference to traditional roles of patients and health professionals – and the maintenance thereof – remained prevalent.

When responding to the statement 'telehealth helps improving my knowledge of my health condition', the majority of patients using telehealth that answered to the online survey responded positively. In light of the above and noting other findings of the project, we can conclude that patients are willing to take a greater role in the management of their conditions.

The national workshops expanded on this subject highlighting the opportunities presented by telehealth in terms of favouring the involvement of patients in decisions concerning healthcare and in the monitoring of treatment and care progress in partnership with health professionals. Increased confidence in dealing with their symptoms and greater independence were also mentioned as positive outcomes of telehealth contributing to the empowerment of patients.

These findings are in line with the literature review which suggested that patients usually feel more involved in their care and more able to manage their own care when using telehealth.

Recommendations

- The design of telehealth services and their evaluation must integrate the concepts of patient empowerment and self-management. Telehealth services must be evaluated to check the quality and patient-centeredness of telehealth services through patient centred outcomes as indicators.
- Confidence about using telehealth services applies to patients in terms of both having confidence in themselves and being confident that healthcare providers have the necessary skills to provide the services through telehealth applications. It is therefore needed to identify and map the necessary telehealth related skills that health professionals must incorporate in their practice.
- Implementation strategies must be supported with appropriate education and training. E-Heath and telehealth strategies need to integrate education and training in their planning activities to provide the necessary education and skills to the end users, especially health professionals at all

levels of their education. E-Health literacy must also be included.

4.4.2.2 Reduced anxiety

Key finding

Patients believe that telehealth can reduce the feeling of anxiety relating to their health status and make them feel more relaxed knowing that vital signs are regularly monitored.

Linked to the previous finding, the literature review highlighted another important benefit for patients, this time having to do with the feeling of security and related reduced anxiety resulting from the fact that patient's vital signs are constantly monitored thanks to telehealth.

Knowing that vital signs are regularly monitored combined with the possibility offered by various telehealth services to make sure health professionals are alerted in real time in case of early indicators of deterioration is regarded as significantly reassuring, especially for those patients who are particularly worried about their health status.

This aspect was further explored throughout the project, especially in relation to family members and relatives looking after the patient. With the online survey we found out for instance that 41% of the patients think that when using telehealth their family and relatives are less worried about their health condition, while only 16% disagreed with this statement. This in turn suggests that patients also believe telehealth could bring about major benefits and quality of life improvements for relatives and informal carers as well.

4.4.2.3 Economic benefits

Key finding

The majority of patients and health professionals consider that telehealth can yield important economic benefits for the patients, especially for those living far from healthcare facilities.

There is a quite strong consensus among patients – as well as health professionals – on the fact that telehealth can yield important economic benefits for the patients as a result of reduced travel expenses for ambulatory visits as well as travel expenses for relatives caused by hospital stays, but also through the minimisation of the sick leave days caused by their illness.

When it comes to patients' expenses for healthcare, a clear majority of patients using telehealth - think that telehealth saves money they spend on healthcare. Healthcare costs are not only direct expenses, i.e. less patients may have to pay for out-patients and in-patient services, but also all indirect costs associated with it, e.g. travel, days off work, etc.

On the other hand, as discussed further down in this document, patients do have, however, some concerns regarding the affordability of telehealth for the large patient population, especially if patients have to bear the costs for the purchase and maintenance of telehealth application as well as pay high fees for telehealth consultations.

4.4.2.4 Better health and quality of life are desirable benefits, yet not definitive conclusions can be drawn

Key finding

Although commonly touted as a means to improve patient's health and quality of life, there is no large consensus among patients and health professionals regarding whether telehealth could actually deliver such benefits.

The literature review showed that a key concern for patients' when deciding on whether to adopt

telehealth is an expected improvement of their quality of life. Improvement in patient's quality of life can stem from different factors, such as better health condition, reduced morbidity, and mortality risk, increased self-confidence, better awareness of symptoms, improved independence because of unnecessary visits and emergency readmissions, and many others.

Chain of Trust suggests us that patients would use telehealth if this could bring about any of the abovementioned benefits, but there is no broad consensus across the various user groups on whether telehealth could actually do so. This holds particularly true in relation to the perceived relationship between the use of telehealth and improvement in patient's health status. As mentioned at the beginning of this chapter only less than one every five non-user patients (17%) who responded to our online survey believes that the use of telehealth would lead to any significant health improvement, while this holds true for the 43% of patient users.

Health professionals are slightly more positive on that matter with 21% of non-users and 49 % of users expecting improvements in their patients' health status as a result of the integration of telehealth in the care process.

As far as other quality of life-related aspects, the number of patients who believe there is a positive correlation between the latter and the use of telehealth is larger (48%) as it was also confirmed by the outcomes of the national workshops.

The information gathered by the Consortium does not permit, therefore, any definitive conclusion regarding whether or not telehealth in the view of patients and health professionals could lead to improvement in patient's health condition as well as other quality of life-related aspects. This holds particularly true for the non-user component of the population investigated by the Chain of Trust project.

Recommendations

- The Consortium recommends investing in further research to identify how the benefits of telehealth lead to a better quality of life for patients.
- The Consortium also recommends that in order to ensure that assessment of Quality of Life (QoL) associated to the use of telehealth is as patient-centred and personalised as possible, existing QoL indicators should be improved and adapted to the specific profiles of patients (e.g. disease, morbidity, age, family and socio-economic situation, etc.). These indicators need to be identified with the patients and their informal carers and support should be sought from patient organisations, academia, and health professionals.

4.4.3 Benefits to health professionals

4.4.3.1 Potential to increase cooperation amongst healthcare team

Key finding

The vast majority of health professionals agree that telehealth leads to improved cooperation in the healthcare team.

According to the literature, a major expected benefit of telehealth for health professionals is the possibility to improve the cooperation among different health professionals.

The issue was explored at different stages through project implementation with the online survey revealing that 65% of health professionals (almost 80% if we considered only users) think that telehealth can improve cooperation among health professionals. This is an extremely important finding which is reinforced by the fact that only 5% of health professional respondents actually

disagreed with this statement.

This element was extensively explored in the various national workshops, especially by the nurses, who drawing on their daily practice emphasised that a major pitfall of current system of care is that the various health professionals involved in taking care of a patient are not or not sufficiently linked with each other. Similarly, pharmacists highlighted that one of the biggest barriers they currently face in delivering services is the lack of communication between pharmacy and the rest of the health care services, and that pharmacies are not regarded as a part of integrated healthcare pathways.

On that point, both nurses and pharmacists highlighted that telehealth would be very beneficial if it could enable seamless cooperation between all different health professionals involved in a patient's treatment and care process, including those working in different settings. Pharmacists also remarked that telehealth would be very welcome if it offered community pharmacists the opportunity to become more involved in the healthcare pathway of the patient.

This latter element was also raised by some patients who participated in the joint national workshops, especially in Norway, emphasising that without effective cooperation among different healthcare providers' and healthcare levels (primary, secondary, and tertiary) the use of telehealth could pose major challenges to patients using telehealth, especially for those with complex diagnoses and/or co-morbidities.

A major issue in this regard, mentioned by various professionals groups in the different countries where Chain of Trust national workshops took place is the lack of interoperability between systems used in different hospitals and healthcare centres. Health professionals believe that these issues if not promptly addressed at national and European level could seriously threaten remote collaboration among professionals and health information exchange to the detriment of quality of care and patient safety.

For the very same reason health professionals highlighted that diffusion of telehealth within healthcare needs to be connected with the implementation of nation-wide Electronic Health Records, which is paramount to effective health professionals' cooperation.

4.4.3.2 Possibility stay more in touch with patients

Key finding

A major benefit health professionals expect of telehealth is the possibility of staying more regularly in contact with patients.

A key expected benefit of telehealth for health professionals which emerged in particular in some national workshops, is the opportunity presented by telehealth to allow more regular contacts between health professionals and patients. We discussed this already when addressing the various issues pertaining to the impact of telehealth on patient – health professional communication, emphasising how all this was particularly welcome by the nursing community.

This feeling is also shared by pharmacists who see major benefits in terms of more holistic follow up of pharmaceutical treatment, which again emphasises the potential of telehealth to actually enable more regular contacts between patients and health professionals.

4.5 Main barriers of telehealth

The Chain of Trust revealed that there are still some major issues which need to be addressed sooner rather than later in order to foster user acceptance of telehealth, especially among the more sceptical component of end users. Not surprisingly, patients and health professionals who have

never used telehealth services tend to see more barriers to telehealth adoption.

There is sufficient evidence, however, suggesting that many of these barriers are not insurmountable and that progress is being made in overcoming these obstacles. Many of the barriers commonly associated with the usability of telehealth services and applications can be for instance addressed though more effective training, while others, such as the level of perceived privacy and intrusiveness of telehealth in patients' life can be offset if telehealth delivers other benefits.

4.5.1 Common barriers for patients and health professionals

Likewise benefits, there are some potential issues in telehealth on which there seems to be large consensus among patients and health professionals involved in the various Chain of Trust activities. These are presented below.

4.5.1.1 Potential impersonality of telehealth services

Key finding

Although telehealth is perceived as more impersonal (at least by those who never used it), this alleged impersonality does not represent a barrier to adoption in so far as telehealth does not eliminate face-to-face contacts.

The literature review revealed that there is no unanimous view with regard to the impact of telehealth on patient-professional interaction. Many studies have revealed that, although regarded as an acceptable solution, both patients and professionals have major reservations about using telehealth because they feel that technology-mediated communication typical of telehealth would not lead to establishing and maintaining the type of health professional - patient relationship that would allow healthcare delivery to be effective. Those who perceive telehealth services negatively tend to place emphasis on the fact that technology-mediated communication results in patients becoming "objects" of healthcare as telehealth is thought not to enable health professionals to capture patients' emotions and feelings during consultations, thereby neglecting the importance of psychological factors in the whole process.

The perception of telehealth as being impersonal is a primary barrier to considering it as an option for both professionals and patients. Professionals continue to regard this element as one of the main reasons why they maintain a strong preference for face-to-face visits, despite the fact that the majority of professionals who have used some form of telehealth have reported relatively high levels of satisfaction with these services.

This seems to suggest that no matter how efficient and reliable a telehealth-based encounter is, it cannot fully replace face-to-face contact between health professionals and patients. For example, a combination of home telecare and in-home visits was singled out as the best choice by elderly patients.

When the Consortium analysed more in detail this aspect in the successive stages of the project, it appears that the 'impersonality' barrier is increasingly watered down. When it comes to the contact with health professional delivering telehealth services, according to the online survey, patient users are divided about the impersonality of telehealth consultations. Health professionals showed a similar division when responding to the online survey.

The findings of the literature review cited above were further supported by the health professionals that participated in the various national workshops organised in different countries. Health professionals' focus groups rather disagreed with the findings of the literature review suggesting impersonality as a primary barrier for the development of telehealth. More concretely, doctors who

participated in the focus groups and were more familiar with telehealth reasoned that 'impersonality has never proven to be a barrier', a conclusion that was supported by nurses and pharmacists who were familiar with telehealth services.

In the light of the results described above, it seems that views are divided on the perception of impersonality as a barrier for further use of telehealth. It can be concluded that although telehealth is perceived as more impersonal (at least by those who never used it), this alleged impersonality does not represent a barrier to adoption in so far as telehealth does not eliminate face-to-face contacts.

Recommendation

- The Consortium recommends education and trainings to be provided on communication and interaction in using telehealth services to both patients and health professionals. Bearing in mind that both parties have responsibilities in establishing effective communication, trainings on the ways of communication are of crucial importance in teaching patients and health professionals the best way to interact when they are not face-to-face.

4.5.1.2 Potential difficulty to capture and evaluate the physical and emotional condition of the patient

Key finding

Most patients and health professionals have concerns regarding the ability to fully capture the physical and emotional situation of a patient via technology mediated consultations.

Patients and health professionals seem to share similar concerns regarding professionals' ability to fully capture their physical and emotional situation during technology-mediated consultations.

While evidence gathered in the literature review is somehow equivocal, not allowing any definitive conclusions on this important matter, the Chain of Trust online survey told us that 53% of patients is concerned about the ability of health professionals to evaluate the physical and emotional conditions of the patient during telehealth consultations. This figure rises to 58% among health professionals. For all groups this opinion is shared by both users and non-users of telehealth. Our findings emphasises that capturing emotional situation of the patient may indeed be challenging, but there is a general feeling that this perceived barrier could be easily overcome through providing ad-hoc training to health professionals and ensuring that regular necessary face-to-face contacts are maintained.

As discussed earlier in the document, if not properly managed, this element could pose some major challenges to effective trust-based communication between patients and health professionals.

4.5.1.3 Ability of health professionals to draw accurate conclusions when using telehealth

Key finding

Patients and health professionals are concerned about the ability of health professionals to draw accurate conclusions through telehealth

Linked to the previous issues, we have tried to shed some light on whether the various user groups are confident health professionals can draw accurate conclusions when using telehealth. This is indeed a very important element behind user acceptance that has been extensively investigated in the scientific literature in an attempt to assess whether there are important differences in terms of clinical effectiveness - the measure of the extent to which a particular intervention works from a clinical point of view - between face-to-face and telehealth consultations.

The literature told us, however, that evidence regarding the effectiveness of telemedicine is still limited, but also that there are concerns among health professionals regarding their ability to provide adequate care through telehealth and make accurate decisions based on the results of telehealth consultations and remote gathering of patient's data.

Some studies have reported that patients themselves are concerned about clinical effectiveness. Some patients believe that despite technological improvements it is not always possible for health professionals to ensure the same degree of accuracy of face-to-face consultations when using telehealth. Other studies, reported that some patients are concerned about the expertise of the professionals they do not know monitoring their health status remotely. Accordingly, they declared that they would use telehealth only if they knew all the professionals involved in looking after them. On the other hand, one must keep in mind that perception of clinical effectiveness is highly subjective and context-specific, since some other studies suggest that the patients are quite satisfied with the health professionals' ability to use telehealth.

These concerns are largely confirmed by our online survey which revealed that 40% of patients believe that using telehealth health professionals are not able to draw conclusions as accurate as they would do during conventional face-to-face visits. Similar concerns where shared by patients and health professionals in the national workshops.

In this sense and linked to patients' views and literature review findings, there is unanimous consensus among the healthcare professional community that telehealth should not replace face-to-face contacts with patients.

Recommendation

Further research should be done on the clinical effectiveness of telehealth and the ways it may contribute to raising the quality of patient care.

In addition to the issues discussed in the previous paragraph, our project identified other potential barriers of telehealth, this type user-specific. These are presented below.

4.5.1.4 Affordability of telehealth services for patients

Key finding

Telehealth services can result in significant extra economical costs for the patients, mainly due to the lack of clear reimbursement schemes across the European countries.

As previously elaborated in Paragraph 4.4.2.3 Economic benefits there is large consensus among patients on the fact that the possibility offered by telehealth to eliminate unnecessary face-to-face visits can yield important economic benefits for patients and their relatives, e.g. reduced costs of ambulatory visits, less travel expenses, etc.

On the other hand, however, patients pointed out that such savings could be offset if the costs linked to the use of telehealth are to be borne by the patients, which could result in significant extra economical costs for the patients, making these services unaffordable to many patients, especially the low-income ones.

The issue was discussed in some national workshops where some patients expressed concerns vis-à-vis the fact that patients may ultimately be requested to bear the entire costs for the purchase and maintenance of telehealth tools and perhaps pay high fees for telehealth consultations. In relation to the latter point, the online survey told us that only one every four patients (25%), notably the better-off ones, would be ready to pay more if telehealth delivered other benefits, while one every three patients (33%) declared they would not pay more for telehealth no matter the benefits this could bring to them.

All this suggests that although we have been only partially successful in involving the low-income component of the patient population, patients do have concerns regarding the affordability of telehealth and the potential negative implications in terms of health inequality if only better-off patients could ultimately afford telehealth and rip the benefits of it.

4.5.1.5 Health professionals' concerns regarding the lack of clarity of legislation applicable to telehealth

Key finding

The lack of harmonised legal framework on telehealth in the EU leaves health professionals concerned as to their liability when providing telehealth services.

Chain of Trust confirmed that there still are some major barriers to health professionals' adoption of telehealth, some of which are country-specific, which need to be addressed through appropriate regulatory action or other measures, and for this reason it can be more difficult to overcome. These issues ranges from licence - such as whether a health professional is actually entitled to provide healthcare remotely or in a country where they do not have a practicing license, malpractice liability, and reimbursement schemes for telehealth.

The current situation is characterised by a lack of harmonised legislation of telehealth across the EU. The health professional's liability when dealing with telehealth is not always clear and varies at regional/national level.

As regards the legal aspects of the data sharing and the scope of liability insurances, the health professionals expressed serious concerns. It is not always clear whether sharing of data by e-tools is allowed under the regional/national legislation. Furthermore, it is even more unclear whether insurances for health professionals cover this kind of legal breaches and to what extent.

The issue at stake here is that although telehealth has been growing and expanding especially over the last ten years, the legal and regulatory environment has visibly lagged behind. It is not surprising, therefore, that health professionals singled out legal and ethical issues associated with telehealth as one of the most important issues hampering its large-scale adoption.

Recommendations

- National legislation in the EU does not always allow health professionals to provide treatment and care to their patients through telehealth means, but only in face-to-face circumstances. A call is made on national legislators to engage with national health professionals associations to assess whether updating legislations on the issue is needed and to what extent.
- Health professionals' liability when dealing with telehealth is not always clear and varies at regional/national level. Regulators are called to further clarify all issues pertaining to liability of professionals when providing healthcare services through the use of telehealth.
- Early cooperation throughout the design of telehealth services among providers (e.g. hospitals), payers (such as insurance companies) and suppliers (IT companies) is crucial to ensure that services are well connected. Developing common standards and common terminology is key to achieving interoperability and requires proactive engagement of all the main stakeholders implicated in or impacted by the implementation of telehealth solutions

Key finding

Health professionals are not willing to further deploy telehealth as long as telehealth services do not become an integral part of the reimbursement schemes of public or statutory health insurance

based services, as well as of the reimbursement schemes of private health insurers.

Undoubtedly, one of the most important barriers for the large-scale deployment and sustainability of telehealth is the lack of adequate reimbursement regulations favouring health professionals. More than a decade-old, this problem is still a main reason of rejection of telehealth by professionals.

Chain of Trust findings confirmed that as long as telehealth services do not become an integral part of the reimbursement schemes of public or statutory health insurance based services as well as of private health insurers, health professionals have either the risk of not being allowed to practice telehealth by their employer, or of losing their own money in a self-employed setting.

4.5.1.6 Lack of technical support and promotion of telehealth by the management of the workplace

Key finding

There is a general feeling among health professionals that telehealth is not properly promoted and supported by their workplace management.

Among the problems identified by the Consortium as major barriers for the uptake of the telehealth services is the lack of promotion of telehealth services by the healthcare managers.

Only 20% of health professionals who responded to the Chain of Trust survey indicated that the management of their workplace promoted the use and implementation of telehealth. Although there is willingness within the group of the non-user health professionals to use telehealth, there is a lack of support and promotion of telehealth from the side of the management of the workplace. This finding is quite indicative of the need to generate interest in the opportunities of telehealth among health managers and favouring the dialogue between the latter and health professionals regarding the introduction of telehealth in the workplace.

What is stated is that it is crucial for the implementation of telehealth services needs to start from the management side, having health professionals and patients willing to use them is not enough. Thus, effort needs to be put from the management side to push for investments, organisational changes, and support to health professionals in using these services.

4.5.1.7 Increased workload of health professionals

Key finding

Telehealth shall not increase the workload of health professionals

Looking at the findings of the literature review, one of the main concerns health professionals point out when asked to name some of the perceived barriers to the diffusion of telehealth practice is the potential increased health professionals could face as a result of the integration of telehealth in routine care.

From the online survey responses analysis it is evident that that health professionals believe that telehealth does not contribute to decreasing their workload. Instead they are convinced telehealth could actually generate more workload, especially in the short term, as emphasised by the participants of the national workshops who already adopted telehealth as part of their normal practice. It is interesting to observe that a small proportion of health professionals using telehealth see a reduction in their workload and almost half of the users disagree with the statement “telehealth helps to reduce workload”. Only 30% of health professional users of telehealth who responded to the survey declared the introduction of telehealth resulted in a reduction of their workload, implying that more effort needs to be put into investigating the impact of telehealth on

healthcare delivery's processes.

By contrast, a non-neglectable segment of non-user professionals who participated in the national workshops stated that no one can say a priori whether this would be the case and emphasised that to avoid negative effects on workload it is crucial to start from the needs of health professionals when considering integrating telehealth in routine practice.

4.5.1.8 Health professionals' concerns regarding patients' ability to use telehealth

Key finding

Interestingly, while most patients seem to be quite confident about their own ability to understand information provided by health professionals during a telehealth encounter, health professionals seem to be less confident about patients' ability to understand instructions and advices received through telehealth.

Findings from the literature review suggested that health professionals, particularly doctors and nurses, seemed to be concerned about patients' ability to use telehealth services, and this was defined as a barrier to using telehealth, especially when the service entails a certain transferring of responsibilities to the patient for the management of the condition. The survey suggested a different pattern as the agreement with this depends on whether the professionals have used telehealth or not. A much greater percentage of health professionals who have provided telehealth services are confident their patients are adequately equipped to use telehealth services.

The European focus groups validated the result of the online survey suggesting that health professionals' trust in patients has a direct link with the training of the patient: the more trained the patient is the more trust from the professional. Additionally, the patients' group recommended IT companies to provide trainings to end-users.

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