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THE INFLUENCE OF TECHNOLOGY ON LONG-TERM CARE SYSTEMS

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Abstract. New technologies may have a beneficial impact on long-term care (LTC) systems by improving the quality, effectiveness and efficiency of LTC provision, and even by decreasing the need for LTC in the first place. Given the great uncertainty about the diffusion and implementation of available technology, there is little point in trying to make quantitative forecasts about the impact of technology. A more useful approach is to study the mechanisms through which technology can have an impact on LTC. This is the subject of Work Package 4 of the ANCIEN project. Both generally and via a number of case studies, it develops a framework to analyse the impact of technology on LTC. The functioning of this framework is illustrated by considering a number of specific long-term conditions, such as dementia, obesity and diabetes.



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1. Introduction

Typically, the provision of LTC has been reactive and episodic, causing an avoidable use of hospitals and residential facilities. The innovative organisational models that are being introduced to prevent, alleviate and control the consequences of compromised functional autonomy are intended to better meet the holistic health and well-being of citizens.

The meaningful use of Information and Communication Technology (ICT) and advanced home equipment may be crucial in the offer of more services. They need to be more targeted and effective to reduce the fragmentation of interventions by social and health operators, and the geographical dispersion of citizens and professionals on the ground.

The greatest impact on the future of LTC will not be due to the ad hoc and scattered diffusion of certain tools among individual citizens-consumers, but rather to large-scale organisational changes of the entire welfare system, supported by enabling technological services aimed at chronic diseases, fragility and healthy ageing. In fact, ICT and domotics may deeply influence the rise of new models of care by shifting the focus from residential care to home, thereby reducing hospitalisations, changing the roles of formal and informal carers and of citizens-patients, reducing functional limitations, frailty and its related risks and lessening the burden on informal carers.

Future coordinated care models with a proactive citizen role may be successfully deployed with appropriate technological support at an increasingly accessible cost, improving both the quality of life of affected individuals and their families, and the economic sustainability of the overall system.

The effects of technology on the LTC sector will be combined with socio-demographic developments, i.e. the increase in the number of elderly people, the reduction in family size, and changing lifestyles. To this end, two contexts should be considered:

- the **direct opportunities** to better adapt individuals to their daily activities and social context, living with long-term conditions and recovering as well as possible from the related loss of functionality, with the resulting chances to alleviate the burden on informal carers and restore their productive role in society to some extent;
- the **indirect effects** that prevent or delay the need for LTC, e.g. by a focus on the risks for frail elderly people, timely interventions to avoid or reduce the consequences of health-threatening events and improve the care for chronic diseases.

The European Union has implemented numerous initiatives in this area, including: AAL-Ambient Assisted Living, ICT for Health and e-Inclusion, now integrated into the framework of the Digital Agenda and of the European Innovation Partnership on Active and Healthy Ageing.

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1.1 Technology-based services as a necessary support to diverse stakeholders

Appropriate technology can assist citizens (and the carers who surround them: relatives, family-paid workers, neighbours, volunteers) to restore or replace, at least partially, the compromised functionalities, to enhance their skills in self-care, to increase the adherence to prescribed therapies, to reduce waiting times and visits, and to decrease morbidity and mortality.

LTC may be increasingly carried out at home to support daily activities and care processes, e.g. to communicate with remote formal carers or other citizens, to measure biological and environmental parameters, to generate reports and alerts, to recall deadlines and appointments, to look for information on available facilities and services, to carry out administrative procedures, and to receive instructions and online educational sessions.

Formal carers can perform a more regular follow-up with additional remote contacts. Operators may reduce their isolation by improving their links with other colleagues; they can decrease their workload on less compromised patients and reduce the risk of errors. Although scattered throughout the territory and having different roles, objectives and tasks, all actors could better communicate with each other, coordinate their activities and share the relevant documentation (subject to the privacy regulations and the beneficiary's consent), according to the individual plan of care, which includes the activities performed at home by the citizen and informal carers.

ICT will allow managers to extract timely indicators related to critical points in care processes (e.g. in situations at risk of non-appropriateness or error), possibly agreeing at a regional and national level on standards about the routine data to be systematically observed and exchanged, to be also used for governance. Managers can ensure a more appropriate allocation of resources, avoid hospital admissions (particularly by reducing inappropriate access to emergency rooms) and encourage the earlier discharge of patients with the guarantee of quality and appropriate management of home care.

Other important stakeholders are policy-makers, who could deploy large-scale organisational changes, enabled by technology, to improve health and well-being in cases of disability and non-self-sufficiency: in fact, awareness has grown that the scale of the phenomena is no longer local and isolated, with spontaneous interventions of particular services, but covers wide areas with the support of appropriate regulatory and governance tools.

In addition, the nascent market for smart 'networkable' home devices offers significant opportunity for the industry on LTC technologies, and is still under-developed in terms of products and services.

1.2 The magic word: integration

Technological services are intrinsically susceptible to various modalities of 'integration':

- integration of equipment and ICT solutions into comprehensive technology services;
- integration among the actors (not only formal carers, but also care recipients and informal carers) into a sort of designated 'virtual team' built around the needs of each individual;
- integration of administrative, operational, organisational, educational, managerial tasks and related documentation;
- integration of social and health care.

The realisation of this 'ideal world' is not hampered by a shortage of potential technological solutions, but by regulatory, economic, organisational and cultural issues, including the lack of a constructive debate to spread awareness of the available opportunities and the chronic shortage of innovators to manage change processes. It is often difficult to transform a pilot experience into a long-lasting routine with a permanent reallocation of responsibilities and resources; the evolution of the phenomenon cannot be left to spontaneous initiatives, but must be coordinated and planned in a regional framework to obtain the maximum benefits for individuals and community.

1.3 *Direct and indirect influence of technologies on the LTC sector*

The lessons learned, notably from the incredibly rapid spread of the internet and mobile phones over the last decade (and of the software to recognise shapes, movements and speech) make it clear that any precise forecast of future evolution of technologies is quite futile. However, it is still possible to envisage the mechanisms that may lead to a direct influence of the technologies on the recipients of care, on the informal and formal carers within the current LTC processes:

- To augment the opportunities to alleviate the dependency of individuals after a loss of functions, by self-care or by an appropriate replacement of the defective functions;
- To improve safety, the timely detection of potential problems, and reduce the consequences of accidents, by surveillance of the environment, by the prevention of inappropriate actions by individuals or informal carers and by immediate reaction to unforeseen events;
- To support individuals and informal carers in collateral activities, e.g. administrative procedures, education about lifestyles;
- To orchestrate the collaboration of formal carers among themselves and with care subjects and informal carers.

Among the potential indirect influences on LTC processes are some mechanisms that do not involve actual care provision, but nonetheless affect the activities performed within the LTC environment:

- Activities to promote the appropriate adoption of technologies, e.g. by portals with a description of the available devices or services, show-rooms and orientation centres to assist the consumer in the selection of the most suitable equipments and services compatible with budgetary constraints;
- ICT services to support managerial activities, e.g. to assist decision-makers in the set-up of the organisational model and in the management of the system;
- E-learning services to train voluntary and family-paid carers;
- ICT services to facilitate the matching between the families and the family-paid carers.

Additional indirect mechanisms acting on other sectors that could have an influence on LTC in the medium-to-long term may include:

- Assistance in the care of chronic conditions and their predictable consequences, to prevent or slow down the evolution of the diseases and mitigate their (permanent) effects on daily life;
- Improving the effectiveness of interoperable ICT solutions, e.g. to produce and maintain a body of coding schemes and structured knowledge ('infostructure') in a format suitable for computer processing, to assure the semantic interoperability during the care process and the timely calculation of quality indicators for managers and policy-makers;
- To perform research on the optimal usage of available technologies and to direct efforts to fill in the gaps and bottlenecks in the continuum of available LTC services.

Each type of technological solution will have a different strategic and practical influence, depending also on the local regulatory and organisational context. They allow, in most cases:

- the access to current information on social care facilities and on services provided by them, thereby reducing the time spent on administrative steps (downloading forms, submitting requests via the internet, obtaining information on the progress of ongoing steps);

- a citizen to enjoy greater continuity of care, thanks to an information system that facilitates the collaboration of operators and with him/her and the informal carers;
- a citizen and his/her informal carers to manage (also online, safely) his/her personal health information, to manage an agenda and deadlines, to receive recalls and warnings for the correct use of medication or to perform measurements with equipment and instruments, to report problems to formal carers, to improve data-capture with an immediate assessment of data quality in relation to the parameters already measured;
- to access authoritative knowledge in different languages (on diseases, medication, procedures, etc.) and suggestions for an appropriate use of health facilities, providing audio-visual aids, including interactive educational tools on the execution of activities by citizens, for example motor rehabilitation or changes in lifestyles;
- to provide tele-company services, in order to permit citizens to talk to operators, relatives, friends or people with similar problems; to improve comfort, for example, automatically turning on lights, controlling the temperature and air-conditioning of a room; to provide an automatic reader of texts or colours for blind people; to improve security through environmental surveillance and possibly generating reports of faults and alarms.

Aids and services may be purchased by families or offered by providers and voluntary organisations; however it would be useful for citizens, families and decision-makers in care organisations to receive independent consultative assistance on how to select the most suitable technological support to satisfy the needs of an individual.

2. Systemic benefits and barriers

The technological solutions available today can significantly improve the quality of life of citizens and their informal carers, allowing many of them to resume an active role in the community. The LTC system may improve the optimal management of resources, increasing both the quality and the appropriateness of care. The industry may also benefit the provision of services and the design and marketing of devices and ICT solutions.

2.1 Rethinking roles and tasks of actors

Technology can massively impact LTC by altering the existing relations among the various actors; notably, it can:

- alleviate the dependency of individuals, by directly impacting on the impaired functions of citizens and by promoting home-based care. Care recipients achieve their autonomy while staying in a familiar environment and reintegrating into the community;
- ease the burden on informal carers, through services supporting their activities and – if applicable – improve their opportunities to return to work;
- improve safety and the timely recognition of adverse events, through environmental surveillance and by reducing the risks of inappropriate behaviours;
- slow down the evolution of a chronic disease and mitigate the effects on recipients' quality of life and that of informal carers – especially by avoiding transitions to hospital care.

Technology can empower each member of the 'virtual team' built around an individual, by allowing him/her to perform more complex tasks than before, and possibly improving the labour division between players:

- partially self-sufficient individuals may safely perform a greater number of routine tasks, with less support from other actors. This may reduce the hours of presence of the informal carers;
- informal carers, with the help of technology, may substitute professionals in managing several tasks, possibly with a remote professional supervision.

2.2 *Optimising the use of resources and the quality of care*

Three major benefits for quality may be envisaged: increased adherence to guideline-based care, enhanced surveillance and monitoring, and decreased medication errors. The main area of improvement is preventive health; the major efficiency benefit may result in a decreased utilisation of care. Based on a review of the literature, the ANCIEN project identified four dimensions of quality in LTC.¹ The quality dimensions are:

1. Effectiveness; a combination of concepts: effectiveness of care, appropriateness, competence of health system personnel;
2. Safety; a dimension that is closely related to effectiveness, although distinct from it in its emphasis on the prevention of unintentional adverse events for patients;
3. Patient value responsiveness; a combination of concepts aimed at representing the patient's point of view, including satisfaction and acceptability;
4. Coordination; a combination of timeliness, continuity, integration between primary and secondary care, and between health care and social care.

The data collected in WP5 of ANCIEN deal with the use of technology in each country across the four dimensions. The goal was to identify examples of good practice in enhancing the quality of LTC by the use of technology. Further studies should develop a robust and comparable set of indicators to reach an adequate level of accuracy in the measurement of the various dimensions.

2.3 *Meaningful use of data for planning and governance*

The use of data for multiple purposes according to the privacy constraints increases their quality and completeness; in fact the integrated management of the same data in different contexts ensures:

- Reliability. Data are entered once by those who generate them, for their own goals, and then re-used several times (even by different properly authorised players), improving the quality controls, their implicit 'credibility' with respect to the context and then their veracity;
- Efficiency. It avoids having to retype the data already known to the system (also avoiding typing errors), while the data involved for sharing can be continuously synchronised;
- Timeliness. All the data useful to the tasks in progress can be made easily available online for other tasks or retrievable by authorised personnel;
- Friendliness. Data can be selected, summarised and presented in the most appropriate format to each authorised actor and for each different task.

Detailed data generated during the care processes may be a key input to plan resources and activities and to ensure a quality management system able to continuously improve its performances. The more the information systems at all levels of care are integrated, the more system governance and quality assurance may be effective.

2.4 *Obstacles and barriers to innovation*

Different obstacles are slowing down the process of change. The technological solutions should be selected downstream of strategic decisions on the models of care, the main barriers to technology adoption are therefore due to **leadership** (or lack thereof) and not to the specific technology. Other barriers are related to **privacy and security** and to the coherence with the **regulatory system**.

¹ See Roberto Dandi, "Quality Assurance Policies and Indicators for Long-Term Care in the European Union", Enepri Policy Brief No. 11, February 2012.

Finally, there are issues on data management accountability: Who is the ‘owner’ of the recipient’s data? Who should manage, update, and assure the completeness of data? Questions like these need to be answered in a participatory way by involving all stakeholders in the care processes. Most of the obstacles arising from the **connectivity in remote areas** now seem to be overcome, because it is often possible to obtain significant results, even with the exchange of a small amount of data. The **resistance to technology** also seems to be in the process of being overcome, thanks to the growing friendliness of the interfaces, although user-friendliness is still quite a critical issue for an elderly person in the absence of a skilled informal carer.

3. A scheme to explore the influence of technology on an LTC scenario

Technologies may affect the future of each long-term condition in various ways, depending on several factors, e.g. the type and the stage of the condition, other health problems, the individual social context, the background of the local community, and the progress of health care and technologies. Furthermore, the decisions on LTC models and technologies by the policy-makers of a jurisdiction depend on the demographic, normative and economic factors.

A set of description criteria was developed in order to perform a detailed analysis of the possible influences of the technologies on any particular LTC scenario. Partners involved in WP4 of the ANCIEN project jointly assessed the degree of influence of technology in relation to three chronic conditions: diabetes, dementia, and obesity. The aim of this exercise was to formulate a comprehensive and systematic scheme to allow policy-makers to reach informed decisions about technologies in relation to the other priorities of intervention in a jurisdiction (tables 1 and 2).

3.1 Criteria to assess the influence of technology on LTC

The scheme provides a systematic framework to explore an LTC scenario; it therefore allows it to collect and discuss the contributions by stakeholders, to compare various LTC scenarios for the expected evolution of needs and the potential influences of technologies, in order to devise the goals and the milestones of an action plan within a specific local context.

The scheme considers 51 criteria, organised in two sections and a number of sub-sections, as follows:

A. The LTC needs susceptible to technological assistance, with criteria focusing on:

- 1 *The foreseeable evolution of demographic aspects, lifestyles and health care;*
- 2 *The limitations on ADL-IADL that may require LTC;*
- 3 *The required activities of formal and informal carers.*

B. A meaningful use of technological solutions, with criteria related to:

- 1 *The opportunities increased by the technologies;*
- 2 *The potential impact of domotics, equipment and home devices;*
- 3 *The potential impact of domotics, equipment and (remote) devices on ADLs;*
- 4 *The potential impact of domotics, equipment and (remote) devices on IADLs;*
- 5 *The potential impact of devices allowing remote communication: role of formal carers;*
- 6 *The potential impact of devices allowing either the citizen or the informal carer to remotely communicate: reason for contact;*
- 7 *The potential impact of information systems.*

3.2 The analysis of three case studies: dementia, diabetes, obesity

To fine-tune the concepts and show the large variety of mechanisms that may apply to a situation, the scheme was explored in nine situations: three different stages (namely: initial stage, mild situation

with a stable care plan, severe situation with a complex combination of multiple complications) related to three long-term conditions (namely: diabetes, dementia and obesity). For each criterion, the degree of effect was expressed qualitatively, either as ‘null’ (feature not relevant or not applicable), or as one point (negligible effect), two points (mild effect) or three points (strong effect). The assessments were then also represented as colours in synthetic tables (see below).

The case studies indicate the expected variety and provide a qualitative appraisal to raise questions and guide a comparison among a set of scenarios. The field experts in each jurisdiction will need to customise the scheme through various cycles of discussions and assessments, in order to express jointly consolidated and repeatable judgements and to inform the decisions of local policy-makers.

Table 1. A comparative assessment of the care needs for the different phases of the three case studies

i = prevention and initial stages, m = moderate conditions, s = severe conditions (complex situation)
 null = not relevant; 1 green = negligible; 2 yellow = low; 3 red = high

A1. Main feature of each condition requiring formal LTC	dementia			obesity			diabetes		
	i	m	s	i	m	s	i	m	s
prevalence increases with age	2	3	3	1	1	1	1	1	2

A2. Limitations on ADL-IADL	dementia			obesity			diabetes		
	i	m	s	i	m	s	i	m	s
about the beneficiary living alone		2	3		2	3			1
despite the support by the informal carer		2	3		1	3			1
incompatible with the work of the informal carer		2	3			2			
incompatible with a senior informal carer		2	3		1	2			

A3. Required activities by formal and informal carers	dementia			obesity			diabetes		
	i	m	s	i	m	s	i	m	s
multidisciplinary health care activities					1	2		1	2
medical specialist activities (& geriatrician)					1	2		1	2
GP activities		1		1	1	1	2	1	
nursing and other allied activities, incl. education	1	1		1	1	3			1
rehabilitation activities (& occupational therapy)	1	1		1	2				
social activities			1		1	2			1
continuative presence of a person		2	3		1	2			1

B5. Impact of remote communication (role of carers)	dementia			obesity			Diabetes		
	i	m	s	i	m	s	i	m	s
for remote medical visit		1	1			1		1	2
for remote nursing visit					1	1		1	2
to remotely monitor rehabilitation exercises	1	2		1	1	2			

B6. Impact of remote communication (reason)	dementia			obesity			Diabetes		
	i	m	s	i	m	s	i	m	s
for education about LTC and lifestyle	1	1		2	3	1	2	2	1
for instructions & training	1	2		1	1	2	1	2	3
for advice	1	1	1	1	2	1	1	1	2
for company (by formal carers)		1	1			2			1
for company, leisure and support (social network)		1		2	3			1	1

B7. Impact of information systems	dementia			obesity			Diabetes		
	i	m	s	i	m	s	i	m	s
on the organisation of care provision	1	1			1	1	2	2	3
on the synchronisation of the care activities	1	1	1		1	2	1	2	3
to simplify administrative procedures		1	2		1	2		1	2
to increase patient's compliance (reminders, diet)				1	2	2	1	2	3
to facilitate self-assessment (by citizen, informal carer)				2	1		1	2	2
to document the assessments and the care procedures	1	1	1	1	1	2	1	2	2
on managers, to evaluate quality and allocate resources	1	1	2	1	1	2	1	2	2

3.3 Summary of the comparative tables on the three case studies

With respect to the needs for LTC in the different phases of the three case studies, the following notes apply regarding the potential evolution of the prevalence of the condition, the ADL-IADL limitations, and the demand for activities by formal and informal carers.

While the diabetic patient is normally able to cope with the therapy and minor consequences of the disease (if there are no severe complications), the persons in advanced stages of obesity or dementia are unable to perform self-care and remain completely dependent.

As regards the demand for health care activities, social activities and the continual presence of another person (formal or informal carer), diabetes in the initial and moderate stages requires a regular, periodic follow-up by the GP and the specialist. In its severe stage the complications of diabetes demand a good level of coordination among the various specialists. Regarding obesity, in the first stage the GP and the nurse should be able to manage the care plan, including the education of the individual about diet and lifestyle. In later stages, more professionals will be involved. As for dementia, clinical problems are not the most relevant ones with respect to the other issues.

New technologies can allow greater effectiveness and reduce the need for different types of services: hospitalisation, nursing care, home care, informal care, and self-care. In the initial and moderate stages of diabetes and obesity, technology can play a valuable role in delaying the progress of the conditions by increasing prevention and integrating the activities performed by different carers. Medium and severe stages of obesity may be managed with nursing facilities or at home with an informal carer

supported by technology. However, technology cannot replace professional care in keeping a patient at home in cases of severe dementia and diabetes.

Regarding domotics, equipment and home devices, routine data acquisition may be improved by technology in the case of obesity and diabetes, where patients may collaborate in the process. Technology may have a considerable impact on dementia in terms of supervision of the patient and management of the environment, but in general it will play a marginal role in further improving and supporting ADLs; notable exceptions are the tools for supporting mobility and controlling continence in patients with dementia and obesity. Concerning IADLs, a large number of mature technological solutions are already in use and – apart from some particular activity for each case study – further impact will be generally moderate or irrelevant.

Technology could already play an important role in remote monitoring and remote visits, which can be beneficial to patients in terms of increased clinical effectiveness, patient-centeredness, and efficiency. Some further advances may be envisaged concerning remote visits by formal carers for complicated diabetes, which will have some indirect influence on LTC, and about the opportunities for tele-rehabilitation with a direct impact on LTC. Remote communication technologies work significantly in most stages of all the three pathologies (except severe stages of dementia) and could help the patient to be educated, trained, informed by carers, and to stay in touch with his/her own social network.

Finally, integrated information systems may play a critical role in supporting the work processes in care organisations, across all the pathologies, also regarding the administrative issues, the allocation of resources and quality control. Their role is less relevant for dementia, in those processes where the patient needs to collaborate. The effect of ICT on the chronic care model for diabetes is high, with an indirect influence on the related LTC.

4. Recommendations

The recommendations fall within four lines: the provision of technological support to various actors in a favourable context; the promotion of awareness in a country on the issues at stake and on the opportunities offered by technology; supporting the integration of LTC technologies into care processes, and the progressive production of a corpus of reference information ('infostructure') to foster a pervasive and interoperable development of the sector.

4.1 The right context for the development of technology

Many solutions now available are recognised as being effective and sustainable in the international literature. It is also clear that the most important factor for successful implementation is a precise outline of the role of technology within a well-defined path of organisational change, and the presence of leadership to drive the change process. Without an implementation plan clearly redefining the responsibilities, roles, and behaviours of each actor, resistance to change may occur, which hampers the opportunity to get acquainted with technology as an essential component of a new care model and thus to establish a permanent solution.

Operators need to be motivated and reassured that technological change has a positive return, not necessarily in the form of an economic incentive, but rather in a strategic and organisational development, to become part of a coherent, accountable system. The outsourcing of some components of the services to external organisations can be better addressed with the establishment of a regional or national price list.

4.2 Increase awareness of the opportunities offered by technology

A major factor that hinders the development of technology in the LTC sector, although the benefits have been amply demonstrated, is the lack of awareness about all the opportunities offered by technology. In order to best use the limited resources available for LTC, various complementary strategies may be put in place to assist decisions in the public system, the insurance schemes, the voluntary organisations and families.

A first form of intervention is the development and coordination of a network of intra- and inter-regional information centres providing assistance on the rights of citizens; help in choosing the most suitable devices for each individual, providing information on the social and health care organisations (including volunteer organisations) and on their available services. The centres could also produce and distribute (multilingual) material to compare different types of devices and manage showrooms to offer the opportunity to test them. The network of centres could have a web portal, on which documents could be made available to citizens in electronic format and where a discussion on the problems in the LTC sector could take place. A set of pre-competitive ‘living labs’ can also be recommended. These centres would be an innovation space where industries, authorities, organisations, gather their experiences, present national and international best practices, and identify new user requirements for the design of new technologies.

Finally, short training modules could be organised to increase awareness among decision-makers, such as the managers in the municipalities, in the local health authorities and in voluntary organisations. This activity would not only have the goal of preparing them to design a roadmap and to monitor its progress, but also to create a network among managers to exchange information and updates and to support policy-makers in setting priorities and strategies.

4.3 *Improve the demand for industrial solutions*

Industry involvement in LTC is still underdeveloped, even considering the inadequacy of the demand side, which is highly fragmented and with specific difficulties in entering into long-term programmes. Technology is often an issue left directly to the patient-consumer. Valid technological solutions, with proven benefits, already exist; however, unlike other technologies (e.g., diagnostic technology in health care), LTC technologies are still not fully integrated into care processes or daily activities. Researchers and decision-makers should investigate how to assess technologies, from the economic and organisational points of view, in order for them to take more informed decisions about how to update care models.

The mechanism and strength of influence of technologies on each long-term condition is very different across the various phases of its evolution and among the different conditions. The activities carried out in Work Package 4 of the ANCIEN project developed a systematic framework with a grid of criteria to analyse the potential influence of technologies on a series of features (related to ADL, IADL and the mutual roles of the individual, the formal and informal carers), and to work out systematically the specifications for technological solutions within each phase of a long-term condition. As a proof of concepts, the framework was applied to three stages of each of three case studies, respectively to dementia, diabetes and obesity, to show the large difference in the requirements within each scenario.

4.4 *Develop and maintain the ‘infostructure’ for semantic interoperability*

A coherent future application of the technologies in the LTC sector may be accelerated by the production and maintenance of a robust infostructure in a computable format, i.e. a systematic definition of the details about the content shared between applications, made coherent at regional, national or international level. That infostructure, specific to the social and health sectors, includes:

- the systematic description of relevant care processes and related exchanges of documentation among the actors, with the criteria to select the information to be included in the various documents;
- a unique name and an identifier for the main parameters and variables to be collected and exchanged in different contexts, each with a set of the allowed values and their respective codes;
- a definition of each indicator of process and outcome, useful to build a dashboard for decision-makers; the adoption of clear and explicit definitions for indicators (uniform among health care organisations, municipalities and regions) would allow managers to compare similar realities;
- the modalities of interaction between the home equipment and the rest of the information system.

International experience shows that to achieve ‘semantic’ interoperability, a meaningful communication between operators and citizens and the effective governance of the care system, it is necessary to develop and maintain a reference infostructure. The definitions are then made available in a format suitable for electronic processing, both for systems developers and for the users, to allow for the optimal functioning of the overall system together with the infrastructure and basic services for ‘technical’ interoperability (hardware, software, secure networks, master index of citizens and care professionals, electronic cards, etc.).

The content can be built gradually, starting from processes and data considered as most appropriate by the policy-makers in each jurisdiction; the content can then be extended in accordance with the local development plans, also considering the relationship with the efforts on an Electronic Health Record (EHR), which is going to be implemented in several countries and regions. In particular, the infrastructure of the EHR may be used for social care processes other than health care.

In addition, a topic certainly useful to managers is the definition of detailed professional profiles for technology managers and related training plans. Technologies, to be successfully exploited, need innovators able to understand how to integrate them into the care processes, and how to manage the relationships among all the stakeholders and players.

Annex. The available technological solutions

To describe the main features of the technologies, it is useful to distinguish two large classes: on the one hand devices and aids, on the other hand the ICT. It is then possible to consider how their synergy may provide innovative integrated services.

A.1 Devices and aids

A wide range of commercial solutions can be used today to replace, maintain, and improve the functional capabilities of an individual, to assist the delivery of services by operators or to communicate with distant relatives, other patients or operators. The technologies used at home or in residential facilities are evolving towards a favourable relationship between price and performance; they have several things in common:

- they are increasingly miniaturised, portable, with a reduced consumption of energy so that they can be battery powered, often they may be connected to a PC or a mobile phone;
- they allow for a relatively intuitive and friendly interface for wide use by unskilled persons (not necessarily the care recipient), e.g. by touch screen, interpretation of voice or movements;
- they can be produced on a large scale at affordable prices;
- they often create the opportunity for enhanced, integrated services.

Several tools are passive, stand-alone, and not necessarily ‘electronic’: the technological innovation may be hidden in advanced materials, in the production process or in the innovative ergonomic design. Each device is typically designed for a particular function in a well-defined context and its specific impact is therefore necessarily limited, unless it is integrated within a ‘system’.

A.2 The phenomenon of ICT

Information technologies are inherently flexible and pervasive, able to manage the acquisition, storage and sharing of data, information and knowledge for diverse purposes in care delivery, the coordination among the operators, and the management of the facilities. ICT can link the various actors (citizens, informal and formal carers, managers), increase their performance level, make citizens more autonomous within the collaborative processes, and cope with data from a growing number of devices. The introduction of ‘systemic’ ICT solutions acquires a crucial role as a component of a large-scale organisational transformation according to high-level strategic decisions, i.e. in the process of reorganisation and redistribution of responsibilities among the operators and between operators and patient/informal carers.

The greatest impact could come from the coordination and a targeted communication among formal carers and with the citizens, to ensure the continuity of care and the synchronisation among the activities. Many countries are moving towards the concept of ‘connected health’, not only linking the information systems (i.e. interoperability), but also helping people to collaborate.

A.3 The synergy between ICT and devices

The combination of ICT and devices overcomes space-time obstacles, creating new opportunities for tele-care and tele-health in LTC. The solutions are evolving to incorporate the ability to manage and communicate information through the internet to transmit data or to facilitate the interaction with remote operators (in addition to face-to-face interactions), such as in the case of home automation, either for monitoring or for comfort. The home devices involve new care services as a structural component, as they will require public or private contact centres to manage the interpretation of data from the equipment, to provide an adequate return to citizens and informal carers, and to assure the technical support for the maintenance of equipment and to troubleshoot connection problems.

Launched in January 2009, ANCIEN is a research project financed under the 7th EU Research Framework Programme. It runs for a 44-month period and involves 20 partners from EU member states. The project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular:

- 1) How will need, demand, supply and use of LTC develop?
- 2) How do different systems of LTC perform?

The project proceeds in consecutive steps of collecting and analysing information and projecting future scenarios on long-term care needs, use, quality assurance and system performance. State-of-the-art demographic, epidemiological and econometric modelling is used to interpret and project needs, supply and use of long-term care over future time periods for different LTC systems.

Work Packages. The project started with collecting information and data to portray long-term care in Europe (WP 1). After establishing a framework for individual country reports, including data templates, information was collected and typologies of LTC systems were created. The collected data form the basis of estimates of actual and future long term care needs in selected countries (WP 2). WP 3 builds on the estimates of needs to characterise the response: the provision and determinants of formal and informal care across European long-term care systems. Special emphasis is put on identifying the impact of regulation on the choice of care and the supply of caregivers. WP 6 integrates the results of WPs 1, 2 and 3 using econometric micro and macro-modelling, translating the projected needs derived from WP2 into projected use by using the behavioral models developed in WP3, taking into account the availability and regulation of formal and informal care and the potential use of technological developments.

On the back of projected needs, provisions and use in European LTC systems, WP 4 addresses developing technology as a factor in the process of change occurring in long-term care. This project will work out general principles for coping with the role of evolving technology, considering the cultural, economic, regulatory and organisational conditions. WP 5 addresses quality assurance. Together with WP 1, WP 5 reviews the policies on LTC quality assurance and the quality indicators in the EU member states, and assesses strengths, weaknesses, opportunities and threats of the various quality assurance policies. Finally WP 7 analyses systems performance, identifying best practices and studying trade-offs between quality, accessibility and affordability.

The final result of all work packages is a comprehensive overview of the long term care systems of EU nations, a description and projection of needs, provision and use for selected countries combined with a description of systems, and of quality assurance and an analysis of systems performance.

Principal and Partner Institutes

CEPS is responsible for administrative coordination and dissemination of the general results (WP 8 and 9). The Belgian Federal Planning Bureau (FPB) and the Netherlands Bureau for Economic Policy Analysis (CPB) are responsible for scientific coordination. Other partners include: German Institute for Economic Research (DIW); Netherlands Interdisciplinary Demographic Institute (NIDI); Fundación de Estudios de Economía Aplicada (FEDEA); Consiglio Nazionale delle Ricerche (CNR); Università Luiss Guido Carli-Luiss Business School (LUISS-LBS); Institute for Advanced Studies (IHS); London School of Economics and Political Science- Personal Social Services Research Unit (PSSRU); Istituto di Studi e Analisi Economica (ISAE); Center for Social and Economic Research (CASE); Institute for Economic Research (IER); Social Research Institute (TARKI); The Research Institute of the Finnish Economy (ETLA); Université de Paris-Dauphine-Laboratoire d'Economie et de Gestion des organisations de Santé (DAUPHINE- LEGOS); University of Stockholm, Department of Economics; Karolinska Institute-Department of Medicine, Clinical Epidemiology Unit ; Institute of Economic Research, Slovak Academy of Sciences (SAS-BIER); Center for Policy studies (PRAXIS). Most of the ANCIEN partners are members of the European Network of Economic Policy Research Institutes (ENEPRI).