

A close-up photograph of several hands of different skin tones clasped together in a circle, symbolizing unity and trust. The hands are positioned against a light blue background, and the bottom of the image features a green gradient bar.

PROJECT'S REPORT: MAIN FINDINGS & FINAL RECOMMENDATIONS

CHAIN OF TRUST

UNDERSTANDING PATIENTS' AND
HEALTH PROFESSIONALS' PERSPECTIVE
ON TELEHEALTH AND BUILDING
CONFIDENCE AND ACCEPTANCE





Dear Reader,

We are delighted to share with you findings of the Chain of Trust Project entitled “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. The main objective is to assess the perspective of the main end-users of telehealth services across the EU, exploring whether and how views have evolved since the initial deployment of telehealth, and what barriers still exist to building confidence in and acceptance of this type of service delivery. You can learn more about this project at www.chainoftrust.eu.

This report presents the main findings of the activities implemented by the Chain of Trust Consortium. These activities consisted of a literature review, an online survey and six national workshops, undertaken to gather information on the views and perceptions among patients and health professionals regarding the benefits of telehealth services and their concerns. Four European Focus Groups were held to develop evidence-based policy recommendations to be carried forward at both European and national level.

The findings and recommendations have been presented and discussed at six national roundtables – in Greece, Latvia, Poland, Portugal, the Netherlands, and Norway (the same countries of the national workshops) – with a view to raising awareness among national stakeholders on the project findings and recommendations and promoting the integration of users’ perspective into their national telehealth strategies and programmes.

We are confident that this report will be useful to many of you working in the field of telehealth and eHealth in your efforts to develop policies and services that meet the expectations of the end-users.

With best wishes,
The Chain of Trust Consortium

FOREWORD

BY THE CHAIN OF TRUST CONSORTIUM

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1. THE CHAIN OF TRUST PROJECT

1.1. BACKGROUND

Telehealth refers to the delivery of healthcare at 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

Despite wide acknowledgment of the potential benefit of telehealth services, its use remains limited and with wide disparities across and within Member States due to a number of factors. One of these is poor awareness and a lack of confidence from patients and health professionals. There is in fact little knowledge and evidence about how those who are ultimately meant to use telehealth services actually perceive and experience telehealth.

Entitled “*Understanding patients’ and health professionals’ perspective on telehealth and building confidence and acceptance*”, the European project Chain of Trust was launched in January 2011 to bridge this gap. All target groups identified for this project were represented by their leading representative EU umbrella organisations. Various activities have presented the opportunity to voice their views and have enabled the Consortium to gather qualitative information that reflects both common issues across users as well as aspects particular to the specific groups.

¹ Telehealth should not be confused with eHealth, which according to the definition used by the World Health Organisation (WHO), 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.



1.2. OBJECTIVES OF THE PROJECT

Chain of Trust aimed at seeing whether and how views have evolved since the initial deployment of telehealth, and what barriers still exist to building confidence in and acceptance of this innovative type of service delivery among end-users.

The paramount goal of the project was to advance understanding of end-users' perspective on telehealth services and ultimately enable patients and health professionals across the EU to benefit from the opportunities offered by telehealth.

In order to achieve this goal, two specific objectives were defined:

- To improve available knowledge of the specific views - needs, perceptions of the added value and concerns - among patients and health professionals with regard to telehealth services.
- To increase awareness and understanding of users' perspective on telehealth among patients' and health professionals' organisations as well as health authorities at European and Member State level.

1.3. THE CHAIN OF TRUST CONSORTIUM

The **Consortium partners** are leading European and national umbrella organisations representing the main end users of telehealth services – doctors, nurses, patients, pharmacists and a telehealth competence centre:

Project leader



European Patients' Forum (EPF)



European Federation of Nurses Associations (EFN)



Norwegian Centre for Integrated Care and Telemedicine (NST)



Pharmaceutical Group of the European Union (PGEU)



Standing Committee of European Doctors (CPME)



The Latvian Umbrella Body of Disability Organisations (SUSTENTO)

An **Advisory Board** composed of key e-Health stakeholders at the EU level ensured wide dissemination and outreach of the project findings to relevant groups that were not represented in the Consortium, in order to raise awareness and create synergies between the project and broader e-Health initiatives at the EU level.

Individuals from a cross-section of the patient and health professional community constituted an **End-User Interest Group**. The role of the group was to provide feedback on the project's processes and deliverables, thus forming one pillar of the project evaluation.

1.4. METHODOLOGY



In parallel with the set objectives, the project has been structured around two clusters of activities. The first cluster was dedicated to gathering knowledge on users' perspective and experience of telehealth and the second focused on awareness-raising of such knowledge.

First cluster: Information gathering

This first cluster comprised a mix of quantitative and qualitative methods and approaches to assess the views of patients and health professionals on telehealth.

1.4.1. BASELINE ASSESSMENT: THE LITERATURE REVIEW

During the first quarter of 2011, the Consortium conducted a literature review; 168 sources of scientific and grey literature were identified and reviewed. The analysis provided an overview of the existing knowledge on users' perspectives on telehealth and highlighted a number of under-researched areas and knowledge gaps requiring further investigation.

1.4.2. MOVING BEYOND: THE ONLINE SURVEY

An online survey targeting the four user groups – patients, doctors, nurses, and pharmacists – was run during the

summer of 2011. The purpose 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. Two questionnaires available in 13 languages² were used, one for patients and one for health professionals, addressing both users and non-users of telehealth services.

A total number of 6,704 responses were received (1,646 from patients and 5,058 from the three health professional groups) from 30 European countries (all EU Member States plus Norway, Iceland, and Lichtenstein). Data were analysed through different approaches: exploratory analysis of data frequency by group and all questions as variable; exploration of demographic data including general frequency tables and cross-table analysis; 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.

1.4.3. VALIDATING THE FINDINGS: THE NATIONAL WORKSHOPS

The online survey was followed by six national workshops, organised in Greece, Latvia, the Netherlands, Norway, Poland, and Portugal between October and December 2011.

The main purpose of the workshops was to validate and complement the findings of the previous two activities. In total, 240 participants attended the national workshops, split 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 consolidate the primary project findings. User and non-user participants representing the four different interest groups enabled the capture and comparison of the diverse views and perceptions that exist in relation to telehealth among end-users.

1.4.4. MAKING RECOMMENDATIONS: THE EUROPEAN FOCUS GROUPS

The four European focus groups, each dedicated to one end-user group, were held in Brussels in January-February 2012 and attended by 42 participants. The main aim was to further complement and validate the information collected through the previous activities, and to translate the project findings into a set of recommendations to be taken forward in the activities scheduled for the second phase of the project.

² English, French, German, Polish, Norwegian, Latvian, Greek, Portuguese, Dutch, Spanish, Italian, Romanian, and Lithuanian.

Second cluster: Raising awareness

The project used a variety of methods to raise awareness of the knowledge collected in order to advance understanding of the perspective of the users of telehealth services.

The consortium partners informed other telehealth projects and initiatives (European and national) giving presentations, organising workshops and other joint activities about the project findings.

Communication materials (two videos and one report) were developed to disseminate the project findings to a wider audience and to inform and shape current and future policies on telehealth.

1.4.5. SHARING FINDINGS AND RECOMMENDATIONS: THE NATIONAL ROUNDTABLES

Six national roundtables were held in the same countries as the national workshops. The audience was broadened to ensure that all relevant telehealth stakeholders could participate: policy-makers, industry, health authorities, insurers etc.

The purpose of these events was to raise awareness on the project findings and policy recommendations and to promote the integration of users' perspective in national telehealth agendas and plans. Press conferences were held following the events to disseminate the project results at the national level.

1.4.6. SHARING THE PROJECT'S RESULTS: THE EUROPEAN CONFERENCE

A closing conference was held on 24 January 2013 to share the project's main findings and recommendations with a wide range of stakeholders. Some 100 stakeholders attended the conference, where the project outcomes were presented and the participants explored opportunities for integrating those into future Telehealth and eHealth policies and strategy.



1.5. NOTE TO THE READER

The term User/s

In the project and in this report we use this term with two meanings:

1. Targeted end-users of telehealth applications and services: doctors, nurses, patients and pharmacists;
2. Those end-users within the above groups who have specific experience of telehealth applications and services (or not, in which case we refer to them as non-users).

Citizens vs Patients

While the project aimed principally to explore the views of patients with chronic conditions, inevitably we reached patients who do not fall within this category. This is true mainly for the respondents to the online survey.

However, we have not found disparities in the thinking and perceptions of the two groups and therefore consider the project findings and recommendations applicable to both. Nonetheless, it has to be noted that the seriousness of a chronic condition determines the extent to which a patient will value the benefits, risks and trade-offs of using telehealth services.



Reports, presentations, video and other project-related materials can be accessed at www.chainoftrust.eu



- What do users know about telehealth?
- Where do they find information?
- Do they use telehealth services?
- If so, what is the benefit and what would they like to improve?
- If not, what are the barriers?
- What role does trust play in their choice whether or not to use telehealth services?

A number of user-related questions were identified at the start of the project: What do users know about telehealth? Where do they find information? Do they use telehealth services? If so, what is the benefit and what would they like to improve? If not, what are the barriers? What role does trust play in their choice whether or not to use telehealth services?

These questions still remain largely unanswered some twenty years after the dawn of telehealth services, as was confirmed by the findings of the project activities.

This report intends to answer these questions based on information collected through the various project activities. The following pages present a unique assessment of the views, needs, barriers and benefits related to telehealth from the perspective of patients and health professionals³. The findings illustrate differences and existing similarities in the national and the European context as well as between patients and health professionals already using telehealth services versus those who have not used them.

We hope the findings and the recommendations will be used to inform policies and decision-making processes at various levels: primarily the European Institutions, Member States' health authorities, industry and other eHealth stakeholders.

2. THE PROJECT FINDINGS

³ We use the term "health professionals" to cover doctors, nurses and pharmacists.

2.1. USERS' KNOWLEDGE OF TELEHEALTH AND CURRENT AND POTENTIAL USE

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

Moreover, there is still a widespread lack of understanding of telehealth among the user population, especially the patients. This is the case even in countries where eHealth and telehealth is already widely used.

In an attempt to identify the causes of this poor understanding, patients who participated in the national workshops pointed out the lack of targeted user-friendly communication and information on these services, especially on the benefits telehealth can deliver to people with chronic conditions requiring long-term care.

Health professionals are generally more aware of telehealth, and specifically of how it could eventually improve the way they provide healthcare to their patients. Most health professionals who defined themselves as familiar with telehealth said that their awareness of the services does not necessarily entail previous use.

In addition, the survey showed that health professionals play a major role in informing patients and citizens at large about telehealth services. One in two patients who declared some knowledge of telehealth reported that he/she had received this information from their health professional.

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 user groups.

Despite this poor overall awareness of telehealth, patients and health professionals are generally quite willing to use telehealth.



17% of patients
and 34% of health
professionals
are moderately/
very familiar with
telehealth services.⁴

⁴ This and all subsequent pull-outs are derived from the CoT online survey.



For example, the online survey revealed that while 92% of patient respondents are keen to play a more active role in managing their own condition - which is a fundamental element inherent to the success of telehealth services, hence an essential precondition for acceptance of these services - only 60% of those who have never used telehealth would be willing to actually do so in the short-medium future.

In relation to health professionals, the online survey identified that 70% (all three groups considered) of those who have never used telehealth before would be willing to use it in the short-medium future, but only one in five respondents reported that the management in their workplace promoted the use of telehealth.

Only 29% of health professionals believed that their patients would be in the position to use telehealth services safely. Failing to take measures to ensure health professionals are fully confident in patients' ability to use telehealth safely could ultimately lead to poor willingness to use these services.

The Chain of Trust also found that there is 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 user groups.

All these elements present an opportunity that should be exploited by policy makers in shaping telehealth and eHealth policies, as well as by manufacturers and health organisations when designing and deploying telehealth applications and services.



60% of patients and 70% of health professionals who have never used telehealth would be willing to use it.

2.2. MAIN ISSUES REGARDING **USERS' TRUST AND ACCEPTANCE**

The Chain of Trust revealed that there are still some issues which need to be addressed in order to foster user acceptance of telehealth. These issues can be considered as challenges, opportunities and benefits depending on where we stand in responding to the expectations of those who are ultimately using them.

Not surprisingly, patients and health professionals who have never used telehealth services tend to have more negative views than those who have used telehealth.

In this section we also question some common beliefs on certain issues that are widely considered to be challenging, but which in fact, according to the project findings, can be easily addressed.

2.2.1 THE **HUMAN DIMENSION**

There is a general consensus among health professionals and patients that advances in telehealth have largely been driven by technology and manufacturers rather than by the needs of people. Elements such as human interaction, changing relationship between patients and health professionals, the needs of users, and the relation between users and technology have been largely side-lined, while there is sufficient evidence in the literature and from this project to suggest that these factors are actually crucial to building confidence and trust.



Patient-health professional relations

Building confidence in telehealth is 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 use healthcare services at all, let alone disclose all relevant information that is needed by health professionals to make informed decisions. One of the findings of the Chain of Trust project is that trust does play a key role in shaping patients' and health professionals' decisions on whether to adopt and use telehealth.

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. In the contrary, it is even more important, since the virtual consultations require greater levels of mutual trust among users.

The negative impact of telehealth on patient-health professional relationships and communication could become a major barrier for adoption.

According to the project findings, there is no clear-cut view as to whether and how telehealth could change communication between patients and health professionals. 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 services, despite the fact that the majority of professionals who have used some form of telehealth have reported high levels of satisfaction with these services.

Those who perceive telehealth services negatively tend to emphasise the fact that technology-mediated communication results in patients becoming "objects" of healthcare. In their opinion, telehealth consultations do not allow health professionals to capture patients' emotions and feelings; thus the importance of psychological factors in the whole process is neglected.

Many patients added that they would only use telehealth if they already know the health professionals who will be involved in the process, suggesting that a previously established trust-based relationship is a major precondition to a patient's adoption of telehealth.

These findings tell us that no matter how efficient and reliable a telehealth-based encounter is, it cannot fully substitute face-to-face contact between health professionals and patients. Focusing on the changing interaction between different user groups at the two ends of telehealth will thus be key in promoting the uptake of these services.



61% of patients/non-users and 75% of patients/users believe that telehealth helps to stay more in touch with their health professionals



56% of health professionals/non-users and 68% of health professionals/users believe that telehealth helps to stay more in touch with their patients

2.2.2 THE DELIVERY OF HEALTHCARE

Role of telehealth in relation to conventional healthcare

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 does not intend to replace face-to-face services, and should not be presented as such.

Instead, we should insist on the added value of telehealth to current healthcare services, insofar as it enables integrated care pathways in which face-to-face contacts between patients and health professionals are complemented by regular remote monitoring and exchange of information.

Our findings indicate that to ensure acceptance and adoption, telehealth needs to be integrated into mainstream healthcare services as a complement to and not as a replacement of conventional services.

On the basis of the outcomes of the project activities, we can comfortably say that both patients and health professionals believe that telehealth services, if properly implemented, can reduce burden to the conventional health services. However, in order to avoid undermining mutual trust and to 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 when using telehealth services.

Access and health inequalities

The issue of access and affordability of care for low-income patients was raised in some national workshops. Some patients expressed concerns over the fact that patients may ultimately be asked to bear the entire costs for the purchase and maintenance of telehealth tools and perhaps pay high fees for telehealth consultations.

Moreover, it was highlighted that since low-income and old people have very little access to broadband internet, there might be a risk that only the better-off could ultimately benefit from telehealth.

The Consortium concluded that if we fail to pay thorough attention to current socio-economic, gender and health literacy inequalities to ensure wide accessibility and affordability of telehealth, chances are that existing inequalities would persist or even be exacerbated by the large-scale introduction of telehealth.

Patient safety

A conclusion that can be drawn from the results of the Chain of Trust activities is that health professionals and patients will accept telehealth services only as long as they have at least the same safety and reliability standard as conventional health services.

Telehealth enables health professionals to acquire information on their patients on a more regular basis and therefore to react more promptly. Therefore one would expect that the introduction of telehealth services is conducive to higher patient safety compared to conventional care alone.

However, the literature review indicated that while there are some studies that show a positive correlation between telehealth and patient safety, there is still very little evidence on patient safety in telehealth services. 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 of the emerging safety issues associated with telehealth.



These 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 error⁵.

Therefore, in project's activities safety and reliability-related issues were singled out as problematic for telehealth acceptance, particularly for health professionals.

According to the online survey, half of patient users think that telehealth is as safe as face-to-face services, while non-users tend to think that patient safety is reduced when using telehealth. Views among health professionals are not that different, with half of the users and 30% of non-users indicating that telehealth would be as safe as traditional healthcare services.

These findings were only partially confirmed by the outcomes of the national workshops and the European focus groups.

The feeling that telehealth is at least as safe as face-to-face health services was shared by the slight majority of health professionals and patients who participated in these activities. Some of them emphasised that if implemented properly, telehealth could bring about improvements in terms of patient safety.

Although these findings do not make it possible to draw definitive conclusions as to whether telehealth is considered at least as safe as conventional practice, a key message here is that decisions on whether to adopt telehealth will depend to a great extent on its perceived effects on patient safety.

Organisational aspects

According to the literature review, organisational aspects represent one of the most significant obstacles to telehealth acceptance among health professionals. Telehealth always entails a change in routine, and it is not clear whether this is what health professionals actually want or need. The literature emphasised that change often implies that something is not working optimally, and this contrasts with some professionals' view that they are already providing the best care to their patients.

This could explain why various studies have reported that health professionals resist the adoption of telehealth more than patients.

Another problem identified by the project as challenging for the uptake of telehealth services is the lack of promotion of telehealth services by the healthcare managers. Although there is willingness within the group of non-user health professionals to use telehealth, they resent a lack of support and promotion of telehealth from the management side in the workplace. This indicates the need to generate interest in the opportunities of telehealth among health managers and to favour dialogue between the latter and health professionals regarding the introduction of telehealth in the workplace.

With regard to workload, only a minority of health professionals believe that telehealth contributes to decreasing their workload. Instead, they are convinced that telehealth could generate more workload, especially in the short term. This finding was supported by the experience of participants in the national workshops who were already providing telehealth services as part of their normal practice.

 30% of health professionals/users and 10% of health professionals/non-users think that telehealth reduces their workload

 21% of health professionals said that their management team promotes the use and implementation of telehealth in their service and 43% of health professionals said that their management team does NOT promote the use and implementation of telehealth in their service

⁵ 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.

2.2.3.

CAPACITY OF USERS**Too much responsibility on patients' shoulders**

One in five patients who are non-users of telehealth believe that it would put too much responsibility on their shoulders, clearly pointing to the latter as an element which, if not addressed, is likely to represent an obstacle. This figure rises to one in four patients who said they use telehealth.

The online survey shows that patients either are not confident that they have enough knowledge and the skills required for using telehealth or are not comfortable handling the responsibilities that telehealth involves.

This once again underlines the importance of ensuring that telehealth is supported with adequate health literacy and digital literacy programmes for patients.

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

Self-confidence: usability, technology, skills


One of the most common barriers to user acceptance of telehealth is a perceived lack of knowledge and skills needed to be able to use telehealth. This competence and confidence issue applies to both patients and health professionals, and represents a key variable influencing acceptance of a telehealth service. 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 using telehealth.

The majority of patients using telehealth services indicated that telehealth services are easy to use. An interesting element is that those patients who received training in telehealth thought it was easy to use (more than half of them) while those who did not receive any training found it more difficult.

When looking at the relationship between the questions whether health professionals received 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.



 18% of patients/non-users and 24% of users believe that telehealth would put too much responsibility on patient's shoulders

 37% of non-users and 72% of users in all four groups believe that telehealth is easy to use

Lack of appropriate education and training is perceived as having potentially negative impacts on health professionals' perception of their ability to integrate telehealth into their workflow while ensuring efficiency and patient safety.

Further to the need to address different ways of training, both patients and health professionals groups call on manufacturers to take the 'usability framework' - machines that are easy to use - into account when designing telehealth applications, emphasising the importance of ensuring that applications are simple, user-friendly, and aligned with real user needs.

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

In conclusion, while acknowledging that "technology-related anxiety" - a negative psychological reaction to

technology - has a significant negative impact on attitude and intention to use telehealth, from a user-point of view technology does not seem to be the real issue. Many technology-related concerns could be resolved through integration of user requirements and effective education and training.

2.2.4.

THE LEGAL FRAMEWORK

Lack of clarity in legislation

Chain of Trust confirmed that there still are some barriers to health professionals' adoption of telehealth, which need to be addressed through appropriate regulatory measures. These issues range 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 - to malpractice liability and reimbursement schemes for telehealth.

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

Health professionals expressed serious concerns regarding the legal aspects of data-sharing and the scope of liability insurances.

It is not always clear whether sharing of data by e-tools is allowed under the regional/national data protection legislation. Furthermore, it is even more unclear whether insurance for health professionals covers the potential harm that can arise and to what extent.

Another issue is the lack of adequate reimbursement regulations. Chain of Trust findings confirmed that, as long as telehealth services do not become an integral part of the reimbursement schemes of public health insurance-based services as well as of private health insurers, health professionals will not integrate telehealth into their practice.

It therefore seems that although use of telehealth has been expanding, especially over the last ten years, the legal and regulatory environment has lagged behind. It is not surprising, therefore, that health professionals singled out these issues as among the most important factors that from their perspective hamper the large-scale adoption of telehealth.



Privacy and confidentiality

For the purpose of this project we consider “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 the patient’s right 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 them.

Privacy and confidentiality are commonly regarded as barriers to adoption of telehealth among users. However, all the project activities revealed that patients are willing to compromise on certain aspects of their **privacy** if telehealth would prove to yield other benefits such as increased independence for elderly patients.

The online survey indicated that only a minority of user respondents considered telehealth to have negative implications for patients’ privacy. Less than half of 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.

The survey also revealed that only 13% of patients think telehealth would not fit into their daily lives, indicating that any potential burden is offset by the opportunity to stay in their home environment and enjoy independence, as suggested by some patients in the national workshops.

When it comes to **confidentiality**, the situation is less clear. While from the health professionals’ point of view this is not a major issue in telehealth, the patients’ perspective leaves some issues open.

While the online survey revealed that only 18% of patients believe telehealth could put confidentiality of personal health data at risk, security-related issues emerged very clearly in five of the six national workshops, 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 potential misuse of data and the adverse social consequences of such unauthorised access, e.g. stigmatisation, social discrimination, etc.

At the same time there is a non-negligible group of patients who attach less importance to risks of inappropriate disclosure of sensitive health information. These are usually patients who expect or have enjoyed benefits from telehealth and for whom such benefits outweigh the risk of a damage caused by potential breaches of confidentiality. Patients who use or have used telehealth services tend to be far less concerned.

Turning to health professionals, the literature review highlighted some concerns regarding the lack of clarity of data protection legislation and the risk of facing legal consequences, such as a claim for negligence, breach of contract or breach of confidence. The literature also showed that unauthorised access is a concern for health professionals, as it may affect the integrity and authenticity of patient data. These issues re-emerged in the various national workshops, but there is a general feeling among health professionals that all security-related issues in telehealth can be addressed effectively, just as they were dealt with in other ICT-intensive services.

Although they express several concerns, most patients and health professionals think that overly strict data protection and security systems should not hinder the transfer and sharing of health information, and ultimately the health service. This insofar as effective security and informed consent provisions and procedures are put in place and the users are properly informed about them.



58% of patients
and 69% of health
professionals say
that telehealth
helps to increase
the quality of health
services

2.3. BENEFITS FROM THE USERS' PERSPECTIVE

The usefulness and advantages of telehealth were acknowledged by all four groups of users considered by this project, with no large variations across groups. Perceptions of benefits depend on people's expectations of telehealth. Overall, users tend to have more positive attitudes towards telehealth especially in the way they perceive benefits.

The literature indicated that perceived benefits of telehealth for health professionals *vis-à-vis* conventional services tend to be less significant than benefits for patients. While health professionals may see only changes in routine, patients identify immediate benefits such as more personalised treatment and care plan, better quality of life and reduced travel.

However, Chain of Trust activities demonstrated that this statement is only partially true. Health professionals, regardless of whether they actually use telehealth, do not seem to narrowly regard telehealth as a process of technology inclusion within 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.

In this section we therefore present the main benefits of telehealth as perceived by users. We begin by presenting benefits that are common to the four user groups and conclude with an overview of patient- and health professional-specific benefits.

2.3.1. COMMON BENEFITS

Improved quality of care

One of the benefits of telehealth identified through the project is the contribution to better quality of care. Some studies assessed for the literature review indicate that nurses have positive experience of 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.

Similar to the nurses' views, the majority of physicians and pharmacists think that adding telehealth to already existing conventional services has a potential to improve the quality of health services,

and that therefore telehealth is a valid complement to conventional healthcare services.

Since high quality of healthcare services is the key driver for health professionals, the impact of telehealth on the quality of their services is a major element in their willingness to take up telehealth.

As regards the patients, the majority of the telehealth users indicated that telehealth improved the quality of healthcare; half of non-users agreed with this statement.

Improved access to healthcare

Patients and health professionals believe that telehealth can 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 project in relation to two main aspects: (a) geographical, i.e. whether telehealth can improve access to healthcare for people living in underserved areas; and (b) socio-economical, i.e. whether telehealth can improve access to healthcare for disadvantaged groups of people.

The patients' view is that telehealth has the potential to improve the quality as well as access to healthcare for patients living in underserved areas, and to a lesser extent, for socio-economically disadvantaged patients.



71%
of patients/users

51%
of patient/non-users

60%
of health professionals
think that the addition
of telehealth improves
patients' adherence to
treatment and care

Moreover, they see opportunities to overcome some of the difficulties they face when seeking healthcare, for example in scheduling appointments and travelling to healthcare facilities.

These findings suggest that telehealth could contribute to a reduction of health inequalities and to more accessible and sustainable healthcare. However, the project could not draw a conclusion because the views of patients belonging to lower socio-economic groups were only captured to a small extent.

As regards health professionals, most of them believe that telehealth has the potential to improve access to healthcare, at least geographically; this assumption applies particularly to patients living in underserved areas.

Improved patients' adherence

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

According to the online survey, patients think that through their more active involvement in decisions concerning their health as enabled by many telehealth services, they are more aware of the importance of adhering to treatments, thus improving their adherence.

Regular follow-up by health professionals enabled by the integration of telehealth in chronic disease management is considered to be conducive to better adherence. When asked about whether telehealth improves patient adherence, similar to the patients' view, more than half of the health professionals responded positively.

We can conclude that since patient adherence is among healthcare providers' primary concerns, they would be in principle more willing to accept telehealth if this leads to better adherence among patients.





2.3.2. BENEFITS FOR HEALTH PROFESSIONALS

Improved co-operation with colleagues

Telehealth has a potential to improve co-operation in a healthcare team and this is very positively received by health professionals. This element was extensively explored in the national workshops, especially by the nurses, who emphasised that a major pitfall of current systems of care is that the various health professionals involved in the patient care often do not interact sufficiently. Similarly, pharmacists highlighted that one of the challenges they currently face in delivering services is the lack of communication between pharmacists and the other healthcare providers.

Co-ordinating patient care is challenging, as it takes effort to maintain efficient communication between different health professionals involved and across different health organisations. The potential to facilitate co-ordinated care is a major benefit which health professionals expect of telehealth.

Moreover, telehealth services provide the possibility for health professionals to consult/be consulted remotely (by) their colleagues, thus avoiding unnecessary referrals and travel, and offer expertise and support that reduce professional isolation.

However, this co-operation through telehealth cannot take place without interoperability of systems. The health professionals who participated in the national workshops flagged the lack of interoperability between systems used in different hospitals and other healthcare facilities. They believe that, if not promptly addressed at national and European level, these issues could negatively affect collaboration in a healthcare team and health information exchange, to the detriment of quality of care and patient safety.

Continuity of care

The literature review indicated that health professionals tend to have positive perceptions of telehealth insofar as these services enable them to have a more continuous therapeutic relationship with patients and increase the quality of healthcare they provide.

The results of the online survey and the national workshops show that health professionals acknowledge that telehealth helps them to stay more regularly in touch with their patients,

which is a fundamental condition for maintaining trust and caring for people with chronic conditions.

Regardless of whether they actually use telehealth, they do not seem to be looking at telehealth just as a process of technology inclusion in healthcare. Rather, they acknowledge that adding telehealth to the conventional care has a potential to change the delivery of care for the better and to enable the active participation of patients in their own care, which they perceive as a desirable outcome of telehealth.

2.3.3. BENEFITS FOR PATIENTS

Patient empowerment

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

The majority of patients using telehealth answered positively to the online survey statement “telehealth helps improving my knowledge of my health condition”. Increasing knowledge on one’s health condition is indeed a pre-requisite for patient empowerment.



80% of health professionals/users think that telehealth can improve co-operation among health professionals



68% of health professionals/users and 55% of non-users said that telehealth helps them to stay more regularly in touch with patients



92% of patients would like to play a more prominent role in the care process

Although it is an important aspect, only a few studies have explored the issue of whether 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 project 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. The national workshops expanded on this subject, highlighting the opportunities presented by telehealth to favour the involvement of patients in decisions concerning healthcare and in the management of treatment and care. Increased confidence in dealing with their symptoms and greater independence were also mentioned as positive outcomes of telehealth contributing to the empowerment of patients.

Quality of life

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, increased self-confidence, better awareness of symptoms or improved independence.

Chain of Trust suggests 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 the patient's health status.

Only 17% of non-user patients and 43% of users who responded to the online survey believe that the use of telehealth would contribute to significant health improvement. For the health professionals, 21% of non-users and 49% of users are positive about this point.

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

A significant element indicated by patients is 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, combined with the possibility to alert health professionals in real time in case of early indicators of deterioration, is regarded as significantly reassuring. This is relevant also for informal carers looking after the patient, thus suggesting that telehealth could bring benefits and quality of life improvements for them as well.

However, the information gathered by the project does not permit any definitive conclusion regarding whether or not telehealth in the view of patients and health professionals could lead to improvement in a patient's health condition as well as other quality of life-related aspects.

It is nonetheless an important expectation from the patients' perspective which should not be neglected.

Economic benefits

There is consensus among patients and health professionals on the fact that telehealth can yield some 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 sick leave days caused by their illness.

On the other hand, patients have some concerns regarding the affordability of telehealth for the broad patient population, especially if patients have to bear the costs of the purchase and maintenance of telehealth applications and to pay high fees for telehealth consultations.



17% of patients/non-users, 43% of patients/users, 21% of health professionals/non-users, 49% of health professionals/users think that the use of telehealth would contribute to significant health improvement.



2.6. DRAWING CONCLUSIONS: KEY DRIVERS FOR USERS' ACCEPTANCE

From a user point of view, some of the issues that are traditionally considered as the main barriers to telehealth adoption and wider use may not necessarily be the real issues.

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

In this respect, it is important for fostering acceptance among users to ensure that the following elements are addressed:

- To accept telehealth, patients and health professionals want it to be user-centric as opposed to technology-driven;
- Telehealth should not negatively affect the patient–health professional relationship, but rather aim to increase mutual trust;
- Telehealth needs to deliver real benefits and add value to users in relation to solely conventional healthcare;
- Health professionals and patients will accept telehealth services only as long as they have at least the same safety and reliability standard as conventional health services;
- Self-confidence and competence in using telehealth services and mutual confidence between users, are crucial and should not be underestimated.



3. PROJECT RECOMMENDATIONS

3.1. MAIN RECOMMENDATIONS

Awareness and understanding

1. Awareness campaigns on telehealth services and benefits should be organised at Member State and European level, targeting both patients and health professionals;
2. The adoption of a harmonised European 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 must be user-driven

3. Telehealth services must **embrace users’ needs**. Therefore, patients and health professionals need to lead the design of telehealth services so that their needs, preferences and limitations are optimally addressed;

4. To build trust in telehealth, it is necessary to **maintain face-to-face consultations** between health professionals and patients and to seek agreement in defining the right balance of face-to-face and telehealth-mediated interactions;

5. An incentive system should be introduced to favour the deployment of telehealth services that **lead to user-centred improved health outcomes**. This should be adopted at different levels: policy-making, eHealth action plans; funding and procurement.

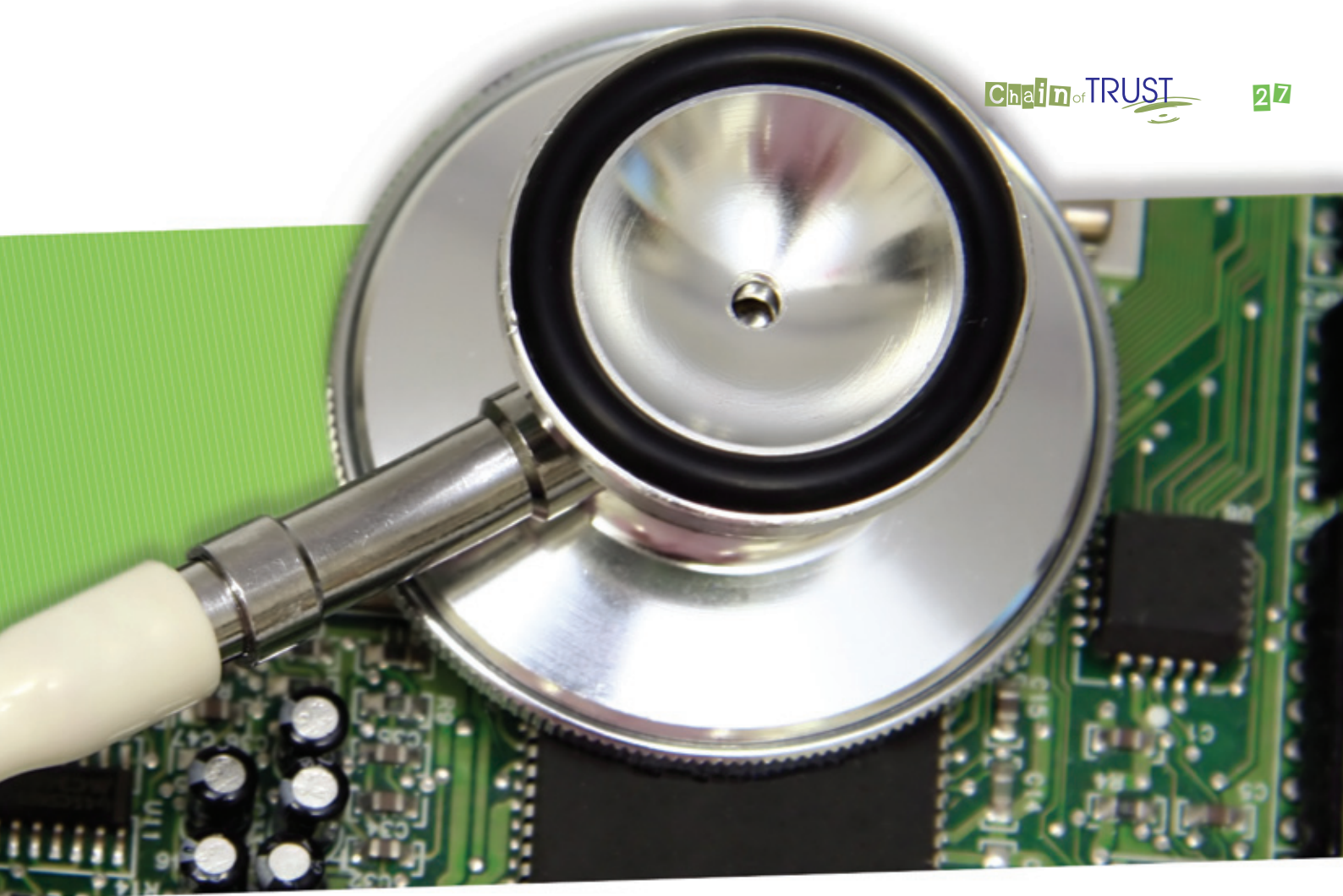
Education and support are a must

6. eHealth- and telehealth-related **knowledge and skills** should be included as a subject in health professionals’ curricula and be part of Continuing Professional Development programmes according to the different professional needs;

7. Patients should be provided with **education and training** to empower them with the skillset required for new ways of communicating and interacting in the use of a telehealth service;

8. **Informal carers** should be provided with access to training and support systems to be able to take up the changes in care entailed by the introduction of telehealth;

9. **Healthcare management** should support health professionals to effectively integrate telehealth in the delivery of care on the 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.



The political commitment that is needed

10. **National strategies** on eHealth and telehealth need to be supported through the involvement of organised civil society, to ensure that they are long-term and minimally impacted by political changes;
11. Institutions responsible for eHealth and telehealth strategies and action plans should engage users as well as other stakeholders in an effective and **transparent dialogue and collaboration** throughout the entire cycle of telehealth services, from development to implementation;
12. European and national strategies on eHealth and telehealth should take into account the need to clarify new roles and responsibilities and to review data protection and security, liability and reimbursement schemes in order to provide **a clear framework** to support wider implementation of telehealth;

13. The EU should support the **creation of synergies** between different telehealth and eHealth initiatives so as to avoid duplication and promote the sharing of good practices that have proved to be secure, safe and cost-effective, while incentivising innovation and competitiveness;
14. The EU should support Member States in providing the required **infrastructure** for telehealth by promoting the use of EU funds, particularly Structural and Cohesion Funds;

Telehealth in support of healthcare delivery

15. Member States should exploit the opportunities offered by telehealth in order to **close the gap** between patients' and citizens' needs for services and their accessibility, quality and equity;

16. **Telehealth must be used to support, optimise and complement the delivery of healthcare;** facilitating co-ordination throughout the healthcare process and between different sectors (social and healthcare) involved, and supporting inter-professional collaboration and teamwork;
17. The implementation of telehealth should go hand-in-hand with setting up **community-based care and support systems** for patients and their informal carers, to ensure a balance between their more active role in self-management and the risk of telehealth adding a burden and responsibilities they are not able to bear.

3.2.

RECOMMENDATIONS SPECIFIC TO HEALTH PROFESSIONALS

- The implementation of telehealth services must be accompanied by supporting organisational changes, equipment availability and education. It is important that the management promote these services when there is added value and incorporate sufficient technical facilities for health professionals to provide high quality care.
- EU funding should support and foster the collaboration of health professionals through the establishment of networks and the development of guidelines for evidenced-based telehealth services, in order to promote efficient, safe and proven practices on telehealth.
- Confidence about using telehealth services applies to patients in terms of both having confidence in themselves and being confident that healthcare providers are competent to provide the services through telehealth applications. There is therefore a need to identify and map the necessary telehealth-related competencies which health professionals must incorporate into their practice.
- Training on eHealth- and telehealth-related knowledge and skills should be included in the health professionals' curricula and be part of Continuing Professional Development programmes according to the different professional needs.
- National legislation in the EU does not always allow health professionals to provide care and treatment to their patients through telehealth, but only in face-to-face situations. National legislators should engage with national health professionals' associations to assess whether legislation on the issue needs to be updated, and to which extent.
- Health professionals' liability when dealing with telehealth is not always clear and varies at regional/national level. Regulators are called on to further clarify all issues relating to professional liability when providing healthcare services through the use of telehealth.
- Early co-operation among providers, payers and suppliers throughout the design of telehealth services is crucial to ensuring that services are interoperable. Developing common standards and common terminology is key to achieving interoperability and requires the proactive engagement of all the main stakeholders involved in or impacted by the implementation of telehealth solutions.

3.3.

RECOMMENDATIONS SPECIFIC TO PATIENTS AND INFORMAL CARERS

- Patients should be provided with education and training to empower them with the skillset required for new ways of communicating and interacting in the use of a telehealth service.
- Informal carers should be provided with access to training and support systems to be able to take up the changes in care entailed by the introduction of telehealth.
- Telehealth services need to be affordable, useful, user-friendly, and must be designed to support daily life and usage. In light of an ongoing assessment, telehealth services should be adapted to the evolving needs of patients and evolving technology.
- The role of informal carers should be acknowledged; they should have equal rights as patients to access training and support mechanisms for managing the additional responsibilities and tasks when caring for patients who use telehealth services. However, telehealth should not add to their burden.
- Telehealth should serve the needs of the most vulnerable patients as a priority. 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, or persons/families having to manage multiple diseases or conditions.
- 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 using patient-centred outcomes as indicators. A quality-control system should be developed for this purpose.
- Further research should be done on the clinical effectiveness of telehealth and the ways it may contribute towards raising the quality of patient care. Future research should also identify how the benefits of telehealth lead to a better quality of life for patients.
- In order to ensure that assessment of Quality of Life (QoL) associated with 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.
- Telehealth services and their usability should be adapted to the evolving needs of patients and evolving technology. As many chronic conditions worsen over time, the needs and capabilities of patients usually change much more quickly than that of people without a chronic condition. Therefore, the needs and capabilities of patients using telehealth have to be regularly re-assessed, while, telehealth services and applications need to be flexible to adapt to these changes.

3.4. RECOMMENDATIONS TO FACE COMMON BARRIERS

- In order to protect privacy and confidentiality, the Consortium recommends that measures be taken at the European 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.
- Appropriate and understandable information on security provisions and procedures should accompany telehealth services so as to increase the trust of users.
- Data protection and security systems should not hinder the transfer and sharing of health information and ultimately the health service. Consent and processing modalities must respond to the expectations of both patients and health professionals.
- In order to increase the confidence of patients and health professionals in using telehealth services, manufacturers should 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 should be used only when there is clear added value to complement conventional healthcare, and provided that the patient-health professional relationship and trust is not undermined by the introduction of telehealth to the services.
- Implementation strategies must be supported with appropriate education and training. E-Health and telehealth strategies need to integrate education and training to provide the necessary education and skills to the end users.

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Project leader



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Chain of TRUST

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

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