User Empowerment in Telehealth Practice: The TeleSCoPE Project Approach

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ABSTRACT

Over the last two decades the use of telecommunication technology has grown popular in clinical practice and healthcare management all over the world. Its spreading, originally aimed at reaching remote areas, has been promoted by the anticipation of a major demand of telehealth services, wedded to the reduction of the availability of economical resources. At present, telecommunication technology offers solutions ready to cover the most diverse health-related issues, and the needs of society as a whole. Simultaneously to the development of the tele-support to traditional care, various debates regarding new possibilities offered by at-a-distance provision of healthcare have cropped up. Jointly rose from the ranks the need for alignment, both within and between the European nations, of the standards for the rising services, in order to facilitate their further use and to create trust around these new born means. The European project TeleSCoPE – Telehealth Service Code of Practice for Europe - is positioned in this framework. The European Code of Practice for telehealth services, the main output of the project, addresses tutelary issues evaluated and agreed among telehealth agents, in a user-centered view. Researching the different aspects related to user safety and satisfaction, rose the issue concerning the role of the users towards their health. The empowerment of the user is such a central matter that it led the partner group to the creation of an unambiguous glossary, where the top-down term "telemedicine" is replaced by "telehealth", highlighting the excess of the merely clinical approach, in favor of an interaction between service provider and user/carer aimed at health in its wider and more comprehensive meaning, then covering social, psychological and physiological aspects, as well as well-being. This paper discusses the core of the TeleSCoPE Code of practice, regarding user empowerment, and provides a small review about the acceptance, the appreciation and the efficacy of personal involvement of users/patients in the provision of healthcare, according to the available literature

Keywords: User Empowerment, Telehealth, User Centred Approach, TeleSCoPE

INTRODUCTION

The beneficial effect which pervasive introduction of ICTs in the healthcare sector may have on both social and economical issues is a central subject of debate in European Commission (EC) agencies. In rigid and regulated contexts such as healthcare, a variation in established treatment protocols is difficult to introduce, if it is not supported and willfully promoted by national and European policy makers. It follows that, despite the maturity of available technological solutions, tangible introduction of ICT in healthcare sector, exceeding the experimental boundaries, is deeply dependent on the effort that policy makers put in its adoption at society level.

Consistently, the "building confidence in and acceptance of telemedicine services" was among the issues addressed in the framework of the Health Programme 2008-2013 "Together for Health". TeleSCoPE project Telehealth Services Code of Practice for Europe (Telescope, 2013), approved within that framework, contributed to EC efforts for technological innovation in healthcare, developing the Telehealth Services Code of Practice for Europe, a quality benchmark for telehealth services assessment and certification.

The Code is the result of a thorough research on existing literature on the subject, combined with feedback gathering from relevant stakeholders (i.e. users and carers associations, service providers, governments and public companies, policy makers etc.), in order to shape the content of the Code around actually established needs. It ranks as a framework in the arena of preventative and public health, establishing a relationship of trust between users and providers, and defining a set of needed operative standards both for clinical health and wider well-being.

The opening to the well-being-related area of health (thus considering the whole telehealth spectrum), makes the TeleSCoPE approach innovative, since the Code does not merely apply to clinical and medical practice, hence not referring to telemedicine only, but extends its regulating scope to all the range of possible health-related service activities that are provided by means of ICTs.

The Code addresses both the role and needs of users in a central way, focusing on the relationships between user and service provider, while trying to put in place a safety and quality guarantee that can protect users in their access to services, giving prominence to their views, choices and perceived satisfaction about the provision. This approach, therefore, both empowers users and makes them more aware, more involved and more active in the management of their own health.

TELESCOPE CODE OF PRACTICE

Structure of the Code

TeleSCoPE Code of Practice (Telescope, 2013) ranges over nine thematic sections; each of them contains specific clauses (numbering 54), covering the widest possible spectrum of relevant issues, which establish principles and requirements related to regulation aspects involved in the provision of quality telehealth service (Fig 1 below).
More in details the topics addressed are personal data management, moral and ethical issues, governance and financial matters, service operational requirements (as staffing and staff management, contact with patients, service users and carers, interpretation and responses) and technological considerations comprising service location, communications networks and hardware.
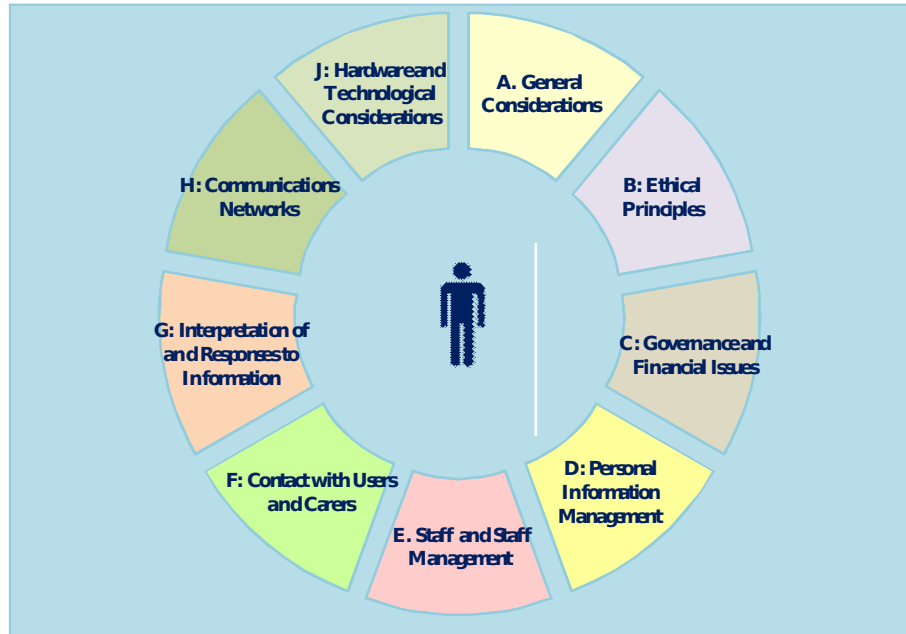
Figure 1. Figure 1: Structure of the TeleSCoPE Code of Practice. (Adapted from TeleSCoPE Project, 2013)

As it is clearly shown in Figure 1, the Code has been shaped around user's needs, since the user is the central beneficiary of TeleSCoPE action. The methodological approach of keeping the user at the centre of the Code has imposed significant choices, both for the positioning of the code within the telehealth environment, and for its level of detail and prescriptiveness.

The TeleSCoPE project, therefore, operates in the area of telehealth, and defines it in the Code as "the means by which technologies and related services concerned with health and well-being are accessed by people or provided for them, at a distance". As a consequence, the Code applies to preventative and public health, and it underpins the promotion of both clinical health and well-being for people of all ages.

Ambitions of the Code

Telescope Code of Practice has the double role of providing guidance for quality service provision on the one hand, and on the other hand of enhancing user empowerment, through a major involvement in their own health management and preservation. It applies to services provided through ICT technologies, dealing with individual health and well-being.

On the "regulatory" side the Code aims at influencing: the quality level of organization of telehealth services and the procedures and practices within it, the ease of access to services by users and carers, the attention to consistency in service quality and to the competency requirements for service staff by providing a benchmark standard

Regarding user centricity, the ambition of the Code (beyond the frontiers previously achieved in telemedicine ruling) is for users, no matter whether healthy or not, to be able to choose the best service for their own needs. In order to achieve this goal, the service provided should be transparent and especially should recognise user's right to exercise choices about services and service options; should admit user's explicit consent to the way in which personal (including health) information is gathered, stored and used; should have user's views and opinions heard and taken into account (and, where appropriate, those of carers); and should recognise and protect user's human rights and dignity.

The terms "individual well-being" and "user empowerment" hold a central position in the conceptualization of the Code. Well-being does not have a univocal definition (Deiner et al., 1999; Larsen et al., 2008), it is the result of different aspects including life satisfaction , engaging, and a self perceived goodness in the physical, economic, social, emotional and psychological sphere (Csikszentmihalyi et al., 1999). Well- being is recognized to impact on

relevant health outcomes as: self-perceived health, longevity, healthy behaviours, mental and physical illness, social connectedness, productivity, factors in the physical and social environment (Lyubomirsky et al., 2005). TeleSCoPE adhered to this view and, by virtue of this, it first defined telehealth (including telecare and social-alarm services), as its area of interest, rather than focusing on strictly medical-services. In line with this vision the Code always refers to the person as "user" rather than "patient." This issue also highlights the willingness to put individuals at the centre of the action, promoting user empowerment, which inspires most of the clauses in the nine sections, composing the Code, especially the B, D, F and H sections.

To be compliant with the Code, telehealth services will be pushed to adopt approaches by which users and carer are encouraged to assist in service planning and development and to take greater responsibility for their own health.

USER EMPOWERMENT

As stated above, user empowerment, in the specifc setting of health, is the action of helping people gain control of processes related to health care and increase their capacity to actively understand and influence their health status. More engaging medical approaches to patients are shown to result in better treatment outcomes. In detail, relevant scientific literature stresses that a model of care involving patient/carers in the choice of their care pathway, relates with an improvement in compliance to the treatment (Roter et al. 1998), in a reduced level of anxiety (Morris et al. 1988), possibly resulting in more positive outcomes in health care (Bertakis et al. 1997; Greenfield et al. 1999). Enabling individuals to achieve higher levels of information and built a care model on the agreed objective of arriving at a treatment decision, based on the doctor's knowledge and the patient's preferences, is a new target for both international and national policy makers.

E-health care provision, enhancing a faster and easier accessibility to personal and electronic records and modeling itself on the most diverse health-related user needs, thanks to the ICT solutions, is concretely able to empower the consumer (Eysenbach et al., 2001).

Even though, necessarily, an extensive research is needed in order to fully consider the issues concerning empowerment and its perception at community level, from available literature (Zarcadoolas et al, 2013), regarding the opportunities and concerns around user empowerment through e-health, emerges a basic collective worry especially regarding ethical and safety aspects, which is usually overcome by the confidence in a future technological advance and trustable management of e-health services, especially for the safeguard of the most vulnerable subjects (i.e. elderly, people with disability and needy persons) (Leuty et al., 2013; Safran et al. 2003).
It follows that in order to make empowerment a common practice, it is necessary to first building confidence in and acceptance of telemedicine services.

CONCLUSIONS

The widespread provision of telehealth services at European level could bring about positive outcomes and have a beneficial impact on both medical practices and the general well-being status of the population. However, at present there is still a lack of standards or requirements, shared by EU member states, to deploy and set-up this type of services, since existing regulations are only at national level. The TeleSCoPE project aimed at solving this issue by developing and introducing a comprehensive European Code of Practice that may function as a quality benchmark against which services can be assessed and certified. The Code of Practice was developed by taking the central role played by users in this field as a starting point. It acknowledges, in fact, the importance that service providers properly take into account users' views and choices, in order to adapt to their needs and shape the provision around them, rather than the opposite. The Code also ensures that user privacy and safety are duly protected, by setting-out specific requirements about how personal data and information should be managed, as well as providing guidance to build a trust-based relationship between users and service staff.

In summary, the Code of Practice released by the TeleSCoPE project addresses the important issue to provide a common framework to host an European convergence of directives ruling the technological solutions devoted to at-a-distance provision of healthcare. In such a context, the concepts for the definition of quality requirements parallel the statements pointing to keep user centricity as the focus of the Code. In so doing, the Code extends the domain of

health teleservices including rules focused on users' empowerment in the perspective of their well-being, and shapes in this direction the future developments of European regulation of telehealth services.

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