

Research Review Paper ■

Telescope – Telehealth Services Code of Practice for Europe

Telescope – Kodeks storitev zdravja na daljavo za Evropo

Institucije avtorjev / Authors' institutions: MKS Elektronski sistemi, d.o.o., Ljubljana, Slovenija (DR); NSIOS – Nacionalni svet invalidskih organizacij Slovenije (TJ); Coventry University Enterprises Ltd., Health Design and Technology Institute, UK (MF, RR).

Kontaktna oseba / Contact person: Drago Rudel, Rožna dol. C. XVII/22b, 1000 Ljubljana. e-pošta / e-mail: drago.rudel@mks.si.

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Drago Rudel, Tine Jenko, Malcolm Fisk, Roberts Rose

Abstract. We present the European project TeleSCoPE – Telehealth Services Code of Practice for Europe. It is developing a comprehensive Code of Practice that relates to those aspects of telemedicine and telecare that are delivered in people's homes and mediated through ICT. This is a 3-year project (2010-2013) co-financed by the European Executive Agency for Health and Consumers. Among 13 project partners from 7 countries, two are from Slovenia. The main output of the TeleSCoPE project will be the Code itself and associated plans to facilitate its adoption by the EU member states. Among its side products is the glossary of terms in telehealth, which was used as a key document when preparing a foundation document for a national strategy on telehealth in Slovenia.

Izveleček. Predstavljamo evropski projekt TeleSCoPE – Kodeks storitev zdravja na daljavo za Evropo. Cilj projekta je izdelati minimalni standard kakovosti zdravja na daljavo (telehealth), ki jih želimo uvesti v državah EU. TeleSCoPE je trileten projekt (2010-2013), ki ga sofinancira evropska Izvršna agencija za zdravje in potrošnike, v katerem sodeluje 13 partnerjev iz sedmih evropskih držav, med njimi tudi dva iz Slovenije. Poleg samega kodeksa bo projekt dal tudi druge rezultate, npr. pojmovnik z definicijami s področja zdravja na daljavo. Slednjega smo v Sloveniji že uporabili pri pripravi strokovnih izhodišče za nacionalno strategijo zdravja na daljavo.

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Background

Higher demands for lifestyle quality have been increasing needs for different health and social care services in Europe. Additionally, demographic changes in our ageing society, individualized family structures and increasing number of chronic illnesses rise demands for long-term care services. New concepts of care are required to provide such services as the old models of the services provision are often too demanding. According to the European Commission new technologies have the potential to revolutionise healthcare and health systems and to contribute to their future sustainability.^{1,2} It has issued recommendations to overcome, or at least to mitigate those problems. One of them is to develop and introduce new health services based on ICT (telehealth services) and on new, more effective organisational models.

There are increasingly clear indications, albeit from fragmented evidence, that telehealth can help reduce costs and be as effective as or more effective than traditional forms of care.^{2,3} The evidence base in part relates to large scale studies and, at the other extreme, to a number of pilots or trials. And although the latter initiatives have often not been subsequently embedded into the mainstream of service delivery, the number and range of telehealth services is rising inexorably.

However, before many of the opportunities of telehealth are fully realised (or realisable) there are a number of hurdles to be overcome. They relate to misunderstandings about the nature and place of telehealth within the range of technologies and services. There is a lack of standards that would give a solid base for the service quality. Some of the barriers to the adoption of telehealth technologies (and, therefore, the reconfiguration of some services) arise because of misunderstandings around its role or simply because users/patients and also health and social care professionals don't know about its potential. Currently no telehealth service code exists in Europe. A European project TeleSCoPE - Telehealth Services Code of Practice for Europe

aims at developing such a code to fill a void.⁴ It is developing a comprehensive Code of Practice for telehealth services that relates to those aspects of health and social care services that are delivered in people's homes and mediated through ICT.

What is Telehealth?

TeleSCoPE project partners understand telehealth as: *"the means by which technologies and related services concerned with health and wellness are accessed by or provided at a distance for people and/or their carers (at home or in the wider community) in order to facilitate their empowerment, assessment or the provision of care and/or support"*.

The care and support pointed to in this definition is seen as being accessed or provided in relation to people's health (including clinical health) and well-being; and as always involving and including the service user, client or patient.

In addressing both clinical health and well-being (wellness), telehealth is considered as having a remit that covers aspects of both telemedicine (when used in the home) and telecare. Its embrace, therefore, includes services for or accessed by a wide range of people with different kinds of health and support needs. It requires to be considered, furthermore, in a context where it and a wide range of assistive technologies can be harnessed by people in order for them to manage their own conditions and, to different degrees, to be self-supporting in home, community and work contexts.

Telehealth sits, therefore, at the cusp of services that operate according to medical models (i.e. delivering services to patients largely based on professional judgements regarding their needs) and social models of care (i.e. where people have greater choice in accessing and using services). As noted in the ensuing section, the TeleSCoPE perspective is firmly oriented towards the latter and points, therefore, to the need for a "paradigm shift" away from medical models to social models of service provision.

The need for telehealth responds to most people's wish to stay at home. Telehealth contributes to the growing needs of people with chronic and long-term conditions (for example, by making sure that hospital or institutionally based services are better targeted) and to the preventative health agenda (by helping people to better manage their own health).

TeleSCoPE project

The TeleSCoPE is a 3-year European project (2010-2013) co-financed by the European Executive Agency for Health and Consumers. Among 13 project partners from 7 EU countries (UK, Ireland, Belgium, Italy, Hungary, Bulgaria and Slovenia) there are two from Slovenia: MKS Electronic Systems and NSIOS - National Council of Disabled People's Organization of Slovenia. The project partners bring in expertise, skills and experiences from different fields of potential telehealth service applications: telecare, telemedicine, standardisation, ethics, businesses (SMEs) and represent several groups of disabled potential users.

General Objectives

The aims of the project are to influence European-wide confidence and acceptance by influencing a common approach on the political level (harmonisation), semantic level (agreeing common priorities), level of education and awareness raising (evaluation, monitoring and analysis and reflection on good practice). TeleSCoPE's objectives meet commitments within the EU Health Programme to

- Improve the physical and mental well-being of European citizens;
- Harmonize the provision of health, and its knowledge in all the member states;
- Improve citizens' health security;

- Reduce health inequalities; and
- Generate and disseminate health information and knowledge.

TeleSCoPE directly responds to the European Commission communication on telemedicine for the benefit of patients, healthcare systems and society.² The primary objective of TeleSCoPE is to develop a comprehensive Code of Practice for Telehealth Services (i.e. relating to that aspect of telemedicine delivered in the home and normally mediated through ICT). The project directly supports the Commission Action Point² to "improve confidence in and acceptance of telemedicine". It also contributes to the Action Points to collect "good practice on deployment of telemedicine services" and the addressing of issues (requiring for Member States) around accreditation, privacy and data protection.

The strategic relevance relates to the fit with EU initiatives that promote healthy lifestyles, healthy workforce and healthy life-years, social inclusion and engagement, economic and social development, ICT application and the co-ordination of policies and programmes within member states. The context includes i2020, the Ageing Well platform, the eHealth Action Plan, the Green Paper on a European Workforce for Health.⁵

With regard to the Together for Health programme, TeleSCoPE contributes to a number of parameters, but most especially to health promotion and the reduction of health inequalities; increasing healthy life years and promoting healthy ageing. The project also endorses the European Public Health Programme objectives concerned with:

- Improving citizens' health security;
- Promoting health, including the reduction in health inequalities; and
- Generating and disseminating health information and knowledge.

For promoting health and addressing the preventative agenda there are growing numbers of telehealth services where the provision of technologies is complemented by approaches that support people in adopting better lifestyles (through, for instance, health coaching and/or rehabilitation work). Vital signs monitors additionally permit the identification of measures that can indicate changes in people's wellbeing and enable speedier (preventative or remedial) interventions.

For the generation and dissemination of health information and knowledge, we see an essential role of telehealth services as including, where needed, the education of patients/users. This perspective is, of course, the natural concomitant of services where providers and patients/users work in partnership with the latter informed, guided and motivated as appropriate.

With regard to interoperability it complements work of CEN/CENELEC/ETSI in M403 and TC251 on Health Informatics (e.g. in WG2 regarding health records, data use, etc.).

Specific Objectives

The main output will be the Code of Practice itself and detailed plans to facilitate its adoption and continued development. The main outcome will be adoption of the Code and its use within member states to underpin service frameworks that contribute to the well-being of EU citizens.

The European Code of Practice for Telehealth Services being developed within the TeleSCoPE project offers a quality benchmark and will provide much needed guidance for telehealth and telecare service providers, clinicians, carers, purchasers and other interested parties. It responds to the increasing number of calls for such a quality benchmark that arise from increasing healthcare needs due to demographic changes and the imperative to adapt service frameworks to respond to those needs.

By establishing a quality benchmark the Code will help to improve the link between service providers and users. It will help increase the level of trust between the parties concerned.

The Code sets benchmarks around such matters as data privacy, access to information, moral and ethical issues, staff and management etc. It will provide particular benefits for older and frail people, people with chronic conditions, cognitive, physical and sensory impairments (including dementia and learning disabilities), drug or alcohol dependency and/or mental health problems.

Overall it is considered that the relevance of telehealth (and *ipso facto* this Code) has particular applicability in the context of:

- Long-term conditions – mainly focused on older and frail people to people with chronic conditions, cognitive, physical and sensory impairments (including dementia and learning disabilities) and/or mental health problems.
- Lifestyles and preventative agendas – with a broader focus by which better health is both maintained and the management of any long-term condition is achieved at the same time as users have high levels of continuing and meaningful involvement in work, home and social life. This range now extends to include lifestyle "challenges" arising from diabetes or obesity to drug and alcohol dependency. Linked with all are issues of medication compliance.

In involving a range of partners with skills and experience, the Code will address aspects of service delivery relating to different configurations; kinds of providers and commissioners; and user (patient) groups. It recognises the role of health and allied professionals (including OTs, health coaches, pharmacists, telecare staff) in the delivery of telehealth services.

Methods and Means

A robust, but simple, methodology is proposed. The main components of the methodology relate explicitly to project Objectives. These are as follows:

- Gathering of the evidence base;
- Developing the Code;
- Validating the Code;
- Publishing the Code; and
- Establishing the prerequisites for mainstreaming the Code.

A precondition is the shared understandings of the sometimes confusing terms that are encountered (telemedicine, telehealth, telecare, eHealth, now extending to mHealth and uHealth, viz. mobile and ubiquitous health).

The Code robustness is absolutely necessary in view of the vulnerability of many potential beneficiaries of telehealth.

Roles for partners are assigned in relation to their knowledge and expertise. Some work will involve visioning the shape of services as facilitated by the use of new technologies. Attention will be given to the implications of video communication; the application of RFID and AIDC (automatic identity and data capture) technologies; services delivered via mobile networks; the implications of worn, carried or implanted devices; tags and smart fabrics and dressings; robotics; and the way that services facilitate health and lifestyle coaching.

The primary means of developing the Code will be through desk-based work, extensive research and consultations with key stakeholders, including government agencies and users (patients). Governments and appropriate agencies within all member states will be engaged with and their involvement facilitated. Detailed work with users will be more localised (in some five member states)

but will involve the range of patient groups noted above.

Outcomes

The main outcome of the TeleSCoPE project is the establishment of a European Code of Practice for Telehealth Services. It is envisaged that the Code will be adopted in European Union member states.

In April 2012 a draft version of the Code of practice (see Figure 1) was issued and presented at the Med-e-Tel 2012 conference in Luxembourg.⁶ The framework of the Code is presented in Figure 2. The Code content is divided into three sections:

- A. General Considerations (European and Country Contexts; Moral and Ethical Issues; Governance and Financial Considerations; Personal Data Management)
- B. Buildings and Technological Considerations (Buildings; Communications Networks; Hardware and Other Technological Considerations) and
- C. Service Operational Requirements (Response; Contact with Users and Carers; Staffing).

The person who accesses telehealth services is represented by the figure at the centre. Their position symbolizes the paramount importance of their being at the focus of services, able to exercise choices about the services they access, and with their views and opinions taken into account by service providers.

The draft of the Code of practice has been sent to over 400 selected stakeholders to get their response and potentially contribution for the draft Code improvements. The final version of the Code will be available in April 2013.



Figure 1 Cover page of the TeleSCoPE – Telehealth Services Code of Practice for Europe.

The Code preparation works are based on several foundation documents covering literature review on telehealth evidence (Foundation Paper 3),

ethical aspects (Foundation Paper 2) and glossary of terms (Foundation Paper 1).⁷ The latter was used as a key document when preparing a foundation document for a national strategy on telehealth in Slovenia.

There are, however, a number of longer term (and less tangible) outcomes that relate to the regulation and growth of telehealth services. These arise through:

- The benefits to people’s health (and their engagement in the economic and social lives of their communities);
- Associated cost savings among all the governments of member states (through the ability to deliver healthcare services in better and less costly ways, better medication compliance, lower dependency, fewer unnecessary hospital admissions, etc.); and
- Environmental benefits through lower energy consumption arising from fewer trips for patients, caregivers or service staff.

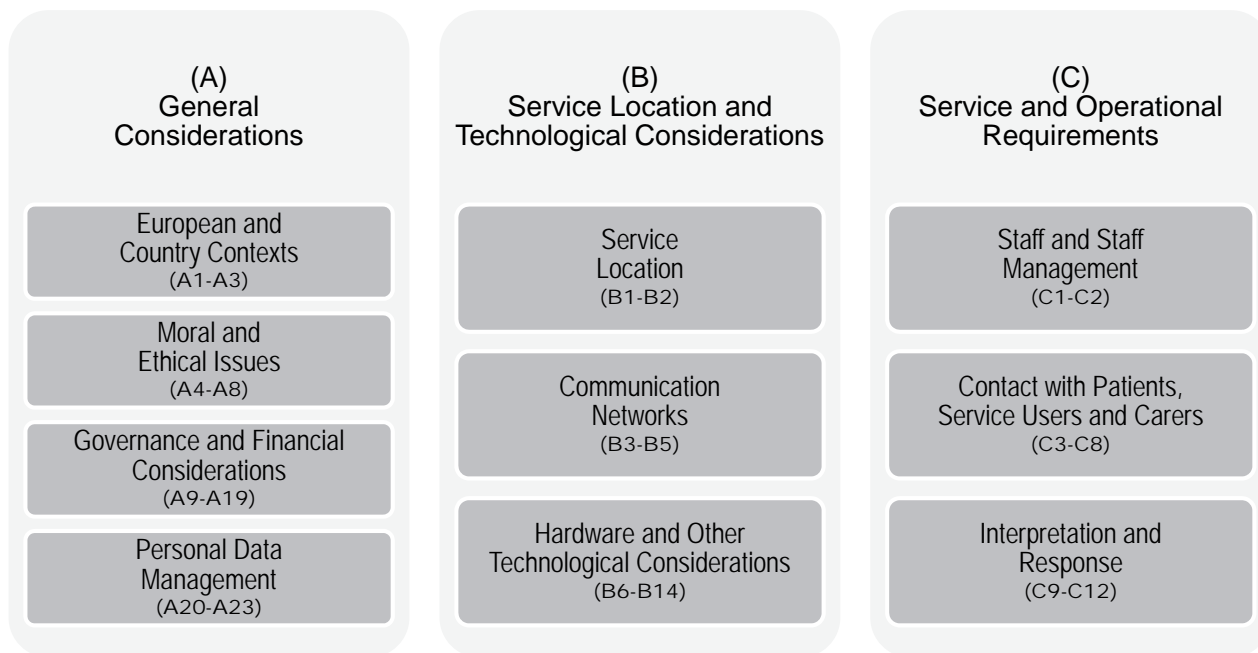


Figure 2 Areas covered by the Telehealth Services Code of Practice for Europe. Letters A, B and C designate parts of the Code.

Conclusion

The TeleSCoPE project will create a strong EU network of organisations representing government interests of member states, manufacturers, supplier, academics, service providers and service users in the field of telehealth. And, while it is not its primary role, it is expected that the Code will help to guide the way in which telehealth services develop in the European Union.

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