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# A Holistic Approach to the Sustainable Empowerment of the Ageing Society

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## Abstract

This paper presents a new European initiative to support the sustainable empowerment of the ageing society. Empowerment in this context represents the capability to have a self-determined, autonomous and healthy life. The paper justifies the need of such an initiative and highlights the role that telemedicine and ambient assisted living can play in this environment.

## 1 Motivation

The demographic change has profound effects on societies, due to alteration in age, birth rate or migration movements. One effect is the ageing of societies, which challenges societies either to enlarge institutional care or to find alternative solutions to care the elderly. One of the biggest current challenges is to sustainably empower the individuals and communities of the ageing society. For us, empowerment characterizes the strategies and the process to enable individuals to have a self-determined, autonomous and healthy life and additionally to support communities by incorporating new technological and management approaches in integrated home care to better provide for its (elderly) people. Considerable hopes are placed on Ambient Assisted Living (AAL) and e-health (telemedicine) technologies to cope with those emerging confronts. The new technologies are expected to withdraw pressure from health and social care systems by assisting elderly people in independent living. However, most of these new technologies currently address a narrow spectrum of daily needs for elder citizens with dysfunctions: security (e.g. red buttons); health monitoring; extending certain functional capacities (e.g. different technical aids); social ties (e.g. various communication platforms). Comparing this technical status quo with the hierarchy of needs of individuals as well as of collectives reveals obvious gaps between available technologies and crucial aspects of quality of life. Activities and demands of daily living are not completely manageable by technical assistance but also need human capacities and contributions (e.g.

support in dressing, feeding, household activities). Particularly rural communities envisage an extraordinary challenge: Local resources are often diminished due to migration of professionals and young people to cities, leading to the deterioration of services and assistance formerly provided by professionals or neighbourhood and family networks. Several components influence a satisfying and healthy life. The World Health Organization (WHO) formulated in 1948: ‘Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’<sup>1</sup>. This definition has been recently enlarged, and characterizes a healthy life first of all with the prevention of diseases and secondly, in the case of the presence of disease, with the ability to adapt and self manage [Hub11], a concept also known as resilience. Resilience in our understanding leads to empowerment, thus enabling systems to better cope with its challenges. This work adopts the concept of resilience to the context of an ageing society. It focuses on the individual or unit (such as a household or family), living in a certain community/society. To enable such a unit to gain and reach empowerment is the ultimate goal. To our knowledge, resilience as a strategy has not been implemented on a unit/household level nor exists a way of indexing to measure “empowerment” in such a context.

The ageing society refers not only to elderly people. Ageing is a process that begins at conception and goes on throughout life. We develop while ageing and interact with the environment thus shaping and influencing our own health and wellbeing. Yet the environment also shapes our health and wellbeing, it is a circular process. Declining functionality has a close relationship with healthy lifestyle and ageing. Elder people may suffer some physical or mental dysfunctionality as a consequence of ageing. People with other capacities grow older today than ever before in history, thus also profiting from the overall ageing of the society. Handicapped people suffer additional illnesses as a consequence of the duration of their dysfunctionality and of age.

This paper presents the goals and background of a new research initiative (TING-NET) on empowerment of the ageing society. It takes a holistic approach to empowerment and considers the infrastructure and systems that provide not

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<sup>1</sup> <http://www.who.int/about/definition/en/print.html>

only health and household services, but also therapeutic-pedagogical and trustees services in the different participating countries. The research will apply the locality principle to bring the services close to the citizens and help them stay as long as possible in their area, their city/village and their private living space.

TING-NET aims to:

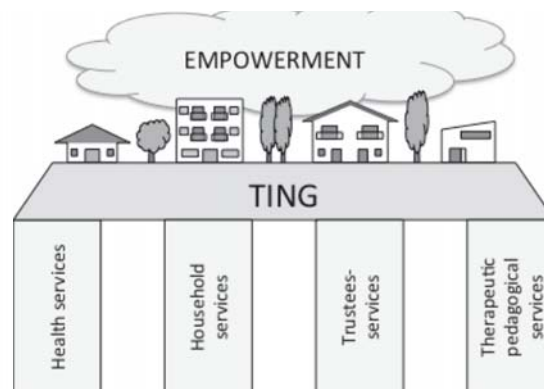
- Analyse how health, household, therapeutic-pedagogical and trustees services are implemented and interrelated in the different countries
- Analyse how new ICT technologies may be combined with care and home management services to improve both the services and their integration in a given community
- Find a European or international consensus on how to define and measure ‘empowerment’ in face of different practices
- Establish ‘best practice’ models as to how to integrate and personalize services and sets (international) defacto standards or guidelines for a sustainable service model with transferable structures and technologies
- Develop examples of transferring the best practices model to concrete, local user communities joining together professionals and practitioners, relatives, friends, neighbours and volunteers. The Action calls this local user community a TING.
- Consider how local user communities (cf. Figure 1) interact, help and learn from each other, building a network of communities (TING-NET).

The word “TING” has two meanings: in Germanic and Scandinavian countries, it represented the people’s assembly in a community and it also denotes an ancient Chinese vessel. It symbolizes therefore both the community and the integration ideal.

The rest of this paper is organized as follows. Section 2 comments on the state of the art of research on AAL, telemedicine or therapeutics pedagogy applied to the empowerment of ageing societies. Section 3 presents the detailed objectives of the TING-NET research initiative. Section 4 shows initial ideas on a possible mapping of a TING in a rural community. Finally, Section 5 closes the paper with some conclusions.

## 2 State of the Art

The WHO European Centre for Environment and Health identified the unequal distribution of health and wellbeing as a major challenge for health governance. Environmental (health) inequalities exist in all regions and countries. Different population groups may face a wide range of inequalities within one country and the results are very diverse between countries. The WHO recommends a general improvement of environmental conditions, and they recommend to share experiences and case studies on successful interventions [WHO1]. This research initiative will address these recommendations by integrating key expertise from different domains, countries and disciplines.



**Figure 1:** A TING is based on a set of basic services

Several classical research areas are related to this research: Firstly, Ambient Assisted Living (AAL) focus on providing support for a population group with disabilities, representatives are JADE (FP7 no. 266422), Synergy-COPD (FP7-ICT-2009-270086), ARMOR (no. FP7-287729) or REACTION (no. FP-7248590), which focus on chronic diseases or HAPPY AGEING that focuses on ICT support for home care (AAL no. AAL-2008-1-113). AAL with focus on advancement of social interaction: CONNECTED CO-LIVING (AAL no. AAL-2009-2-097) or USEFIL (no. FP7-ICT-2011-7) focusing on addressing the elderly social interaction or ALIAS with focus on adaptable ambient living assistance (AAL no. AAL-2009-2). All mentioned cluster examples have a narrow, typically ICT driven focus. This research initiative will exploit links with the European Regional and Local Health Authorities (EUREGHA) to contribute towards the creation of sustainable synergies and policies between regional and local authorities and EU stakeholders in the field of health care systems.

A second area strongly related to this research area is telemedicine, ranging from remote recommendation, chronic care management up to telemetric devices. Example projects are MOMENTUM (no. CIP-ICT-PSP.2011.3.4), a thematic network focused on telemedicine, or DECIPHER PCP (no. FP7-288028) that focused on mobile EHR, national hospital cooperation networks like national telemetric projects or networks of telemedicine centers in some countries. Furthermore, implemented patient care via telemedicine care management in other countries or a project like United4Health (no. CIP-ICT-PSP-2012-6) are also related to this challenge. Pilot projects like SMARTCARE (ICT PSP no. 325158, a telemedicine platform to deliver care services for older citizen neglect the effect of population ageing and other projects are too narrow and more dedicated to a specific disease like dementia in VPH Dementia Research Enabled by IT (FP7-ICT no. 601055 ) or rehabilitation from strokes like in CONTRAST (no. FP7-ICT-2011 ID-287320). The Virtual Physiological Human network of excellence offers a roadmap named DISCIPULUS (FP7/2007-2013) that plans for personalized treatment focusing on healthcare prediction and GRANATUM (ICT-2009.5.3) providing limited focus how to bridge information among biomedical researchers; both are not covering the objectives of this research initiative.

A third area is the non-medical therapeutic intervention. This is particular important to enhance the possibility of

communicating in high age. Associated with medical challenges is a loss of functions for mastering tasks of everyday life. These losses can be prevented or improved through medical rehabilitation such as physical therapy but also through the knowledge gained with therapeutic pedagogy. There are useful inventories for assessment of functioning for independent living for various groups with special needs, which have been developed by occupational therapists and nurses in the USA [Hor13]. Further examples are the EHLE project promoting health education for older citizens (GRUNDTVIG no. 134023-2007-IT-GRUNDTVIG-GMP) and the initiatives to promote healthy nutrition for the group 50+ (in age) by the Association for Health Promotion (ARGEF, Austria) both without integrating trans-domain relevant knowledge; furthermore, the project Empowering Socially Excluded Elderly within Russian Minority (NTERREG IV A project SFE1) with focus on the integration on minority groups at the age of 65 and over.

Finally, the household service and care service area is related to this initiative. As reported in [Ang11, Ang12] two processes are not in line: supporting services professionalization and formalization. As a result illegal employment rises. Two years later, there is no general movement in formalization visible. Regional initiatives try to focus only on specific groups like 'Elderly Men Homely in Kitchen groups' supported by the project Active Ageing in Tampere Region ([www.piramk.fi/aip](http://www.piramk.fi/aip)) or like in the project Designed Innovations for Active Ageing (DAA a Interreg IVC project) on elder people living in larger cities and developing sustainable solution for senior care but neglecting crucial zones like rural areas.

One important technique to tackle the large set of open issues yet not covered in documented projects is the application of CASE management. Case Management is a collaborative process which assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet an individuals health, social care, educational and employment needs, using communication and available resources to promote quality cost effective outcomes [Cms13].-

### 3 Objectives

The first objective of TING-NET is to create a (meta-) model for empowerment. The goal of the meta-model is to provide the scientific community with a possible standard ('ideal') to which against 'real'- local models- can be compared and improved.

The meta-model will extract the best practices from the participating countries in terms of organisation of their health (system), household and therapeutic-pedagogical systems and the current application of technologies. The meta-model can be mapped as an empowerment model in the countries/regions/communities, taking into account the different contexts in terms of legal, political, ethical, cultural and financial differences. Therefore the meta-model will also be an instrument for the stakeholder community to deploy their changes leading to empowerment.

Beyond the innovation aspect, i.e. development of new technologies to facilitate independent living in a community setting, the issues of technology acceptance and financial affordability play a major role. The existence of suitable technologies is a necessary, but not a sufficient condition for achieving an improved quality of life for citizens and increased efficiency of health and social care systems. There are currently significant gaps between advances in technology and the actual adoption of these technologies by social and health care systems as well as by (older) citizens in their home settings. Several barriers exist at various levels and need to be overcome to achieve actual technology acceptance and penetration into social and health care systems. As authors of technology acceptance models have indicated [Di196, Ven08], one of the core issues is use-friendliness of various technologies themselves. Across many European countries, there is still a significant scope for 'translating' and transferring the various new technologies into the social, cultural and institutional context of given countries. At the level of users (or potential users), technology acceptance is a function of age, gender and prior experience of the users. This is partly influenced by a digital divide, which is both economic (affordability of respective technologies) as well as cognitive (willingness to adopt respective technologies). At the level of social and health care service provision systems, the challenge is mainly related to costs and financial efficiency – whether the adoption of new technologies helps to constrain costs or at least prevent these from accelerating. Additional complication relates to the fragmentation of institutional set-up of service delivery in several countries (additional spending on new technologies of some service providers may entail savings for other service providers, which are under a different administration or financing system) and the lack of active coordination to facilitate the transfer of new technologies into those systems.

The second objective of TING-NET is to allow sustainability and resilience. Resilience describes the tolerance of a system against perturbations and is meant as an 'outcome' of empowerment, since it makes systems more prone to sustain and function. This process involves technologies and services.

The core issue is to empower citizens and facilitate their independent living through the new technologies. Technologies have to transfer innovations into the daily practice of citizens and into the regular practice of social and health service providers. Sustainability is therefore reached by keeping the stakeholders in the loop, sending the necessary input to them and receiving their feedback

The two cornerstone elements for sustainability have already been taken into account in the meta-model: user acceptance and financial affordability. Developments at very different fronts are needed, both at supply and demand side:

- Continuing innovation of user-friendly ICT enabled products and services to address the daily needs of people;
- Adaptation of such products and services into the widely varying contexts of community settings across many European countries;



- Advancing technology acceptance in the relevant customer groups with due consideration to the social and cultural contexts and needs;
- Addressing financial affordability to customer groups and financial efficiency for service providers;
- Addressing fragmentation of institutional (administrative and financial) set-up of service provision and providing for effective brokerage of ICT enabled services and products.

Referring to Roger’s theory of diffusion of innovations [Rog03], the practical question is what are the possible strategies to win the early majority to adopt the ICT enabled services and products. On one hand we may expect that the following generations of older persons are more apt to use new technologies as they have used similar technologies earlier over their life course. On the other hand, as the speed of technology advancement increases, adaptation to state-of-art technologies remains an issue for each cohort of older citizens.

The final objective of TING-NET is to establish and consolidate a (European) community for sustainable empowerment of the ageing society.

Ageing society urges for a seamless fusion of different types of services that aim at enhancing the empowerment of individuals and decrease the need for institutionalized support. In fact three communities are envisioned. The goal of establishing these communities is to achieve a long-term basis for research and deployment.

In the first phase, a scientific community will be established to further develop the transdomain, user-centred research on empowerment integrating, harmonizing and possibly standardizing the developments ICT, health, household and therapeutic pedagogics. The knowledge created in TING-NET will be expanded in a second phase to a stakeholder community. The stakeholder community can be further hierarchically organized in two categories. On the one hand, stakeholders can be organized in user stakeholder communities, consisting of directly associated organizations and individuals, who locally map and implement the created meta-model, and their direct users. These communities need to be involved in all partner countries and future joining countries. They have very different situations to address. This needs to be evaluated, before planning networking activities. The situations depend on the development of the individual societies with regard to macro economic and demographic conditions.

On the other hand, stakeholders can also be organized in a planning stakeholder community, composed of government and non-government organizations, but also manufacturers in the different countries, who are involved in planning the application of the resulting model. Currently, critical gaps reside between non-scientific stakeholders. For example, the engineering solutions with advanced capabilities suffer from a lack of awareness at the medical organizations, as well as lack of interest of the manufacturers to develop a wide market for these solutions affordable for all people in need. The question of finances arises and is a crucial inhibitor for a

faster empowerment of people to be able to improve their independent living. The establishment of this planning stakeholders community can show, through focused communication, how to importantly reduce healthcare expenses by applying the created knowledge (the best-practices meta-model). At the same time, it can draw attention of policy-makers across national frontiers. The TING-NET specially aims at contributing with this community to speed up the development of the health and care systems of some of the emerging European countries.

#### 4 A TING Prototype Model

As stated in the previous section, TING-NET aims at developing a meta-model, a kind of guideline on how to assess the citizen and combine different services to support empowerment of the ageing society. This meta-model will later on be mapped to concrete models for specific countries or regions, taking into account their differences and possibilities both in terms of infrastructure and of social and cultural habits. One possible prototype model for a TING in a rural environment is presented in this section.

The process of empowerment is incremental. A self-determined, autonomous, healthy life is not a status reached at some point, but a continuous process of improvement.

The first thing that needs to be done is to capture the current, subjective quality of life of a person and his/her needs or improvement wishes. Very different circumstances may lead to the desire or need to capture the current quality of life; examples are (sudden) dysfunction, decreasing potential or performance or temporal absence of certain abilities (cf. Figure 2).

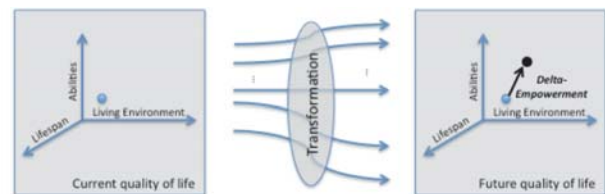


Figure 2: Delta-empowerment

The current quality of life depends on the abilities (sensorial, motoric, intellectual capacities or chronic diseases), the lifespan (i.e. the age) and the living environment (rural, cities, alone, in family, retirement home).

In order to increase empowerment, the desired quality of life has to be stated. Individual subjective preferences are combined together with objective measured potential. The result will be the future quality of life. The distance between both points is the delta empowerment. The target state can be achieved by applying suited transformations. The selection and parameterization of the proposed transformations will be supported by a recommendation expert system. This empowerment improvement process can be iteratively applied. The research activities in this part will address:

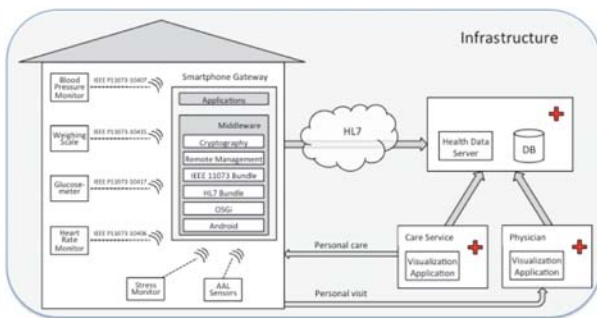
1. Definition of a measureable model for (subjective) quality of life.

2. Definition of empowerment as a distance in the quality of life space.
3. Formalization of transformation actions considering their impact on the quality of life model.

The abstract transformation actions will be mapped to instruments offered by the infrastructure. The classical instruments are personal care at home by members of a care service and personal visits of patients to physicians. This project proposes to extend this infrastructure by an integrated e-health platform. The research activities in this phase will be:

1. Definition, implementation and evaluation of the e-health platform.
2. Mapping of the transformations to the infrastructure instruments.
3. Definition of a usability concept for the platform based on user-friendliness and trust to improve the acceptance of the system by its users (patients and health-professionals).

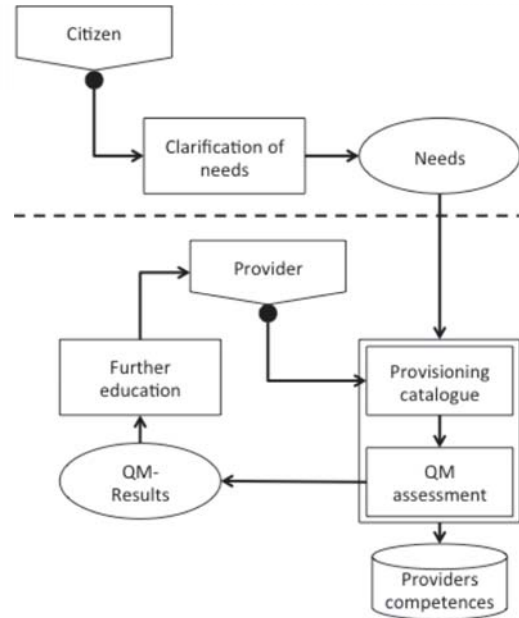
The planned infrastructure can be seen in Figure 3.



**Figure 3:** Telemedicine infrastructure

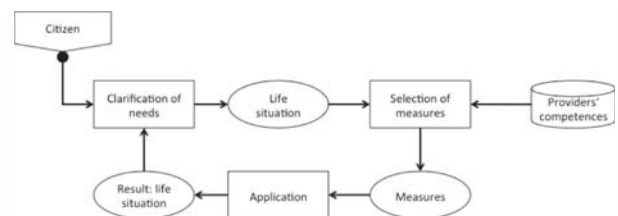
The requirements for this part are: (a) trust and security through encryption, (b) lower-cost through integration of standards and open interfaces for HW and SW, (c) mobility through the use of wireless solutions, (d) scalability and flexibility through a modular architecture (e.g. OSGi), and (e) application of standards (e.g. IEEE11073 for telemedicine devices and HL7). The home infrastructure will also integrate other biometric sensors like stress sensors and AAL-sensors. These sensors should be used to profile and predict the behaviour of the patient within the common living environment. This profile together with the health measures will be used to characterize the current quality of life, support recommendations and evaluate the achieved empowerment. The necessary profiling and behavioural description algorithms will be developed in this project. The infrastructure mentioned serves as a typical installation that is locally available and provides e-health services to each individual. This service is considered to be only one competence needed for an aging society. Other services are for instance domestic services, trustee services and therapeutic pedagogy services. Currently, some of these services are partially offered to individuals by different providers. For these individual persons, it is quite difficult to sort out and decide the need of

support and the provider. It would be desirable to link service providers and citizens through a local service centre that is called TING (cf. figure 1). TING can on the one side collect the information of local/regional professional and non-professional service providers (cf. Figure 4). On the other side, it can help to analyse the level of service



**Figure 4:** Assessment of providers' competences

needed by the citizens and support them to find the adequate measures and providers. TING provides a case-management for a whole (rural) community incorporating a network with all stakeholders.



**Figure 5:** Citizens advice process

Finally, the idea of a TING can be spread to other communities as well, so that, in case of telemedicine, it can form a cluster of TINGs interconnected for service provisioning and data derivation. In the latter case, statistical measures can be taken on a large range of cases, and therefore, help to provide general support to health management and prevention. A possibility that nowadays is not available even in areas of intensive medical research like oncology and its statistical data used for empiric derivation of prognosis.

## 5 Conclusions

This paper presents the basic research objectives of a new European initiative to support the sustainable empowerment of the ageing society. Empowerment in this context represents the capability to have a self-determined, autonomous and healthy life. The complexity in coping with empowerment comes from the fact that it is an extremely heterogeneous field. Several disciplines play a major role and have to be joined together: medicine, ICT, social sciences, therapeutic pedagogics up to legal aspects. Furthermore, different countries/regions/communities have different levels of deployment of infrastructures and also different cultural habits in integrating the ageing society. The current situation in the different countries will be analysed and out of the best practices, a meta-model to support empowerment will be generated. This meta-model will be mapped to the different requirements of the particular real communities. For this meta-model to be sustainable, two main aspects have to be explicitly tackled: user acceptance and political and administrative support, therefore it is very important to create the appropriate stakeholder communities.

An example has been given of a mapping of this meta-model to a concrete model for rural communities, where the community would be organized as a kind of service brokerage centre that would both assess the providers' competence and the citizens' needs and accompany the citizens in a process of recommendation, application and evaluation of measures.

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