



**European Network of Economic
Policy Research Institutes**

**ANCIENT**

Assessing Needs of Care in European Nations

ROLE AND POTENTIAL INFLUENCE OF TECHNOLOGIES ON THE MOST RELEVANT CHALLENGES FOR LONG-TERM CARE

MARTA MAZZEO, PATRIZIA AGNELLO, ANGELO ROSSI MORI

WITH CONTRIBUTIONS FROM

**MARIE-EVE JOËL, ALAIN BÉRARD, MARKO OGOREVC,
VALENTINA PREVOLNIK RUPEL, ROBERTO DANDI, LUCA GIUSTINIANO**

ENEPRI RESEARCH REPORT NO. 113

JUNE 2012

Abstract

This report considers three case studies (namely diabetes, dementia and obesity) for setting up a framework to assess the systemic influences of technologies in the long-term care milieu, using a problem-driven approach in relation to health care. Such technologies could be an enabling factor or a catalyser of advances taking place in the health and social sectors. They offer opportunities to support and amplify relevant organisational changes in the context of innovative care models, which stem from overall policies and regulations of a national or regional jurisdiction to address the future sustainability of health and social care.



ENEPRI Research Reports present the findings and conclusions of research undertaken in the context of research projects carried out by a consortium of ENEPRI member institutes. This report is a contribution to Work Package 4 of the ANCIENT project, which focuses on the future of long-term care for the elderly in Europe, funded by the European Commission under the 7th Framework Programme (FP 7 Health-2007-3.2.2, Grant no. 223483). See back page for more information. The views expressed are attributable only to the authors in a personal capacity and not to any institution with which they are associated. The results and conclusions of this paper are those of the author and are not attributable to Eurostat, the European Commission or any of the national authorities whose data have been used.

ISBN 978-94-6138-214-6

Available for free downloading from the CEPS website (www.ceps.eu)
and the ANCIENT website (<http://www.ancien-longtermcare.eu/>)
© Copyright 2012 Marta Mazzeo, Patrizia Agnello and Angelo Rossi Mori

Contents

Preface.....	i
Executive Summary	iv
1. Introduction	1
1.1 Ageing of the population and new models of care	1
1.2 Technology as an enabling component of the transition.....	2
2. Challenges stemming from the LTC processes	2
2.1 Care needs related to long-term conditions.....	3
2.2 Potential mechanisms for influencing the future of LTC	4
2.3 Influence of technologies on home care	5
2.4 Influence of technologies on residential care.....	5
2.5 Self-care – The care recipient’s perspective	6
2.6 Role of the care manager in an innovative care model.....	7
2.7 Influence of information services on healthy ageing.....	7
3. Direct and indirect influence of technologies on LTC	8
3.1 Scenarios involving technologies related to activities of daily living and instrumental activities of daily living	9
3.2 Indirect influences of technologies on LTC.....	10
3.3 Optimising the use of resources and the quality of care	11
3.4 Preventing and delaying the consequences of chronic conditions	17
3.5 Requirements for the management of information.....	18
3.5.1 <i>Meta-situation 1 – ‘Regular attention’ with predictable MICK needs</i>	19
3.5.2 <i>Meta-situation 2 – ‘Stable care tasks’ with additional, systematic MICK needs.....</i>	19
3.5.3 <i>Meta-situation 3 – ‘Continuous adaptation of variable care tasks’ involving unpredictable MICK needs</i>	20
3.6 Adaptation of the generic situations to the actual contexts	21
4. Framework for the detailed comparison of case studies	22
4.1 LTC needs, from the perspective of technological solutions	22
4.1.1 Main features and stages of each condition.....	23
4.1.2 Limitations in ADLs/IADLs that may require LTC	23
4.1.3 Required activities by formal and informal carers.....	26

4.2	Potential influence of technological solutions	29
4.2.1	Opportunities increased by technologies.....	29
4.2.2	Potential impact of domotics, equipment and home devices.....	31
4.2.3	Impact of domotics, equipment and (remote) devices on ADLs	33
4.2.4	Impact of domotics, equipment and (remote) devices on IADLs.....	35
4.2.5	Impact of devices allowing remote communication: Role of formal carers.....	37
4.2.6	Impact of devices allowing either the care recipient or informal carer to communicate remotely: Reasons for contact.....	38
4.2.7	Impact of information systems	40
4.3	Consolidated tables on the need for and influence of technologies	42
5.	Recommendations	45
5.1	Improving the outcomes of the assessment methodologies	45
5.2	Increasing awareness of the opportunities offered by technology	45
5.3	Setting the right context for developing technology.....	46
5.4	Developing and maintaining the info-structure for semantic interoperability	46
6.	Conclusions	47
	References	50
	Appendices. Main features of the three case studies.....	57
	Appendix 1. Technology-assisted LTC for the diabetic patient	58
	Appendix 2. Supporting home care: Coping with dementia.....	69
	Appendix 3. Role of technology in coping with obesity	82

List of Tables

Table 1.	Assessment of the influence of technology on the tasks performed in home care (summary)	vi
Table 2.	Assessment of the influence of technology on the tasks performed in residential care (summary).....	vii
Table 3.	Assessment of the influence of technology on the tasks performed in home care.....	5
Table 4.	Assessment of the influence of technology on the tasks performed in residential care	6
Table 5.	Examples of initiatives supporting the development and diffusion of technology to improve the LTC quality dimensions	13
Table 6.	Diabetes – Prevalence with age (a)	23
Table 7.	Obesity – Prevalence with age (a).....	23
Table 8.	Dementia – Prevalence with age (a).....	23
Table 9.	Main feature of each condition – Prevalence with age (a).....	23
Table 10.	Diabetes – Limitations in ADLs/IADLs that may require LTC (a)	24
Table 11.	Obesity – Limitations in ADLs/IADLs that may require LTC (a).....	24
Table 12.	Dementia – Limitations in ADLs/IADLs that may require LTC (a).....	24
Table 13.	Limitations on ADLs/IADLs requiring formal LTC (a).....	26
Table 14.	Diabetes – Need for formal and informal care activities (a).....	26
Table 15.	Obesity – Need for formal and informal care activities (a)	27
Table 16.	Dementia – Need for formal and informal care activities (a)	28
Table 17.	Required activities by formal and informal carers (a).....	29
Table 18.	Diabetes – Role of technology (b).....	29
Table 19.	Obesity – Role of technology (b)	30
Table 20.	Dementia – Role of technology	30
Table 21.	Opportunities increased by technology (b).....	31
Table 22.	Diabetes – Potential impact of domotics, equipment and home devices (b)	31
Table 23.	Obesity – Potential impact of domotics, equipment and home devices (b)	32
Table 24.	Dementia – Potential impact of domotics, equipment and home devices (b)	32
Table 25.	Potential impact of domotics, equipment and home devices (b).....	33
Table 26.	Diabetes – Impact of domotics, equipment and (remote) devices on ADLs (b)	33
Table 27.	Obesity – Impact of domotics, equipment and (remote) devices on ADLs (b).....	34
Table 28.	Dementia – Impact of domotics, equipment and (remote) devices on ADLs (b)....	34
Table 29.	Impact of domotics and devices on ADLs (b)	35
Table 30.	Diabetes – Impact of domotics, equipment and (remote) devices on IADLs (b)....	35

Table 31.	Obesity – Impact of domotics, equipment and (remote) devices on IADLs (b)	36
Table 32.	Dementia – Impact of domotics, equipment and (remote) devices on IADLs (b) ..	36
Table 33.	Impact of domotics and devices on IADLs (b)	37
Table 34.	Diabetes – Reasons for remote communication by formal carers (b)	37
Table 35.	Obesity – Reasons for remote communication by formal carers (b).....	37
Table 36.	Dementia – Reasons for remote communication by formal carers (b).....	38
Table 37.	Impact of remote communication (role of carers) (b)	38
Table 38.	Diabetes – Reasons for remote communication by care recipients and informal carers (b).....	38
Table 39.	Obesity – Reasons for remote communication by care recipients and informal carers (b).....	39
Table 40.	Dementia – Reasons for remote communication by care recipients and informal carers (b).....	39
Table 41.	Impact of remote communication (reason) (b)	40
Table 42.	Diabetes – Impact of information systems (b)	40
Table 43.	Obesity – Impact of information systems (b)	41
Table 44.	Dementia – Impact of information systems (b).....	41
Table 45.	Impact of information systems (b)	42
Table 46.	Comparative assessment of the care needs for the different phases of the three case studies (a).....	43
Table 47.	Comparative assessment of the potential technological solutions for the different phases of the three case studies (b).....	43
Table A1.1	Potential influence of technologies on the care tasks for diabetes	64
Table A1.2	Components of a systematic strategy for diabetes care	64
Table A1.3	Key components of a systematic strategy for diabetes care.....	65
Table A2.1	Use of technologies in the initial, mild and severe stages of dementia	79
Table A3.1	Description of the needs related to obesity	85
Table A3.2	Classification of obesity and its relation to the Bariatric Gallery	86
Table A3.3	Potential correlations between health issues and technological solutions	87

Preface

This is the second deliverable of Work Package (WP) 4 “Technological changes” of the ANCIEN project on “Technology-Assisted Long-Term Care”. The first deliverable had a **technology-driven approach**: the goal was to predict which solutions could be relevant in the future. It responded to the following question:

We consider each technological solution. What could be its future use in the long-term care (LTC) sector?

This report instead focuses on three case studies in the LTC milieu (namely diabetes, dementia and obesity), to set up a **problem-driven approach** as a guide to foresee the systemic influences of technologies (and in particular ICT and innovative equipment). Thus, there are several questions here:

We consider the LTC sector. How may technology influence its future?

And, in particular, what reallocation of roles between home care and residential care may it produce?

How may it influence the reallocation of roles between formal and informal carers?

The technologies themselves should not be the main driver of change, even if they could be an **enabling factor or a catalyst** of advances being deployed in the health and social care sectors. Rather, the technologies offer the opportunities to support and amplify relevant organisational changes, perhaps endorsed and made possible by new approaches to regulations, i.e. by reform for the better integration of health and social care sectors.

*In other words, the deployment of technologies must be considered in the systemic context of **innovative care models**, in turn promoted as a consequence of the overall policies of a national or regional jurisdiction to address the future sustainability of health and social care.*

Unfortunately, given the unusually large scale of the action plans, their novelty and their strong dependency on the regulations and historical context of each jurisdiction concerned, the previous partial experiences cannot provide a solid evidence base for predicting obstacles, costs and benefits, making the related decision processes very complex.

Therefore we adopt a systemic approach, concentrating on the health and social care models that can be deployed (and enhanced by the available technologies), rather than a ‘symptomatic’ approach to mere social care, i.e. looking at the direct impact of each technological solution on either the recipients of care, or on formal or informal carers.

Furthermore, we argued in the first deliverable that low-tech tools (which act mainly on activities of daily living (ADLs) and instrumental ADLs (IADLs)) have already reached a reasonable level of maturity; they are already extremely important for the life of the individual and the comfort of the informal carers, for directly alleviating the consequences of impairments. Thus we expect that further improvements may produce only a fragmented and localised impact on future LTC processes, without a significant contribution to the dramatic changes generated by services based on high-tech solutions.

This deliverable draws attention to the expectations raised by advanced technological services and to potential mechanisms to activate their influence on long-term care. We are confident that the efforts made in every country to overcome the current barriers to a widespread diffusion of the technologies (e.g. issues related to privacy, security, safety, infrastructure and costs, which

have already been solved in most other economic sectors) will enable pervasive deployment also in the health sector.

We claim that the influence of technologies on the LTC sector – added to the well-known socio-demographic evolution, with its influence on the number of elderly people, reduction of family size, modifications of lifestyles, etc. – will stem from the evolution of two contexts:

- the indirect effect of progress in health care models, particularly proactive attention to the risks for the frail elderly, timely intervention to prevent or reduce the consequences of health-threatening events and improvements in the care of chronic diseases predictably leading to long-term conditions that are able to reduce/delay their effects; and
- the direct increase of opportunities to help individuals adapt to daily activities and their social context, living as they best can with long-term conditions and recovering as much as possible from the related loss of functions, with consequent possibilities to alleviate the burdens of their informal carers and restore in some measure their productive role in society.

In summary, this deliverable envisages the combined impact of ICT and equipment (either at home or in residential facilities) as an essential, enabling component of innovative care models in the provision of ‘technology-assisted long-term care’.

Fields of long-term care and technologies considered in this deliverable

If not otherwise specified, LTC in the ANCIEN project includes services that are necessary over an extended period of time, i.e. continual in nature or of more than a six-month duration, for the population aged 65+ in the following fields:

- palliative care,
- long-term nursing care,
- personal care services,
- home help and care assistance,
- services and financing in support of informal (family) care,
- residential care services other than nursing homes, and
- other social services provided in a long-term care context.

LTC in the ANCIEN project does not include the services of curative or rehabilitative care, or the LTC services connected with congenital or chronic disabilities that have existed since a younger age. Other conditions and situations are considered in this deliverable, however, when it is possible to envisage the potential impact of technologies that may indirectly influence the future evolution of LTC provision, e.g.

- technologies applied to continual care, which could change the forecasts for the prevalence of the different kinds of disabilities (and of their levels) and thus the need for LTC; or
- enabling technologies that could be essential for introducing innovative organisational models and improving the quality and sustainability of the LTC system, by supporting a rearrangement of the mutual roles of the various LTC actors (recipients of care, informal and formal carers).

This deliverable considers a wide range of technologies. In particular, the discussion includes low-tech technologies for personal use (for example adaptive utensils for feeding or shower seats), smart home devices able to measure and transmit data, and equipment in the environment (e.g. motion-sensor security lights, sensors for gas, smoke or water). Special attention is devoted to information and communication technologies, and their direct and indirect use by care recipients, informal carers, formal carers and managers. Furthermore, the report considers the indirect actions that could have consequences for the level of awareness and appropriate adoption of technologies in the sense just described.

Executive Summary

This deliverable of WP4 on “Technological changes” of the ANCIEN project builds a framework using a problem-driven approach to assess the future influence of technologies (and in particular ICT and home equipment) in the long-term care milieu.

The technologies are just an enabling factor or a catalyser of larger advances being deployed in the health and social sectors; they offer the opportunities to support and amplify relevant organisational changes, perhaps endorsed and made possible by a new approach to regulations, i.e. by reform of the health and social care sectors. Therefore their future influence (either at home or in residential facilities) must be considered in a systemic context, rather than through a ‘symptomatic’ approach that applies each individual technological solution to mere social care.

Research questions

This deliverable provides insight into the following questions:

- We consider the LTC sector. How may technology influence its future?
- What reallocation of roles between home care and residential care may it produce?
- How may it influence the redistribution of roles between formal and informal carers?

Moreover, by focusing on three case studies (namely diabetes, dementia and obesity), this deliverable addresses several more specific questions:

- What could be the future influence of the various technological services to prevent, delay or reduce the progression of a long-term condition and the risk of a functional loss?
- After the loss of a function, what direct support could technology provide to prevent or reduce the need for LTC, e.g. to restore functions, rearrange the related activities or adapt the environment?
- What could be the role of technology in improving the routine LTC processes respectively having an impact on the individual (self-care), informal carers, formal carers, management or organisational models?

We take into account the consequences of the first two specific questions for the evolution of needs for LTC and those of the third question for the mechanisms that may enable new organisational models for LTC provision in the near future. We aim at giving a qualitative estimation of the effects of technologies on the allocation of care activities between formal and informal carers.

Mechanisms for influencing the LTC processes

Generally speaking, in addition to the tools directly acting to mitigate defective functions in order to reduce the dependency of an individual, technology could effectively intervene in various other ways in the care processes:

- by facilitating communication among people, particularly when various actors are involved in different locations;
- by facilitating access to instructions, information and knowledge; and
- by allowing the (decentralised) acquisition of data, e.g. alerts, signals or measures.

Technologies may have a direct influence on the care recipient, the informal and formal caregivers within the current LTC processes through mechanisms that

- augment opportunities to alleviate the dependency of individuals after a functional loss, through self-care or appropriate support/replacement of the defective functions;
- improve safety and detect potential problems in a timely manner, by monitoring the environment and reducing the effects of inappropriate behaviour on the part of the care recipient or informal carers;
- support the care recipient or informal carers in collateral activities, e.g. administrative procedures and education about lifestyles; and
- orchestrate collaboration among formal carers, and with the patient and the informal carers.

Among the ways technologies *indirectly influence* LTC processes, through activities not involving actual care provision but nevertheless performed *within the LTC environment*, are the following:

- activities to support the adoption of technologies, e.g. through portals with a description of the available devices or services, showrooms and orientation centres to assist consumers in selecting appropriate devices;
- ICT solutions to assist with managerial tasks, e.g. to support managers in setting up an organisational model and in the governance of the system;
- ICT services to support matching between families and family-paid informal carers; and
- e-learning services for voluntary and family-paid informal carers.

Further *indirect influences acting in other sectors*, which may have an impact on LTC in the medium to long term, include the following:

- prevention of the events or processes that may give rise to long-term conditions, efforts to slow their progression and mitigate their (permanent) effects on daily life, e.g. assistance in the care of chronic conditions and prevention of their predictable consequences;
- improvements in the effectiveness of ICT solutions, e.g. work to produce and maintain a body of coding schemes and structured knowledge (info-structure) in a format suitable for computer processing, to assure semantic interoperability during the care process and to perform the timely calculation of quality indicators for managers and policy-makers; and
- support for research and field experiments on the requirements for technological support, the optimisation of the related services, the evaluation of their effectiveness and the development of new technological solutions.

According to the analysis provided in this deliverable, each kind of technological solution will have a different strategic and practical influence, depending also on the regulatory and organisational context. It should be noted that interventions in the design of buildings and *in the production* of technologies – e.g. to obtain more effective or cheaper versions of a device, to develop new materials, to set up new production processes and to improve design – are beyond the scope of this deliverable.

Influence of technologies on long-term care

The first important scenario considered here is related to the influence of technologies on the LTC tasks proactively performed by the individual and informal carers in a home care setting. Afterwards, we discuss the influence of technologies on the tasks performed in residential care.

Influence of technologies on home care

Home care involves self-care by the individual, the care provided by an informal carer and the care provided by formal carers, for either a few hours or 24 hours a day. It can be on a temporary, intermittent or long-term basis. It helps the individual to maintain his/her personal independence, comfort and contact with friends and family in the local community. The tasks of formal carers may also include training and provision of a break for informal carers.

A crucial element of a care model is the integration of the care recipient and informal carers in the overall process, in proactive roles. People with long-term conditions become experts themselves in how their condition affects them and their lives; they progressively learn how to manage their conditions. Technologies are currently used to assist the performance of some tasks, but it is often the case that human intervention is not yet replaceable; in the future greater adoption of technologies with a direct impact could be envisaged, in particular for training and remote advice, remote shopping and remote monitoring (Table 1).

Table 1. Assessment of the influence of technology on the tasks performed in home care (summary)

Tasks	Now	Future
Personal care	**	*
Nutritional care	*	*
Practical care	**	**
Mobile night help	*	**
Respite care	—	*
Family carer training programme	*	***

Now = current status of the meaningful use of technology for the tasks

Future = potential to increase the direct support of the tasks

* = negligible effect, ** = slight effect, *** = strong effect

Source: Authors' cumulative assessment.

Influence of technologies on residential care

Residential care should be considered in principle for people who cannot continue living in their own home, even with support from home care services, because they are too frail or are unable to care for themselves. An individual can stay in residential care for a short time (known as respite care), over a longer period or permanently. Most of the tasks require the physical presence of a carer if the individual is not able to be independent.

At present, technologies may be used for some specific tasks, but are far from having a really critical impact. In the future, an advance of expensive but effective and smart equipment could be envisaged for clinical tasks, telemedicine services, administrative services, social networking and safety of the environment, which may be justified in residential care if used for several care recipients. In addition, some further solutions to assist the mobility and the preparation of meals could be subject to extensive deployment (Table 2).

Table 2. Assessment of the influence of technology on the tasks performed in residential care (summary)

Tasks	Now	Future
Accommodation, hotel services	*	*
Food and diet	*	**
Personal hygiene	**	*
Personal care	*	**
Simple treatments	*	**
Health monitoring (e.g. blood pressure, food or liquid intake, weight)	**	***
General medical services	*	**
Specialist medical services	*	***
Exercise activities, neuromotor and cognitive behavioural rehabilitation services	*	**
Alzheimer's or dementia care, mental stimulation	*	**
Counselling and support	*	**
Safe and secure environment	*	***
Transportation to facility and activities	*	**
Social entertainment activities and integration with territorial services	*	***
Social secretarial and personal assistance services;	*	***

Now = current status of technology penetration and meaningful use for the tasks

Future = potential to increase the direct support for the tasks

* = negligible effect, ** = slight effect, *** = strong effect

Source: Authors' cumulative assessment.

Technology as a catalyst for new organisational models

Technology could represent an enabling component in new care models, to significantly improve the quality and appropriateness of care, through various innovative mechanisms that

- improve the capture of the most relevant data for each condition, with an immediate check on their quality and on their relation to available data and knowledge;
- perform remote monitoring of data generated by smart devices, at home or in residential facilities (either continuously or at scheduled times or upon request), with or without local intervention;
- offer the possibility to exchange structured administrative, organisational and clinical data among all the actors involved with the same care recipient;
- facilitate data analysis and comparison among care recipients for self-audit by professionals and for the optimal management of the care plans;
- produce the proper routine data needed to generate timely governance indicators; and
- enable tailored educational programmes – based also on case-specific data – for all the professional and non-professional actors.

Role of the care manager in an innovative care model

The costs of managing care for the frail elderly and the elderly with chronic diseases have been spiralling. Various organisational models have been developed to reduce costs while improving quality and satisfaction, which allocate activities to specific professional profiles and roles in relation to the applicable environment. A new profile, that of a '**care manager**', is emerging in different contexts, to assist the recipient of care and the informal carer in **routine management** of a long-term condition, with a special emphasis on support for self-care. The care manager should be the interface between the care recipient and the various actors in the care system, and should help the care recipient (and the informal carers) in the implementation of a **predefined care plan** and in the recognition of situations that require alert and potential adaptation/extension of the plan.

A comprehensive information substrate on LTC services

The adoption of a coherent information substrate on LTC services in a large jurisdiction should be an essential component of the appropriate implementation of regulatory, organisational and cultural changes. It should eventually involve all the entities that contribute to the provision and governance of health and social care. It may have a potentially huge impact on the roles and responsibilities of all the stakeholders and thus on the provision of LTC.

Its feasibility and effectiveness depends on the *organisational coherence* among the entities in the health and wellness system (i.e. on their **motivation to cooperate**), which in turn depends on the *regulations and on the cultural context* within each jurisdiction.

It should make extensive use of standards and reference material in a computable format, termed 'info-structure', including the definition of reference care plans, datasets and governance indicators, earmarked subsets of coding schemes, guidelines for producing each kind of documentation on the activities performed and the conditions of the individual.

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 observation and monitoring, and fewer medication errors. The main domain of improvement is preventive health; the key efficiency benefit may be the decreased utilisation of care. Based on the review of literature in WP5, the ANCIEN project identified four dimensions of quality in LTC. Further studies should develop a robust and comparable set of indicators to attain an adequate level of accuracy in the measure of the various dimensions. The quality dimensions are outlined below.

- 1) **Effectiveness.** Effectiveness has been defined as a combination of concepts, notably the effectiveness of care, its appropriateness and the competence of the health system personnel.
- 2) **Safety.** This dimension 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.** This quality also combines different concepts aimed at representing the patient's point of view: patient value responsiveness, satisfaction and acceptability.
- 4) **Coordination.** Coordination has been defined as the combination of timeliness, continuity and integration between primary and secondary care, as well as between health care and social care.

The data presented in section 3.3 were collected in collaboration with WP5 and deal with the use of technology in selected countries across the four dimensions, with a view to identifying examples of good practices for enhancing the quality of LTC through the use of technology.

Assessing the influence of technology on the future of LTC

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

A set of descriptive criteria has been developed in WP4, enabling a detailed analysis to be undertaken of the possible influences of technologies on any particular LTC scenario. The intention has been to formulate a comprehensive approach to enable policy-makers to make informed decisions about technologies in relation to the other priorities of intervention in a jurisdiction.

The approach provides a systematic framework to explore an LTC scenario. It facilitates the collection and discussion of the contributions by stakeholders and comparison of various LTC scenarios for the expected evolution of needs and potential influence of technologies in order to work out the goals and the milestones of an action plan within a specific local context.

The framework considers 51 criteria, organised in two sections and a number of subsections as follows:

- a) the LTC needs susceptible to technological assistance, with criteria focusing on
 - i) the foreseeable evolution of demographic aspects, lifestyles and health care;
 - ii) the limitations in ADLs/IADLs that may require LTC;
 - iii) the required activities by formal and informal carers;
- b) the meaningful use of technological solutions, with criteria related to
 - iv) the opportunities increased by technologies;
 - v) the potential impact of domotics, equipment and home devices;
 - vi) the potential impact of domotics, equipment and (remote) devices on ADLs;
 - vii) the potential impact of domotics, equipment and (remote) devices on IADLs;
 - viii) the potential impact of devices allowing remote communication on the role of formal carers;
 - ix) the potential impact of devices allowing either the care recipient or the informal carer to communicate remotely and the reason for contact; and
 - x) the potential impact of information systems.

To fine-tune the concepts and to show the extreme variety of the mechanisms that may apply to a situation, the scheme is explored in nine situations: three different stages (the initial stage, a mild stage with a stable care plan and a severe stage with a complex combination of multiple complications) related to three long-term conditions (diabetes, dementia and obesity). For each criterion, the degree of effect is expressed qualitatively, as either ‘null’ (*feature not relevant or not applicable*) or one point (*negligible effect*), two points (*slight effect*) or three points (*strong effect*). The assessments are then also rendered also colours in synthetic tables (see Tables 46 and 47 in section 4.3).

This approach is new and no previous data exist; field experts in each jurisdiction, starting from the examples provided in this deliverable, will need to customise the scheme and become familiar with it through various cycles of discussions and assessments, in order to express joint, consolidated and repeatable judgements and to inform the decisions of local policy-makers. Therefore the present examples are intended as an interim step towards qualitative appraisals, to provoke questions and guide comparison among a set of scenarios. They currently provide a preliminary indication of the expected variety of mechanisms, which should be explored through subsequent application to real cases in precise local contexts.

Summary of the comparative tables for the three case studies

With respect to the *needs for LTC* in the different stages of the three case studies, the following notes apply to 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 therapy and minor consequences of the disease (if there are no severe complications), persons in advanced stages of obesity or dementia are unable to perform self-care and remain completely dependent. At the intermediate stage, dementia requires more support than diabetes.

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

With respect to the *influences of technological solutions*, several dimensions of the impact of technology have been analysed.

Technology could enhance effectiveness or reduce the need for the different types of services: hospitalisation, nursing care, home care, informal care and self-care. At the initial and moderate stages of diabetes and obesity, technology may play a positive role in delaying the progress of conditions by increasing prevention and integrating the activities performed by various carers. In the most severe cases, technology may help in reducing the need for hospitalisation. Medium and severe stages of obesity may be managed in nursing facilities or at home with an informal carer, if adequately supported by technology. Even so, technology cannot help much in keeping the patient at home in severe cases of dementia and diabetes – more professional care is needed.

With reference to the potential influence of domotics, equipment and home devices, routine data acquisition may be improved by technology in cases of obesity and diabetes, where patients may collaborate in the process. Technology may have a great impact on dementia in terms of monitoring the patient and managing 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 specific activities for each case study – further impacts will generally be moderate or irrelevant.

Technology may 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 in the future in relation to remote visits by formal carers in complicated cases of diabetes, which will have some indirect influence on LTC, and to opportunities for tele-rehabilitation with a direct impact on LTC. In addition,

remote technologies could be a means of communication, enabling the patient to be educated, trained and informed by carers, and to remain in contact with his/her own social network; technology as a communication medium works to a significant extent in most stages of all three pathologies (except severe stages of dementia).

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

Recommendations

The studies performed in WP4 of the ANCIEN project, as described in the two deliverables, have given rise to recommendations that fall under four themes:

- 1) improving the assessment of technological services and the criteria for selecting them in the context of deploying innovative organisational models;
- 2) promoting the growth of awareness in a given country about the issues at stake and the opportunities offered by technology;
- 3) setting a favourable context that will include technological support as part of a well-defined path of organisational change; and
- 4) progressively producing a corpus of reference information (info-structure) to foster the pervasive and interoperable development of the sector.

The recommendations are discussed in detail below.

The ‘technical’ topics, for example those related to infrastructure, security and privacy, are already addressed in most e-government plans and are thus outside the scope of this deliverable.

Improving the assessment methodologies

The mechanisms and the degree of influence of technologies on each long-term condition are extremely varied across the stages of its progression and among the assorted conditions.

Valid technological solutions already exist and their benefits have been demonstrated in a number of projects (e.g. Department of Health, 2011); 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 the criteria to assess the technologies, from economic and organisational points of view, in order to take more informed decisions about how to reorganise and enhance the care models. A starting point could be the scheme presented in this deliverable, with 51 criteria to analyse the potential influence of technologies on features related to ADLs, IADLs and the mutual roles of the care recipient, the informal carers and the formal carers in each phase of a long-term condition.

Increasing awareness of the opportunities offered by technology

A major factor that hinders the development of technology in the LTC sector is the mere lack of awareness of all the opportunities offered by technology.

One form of intervention is the set-up of a coordinated network of intra- and interregional information centres providing individuals with assistance concerning their rights, choosing the most suitable devices, information on social and health care organisations (including volunteer organisations) and on their available services. The centres could produce and distribute material

for comparing different kinds of devices, and manage showrooms to offer the opportunity to test them. They could also set up pre-competitive ‘living labs’, where industries, authorities and organisations could gather experience, present national and international best practices, and identify new user requirements for the design of new technologies.

Short training modules could be organised to increase awareness among the intermediate-level managers in municipalities, local health authorities and voluntary organisations, with a view to supporting top-level policy-makers in setting priorities and strategies, enabling them to design and monitor progress on a roadmap, and creating a network among them to exchange information and updates.

Setting the right context for developing technologies

Many of the solutions available are recognised as effective and sustainable in the international literature. The most important factors for successful implementation are a precise outline of the role of technology within a *well-defined path of organisational change* to establish a *permanent solution*, the explicit redefinition of *responsibilities and tasks* of each actor and the *strong commitment of leadership* to drive the change process.

Operators need to be motivated and reassured that the organisational and technological changes will produce a positive return, not necessarily in the form of an economic incentive, but rather in an organisational improvement that will be part of a coherent, accountable system.

The outsourcing of *some components* of the services to external public or private organisations can be better addressed with the establishment of a regional or national pricelist.

Developing and maintaining the info-structure for semantic interoperability

The coherent, future application of technologies in the LTC sector may be accelerated by the production and maintenance of a robust info-structure in a computable format. More specifically, this may entail a systematic definition of the details for the modalities and the contents for sharing information among applications and with devices – made coherent at the regional, national or international level – in addition to the infrastructure and basic services for ‘technical’ interoperability already being developed (hardware, software, secure networks, a master index of patients and care professionals, electronic cards, etc.).

The info-structure includes the following:

- a description of relevant care processes and related exchanges of documentation among the actors, with the criteria for selecting 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 the set of allowed values and their respective codes; and
- a structured definition of the indicators for processes and outcomes, for building a dashboard for decision-makers that is uniform among health care organisations, municipalities and regions.

In addition, a topic certainly useful to managers is the definition of detailed professional profiles for technology managers and related training plans. The successful exploitation of technologies within the innovative care models needs innovators who are able to understand how to integrate them into the care processes and how to manage the relationships among all the stakeholders and players.

Conclusions

We describe *multiple mechanisms* by which the application of technology, intended as the complementary use of equipment and ICT solutions, can influence the evolution of LTC from within the sector, including through the following ways:

- changing the mutual roles of professionals and informal carers, allowing them to perform tasks currently performed by more skilled individuals (and thus moving the burden from specialised facilities to less specialised ones and eventually to the home). This phenomenon also includes the potential creation of new professional profiles, e.g. care managers, and new jobs (e.g. increasing the number of non-medical professionals in the field);
- optimising the organisation of LTC, by better synchronising the activities of the different formal and informal carers involved, increasing their awareness of one another, reducing the time required for their communication (and thus providing better care with fewer resources, with a positive influence on the status of care recipients); and
- optimising the accuracy of the LTC processes by better monitoring and more timely reactions to events in relation to the care recipient (again improving the quality of care and the care recipient's status).

The three case studies in this report show the extreme differences in the possible influence of various technologies on each stage of a long-term condition. It is impossible to generalise without considering the classification of individuals with respect to the stage of the disease.

The final effect in the years to come will be to reduce the burden of LTC on the formal care system, in two major ways: by increasing the efficacy and quality, but also by transferring the burden to individuals (the recipients of care and informal carers).

There is also, however, the potential of benefits for the recipients of care and informal carers, who may use the current low-tech tools to alleviate the effects of existing impairments and advanced technologies to improve the effectiveness of self-management. These mechanisms may enable them to return to an active life or to take up a suitable position in a working environment.

Each actor will be able to perform additional activities related to care that are presently being performed by more skilled people:

- frail care recipients will have the opportunity to become more autonomous in their routine activities (including in ADLs and IADLs);
- care recipients will require less support by the non-professional people around them (mostly informal carers);
- a number of these care recipients will move under the threshold of LTC needs that require the intervention of a formal carer; and
- a number of tasks will be passed from professionals to non-professionals, including the care recipients themselves, perhaps under the (remote) supervision of more skilled people.

Several devices are purpose-specific, i.e. they are conceived for a specific defective function; therefore, they produce a very circumscribed impact and a general theory is not possible. Still, a small number of them have been selected in the context of the case studies (i.e. obesity and dementia). More generally, considering the influences from the point of view of the defective functions, there are two approaches in place: either to adopt some specific devices able to

alleviate the effects on daily activities (ADLs, IADLs and beyond) or to replace the processes involved with suitable alternate processes with similar objectives, assisted by appropriate technological solutions. Organisational issues (involving the recipient of care as well as formal and informal carers) could often be more relevant than the direct effects of defective functions.

Other significant impacts could be envisaged on the governance of the care system and on the optimisation of LTC provision. Particular attention should be paid to the effects of domotic devices (monitoring and alarms), a register of contacts and indicators for proper governance of the system.

Finally, one should also consider the use of indirect mechanisms, e.g. the education of care recipients and caregivers as well as their access to knowledge (on such topics as management of the long-term condition, patient's rights and administrative issues).

Therefore the effects that could be interesting to policy-makers may perhaps be more related to the systemic organisational changes than to the increase of the market for devices or the ability to cope better with defective functions (by independently assisting each care recipient to perform daily activities).

Role and Potential Influence of Technologies on the Most Relevant Challenges for Long-Term Care

ENEPRI Research Report No. 113, June 2012

Marta Mazzeo, Patrizia Agnello and Angelo Rossi Mori*

with contributions from

**Marie-Eve Joël, Alain Bérard, Marko Ogorevc,
Valentina Prevolnik Rupel, Roberto Dandi and Luca Giustiniano****

1. Introduction

In this deliverable, we first consider the activities performed as part of long-term care (LTC) in various settings, and then we work out the potential role of a wide range of technologies in providing structural support for the processes involved.

Subsequently, we apply these concepts to three different case studies requiring LTC services – diabetes, obesity and dementia – to compare the prospective mechanisms that could produce an actual impact on the LTC context.

Finally, we provide a set of recommendations to facilitate the meaningful use of technologies in the LTC milieu and to optimise their impact.

1.1 Ageing of the population and new models of care

Healthy ageing is currently among the major concerns in the EU:

Ageing of the population together with unhealthy lifestyles are generating an increased prevalence of chronic conditions that place additional strains on both health and social support systems. In this scenario, existing health and social systems must make the transition to new models of care, with a shift towards integrated patient management. (Kolitsi & Roca, 2009)

We claim that innovative, integrated models of personalised, proactive care cannot be fully and effectively deployed without an intense use of adequate technological solutions (e.g. Cheshire and Merseyside Strategic Health Authority, 2005, Department of Health, 2011; for a wide reading list, see King's Fund, 2011a and 2011b). In particular, chronic disease management is a field *with a predictable influence on LTC needs* in which the role of technologies – in support of the 'systemic' deployment of proper care models and effective governance – could be decisive.

A key challenge is the close coordination of the activities of health and social care professionals in shared care, as well as the proactive involvement of care recipients themselves and their families (patient engagement) in the daily management of the diseases.

* Marta Mazzeo and Angelo Rossi Mori are researchers at the eHealth Unit, ITB-CNR, Rome; Patrizia Agnello is a researcher at INAIL, associated with the same eHealth Unit.

** Marie-Eve Joël is Professor at the Université Paris Dauphine. Alain Bérard is Deputy Director, Fondation Médéric Alzheimer, Paris. Marko Ogorevc and Valentina Prevolnik Rupel are researchers at the Institute for Economic Research, Ljubljana. Roberto Dandi is a researcher in healthcare management at LUISS Business School, a Division of LUISS Guido Carli University in Rome. Luca Giustiniano is Associate Professor in Management at LUISS Guido Carli University in Rome.

At the same time, the governance of the health and social care system should become more effective. More specifically, the quality and appropriateness of the processes of care provision should improve and a number of medical errors should be systematically prevented, thanks to a more explicit definition and optimisation of the processes themselves and an appropriate use of technology (ANCIEN Consortium, 2009; Ministry of Health and Long-Term Care, 2007).

1.2 Technology as an enabling component of the transition

Two large clusters of technologies may be considered when discussing the adoption mechanisms and the influence on LTC (Rossi Mori and Dandi, 2012):

- Medical devices and other equipment, such as low-tech tools in the house, are increasingly cheap and smart; several kinds of equipment can nowadays be used at home and do not require especially skilled people for their management.

Usually their functionalities are very specific, related to particular care issues in a well-defined context; the overall organisational impact is therefore limited and the adoption can be spontaneous and incremental. They may increase the responsibilities and tasks of the recipient of care (self-management) and the informal carers.

- Information and communication technologies (ICT) may instead be very flexible and pervasive, to support the capture and storage of data and information, and to assist LTC provision, e.g. to facilitate the coordination of professionals and the integration of social and health care. In addition, ICT is in principle increasingly able to interconnect various technological solutions (either ICT systems or smart devices), enhancing their synergy. Thanks to ICT, the overall performance level of formal carers may be improved and a really collaborative process of care may be developed with the recipients of care and their informal carers.

By nature, the deployment of systemic ICT solutions should be part of large, interdependent organisational transformations in large jurisdictions according to complex policy decisions.

The most relevant influence will arise from the ability to coordinate professionals (especially across different facilities) and informal carers in the provision of LTC for each individual, namely to assure the continuity of care, to support the synchronisation of activities in shared care plans and self-care, and to improve the task-specific communication among all the actors.

Together, the two kinds of technologies allow for remote monitoring and remote support by formal carers in home and residential care, generating new opportunities for telecare and telehealth. Thus they may be expected to produce a huge impact on the evolution of LTC, with the citizen at the centre. Actually, the expression '**citizen at the centre**' means that all the components of the health and social care system should appear in an unitary and coherent way to the care recipient (harmonised with a proactive role for the citizen and informal carer), effectively solving the issues related to orchestrating all the actors from the organisational, administrative, social and clinical points of view.

Information and communication should play an essential role in this context.

2. Challenges stemming from the LTC processes

This section outlines an overall vision of the context of LTC, in terms of needs and processes. This analysis is the basis for the subsequent sections, where we discuss how the different kinds of technological solutions may satisfy those needs and may provide support for the LTC processes.

2.1 Care needs related to long-term conditions

The regulations and the care model determine the set of technological solutions that may be effectively deployed in a given local context and the best mix to be applied to each individual case.

In other words, the care model in principle suggests which is the most appropriate cluster of technological solutions that may be offered locally (in the context of regulations, inter-organisation agreements and infrastructure available at the level of the jurisdiction and the facilities involved), may be affordable by the families and may be compatible with the culture and skills of the care recipient and the informal carers. Note that most of the health and social care activities are able to produce some form of documentation, which is the crucial element of an ‘information substrate’ and could be used in an information system for multiple purposes (see Box 1).

Box 1. Ideal design and use of information systems

In a properly designed information system, each contact should in principle correspond to a note that contains the reason for the encounter, the activities performed during the encounter, possibly the impressions of and the conclusions about the state of the care recipient and any other information relevant for the other actors. Notes of this kind could be also produced – *with suitable semi-automatic, friendly tools* – by the recipient of care and informal carers, for any *relevant* care activity they perform.

The current ICT solutions facilitate the automatic generation of repetitive agenda items, reminders and notes, as they usually prevent the need to retype most of the data and very often reduce the task to pressing just a single key for the timely confirmation of default data.

Such notes and a description of the integrated care plan (with the objectives and roles of each actor, including the care recipient and informal carers) should be sent to a shared record system. An update should be timely, recorded each time the plan is modified, with a link to the previous plan and with the reason for the modification. Ideally, an appropriate selection of data should be made accessible to each actor, according to predefined filters, restrictions and precise authorisation rules, depending on the respective role and consent of the care recipient or his/her legal representative.

This apparently futuristic scenario is not so far from reality; nowadays it is actually the norm in several other economic sectors, e.g. in banking and transportation, or within advanced health maintenance organisations (e.g. Kaiser Permanente in the US and Maccabi in Israel).

The complex issues of privacy and infrastructure in the health sector, especially when multiple organisations are involved, have hampered the diffusion of e-health systems in most countries; however, they are now being addressed by most national e-government plans.

In our analysis, we take into account that in addition to the tools directly acting on defective functions to directly reduce the dependency of an individual, technology could effectively intervene in three major ways in the care processes:

- by facilitating communication among people, particularly when various people are involved in different locations;
- by facilitating access to instructions, information and knowledge; and
- by allowing the (decentralised) acquisition of data, e.g. signals or measures.

Very specialised equipment can be needed when the task to be performed is just a practical human activity, e.g. washing, dressing or preparing meals. Today some activities, e.g. shopping, may be effectively rearranged to be supported by Internet services.

2.2 Potential mechanisms for influencing the future of LTC

In this deliverable, we apply the principles developed in deliverable 1 of Work Package (WP) 4 of the ANCIEN project, concerning the potential direct and indirect mechanisms by which the technologies may influence the future of LTC.

Technologies may have a direct influence on the care recipient, the informal and formal caregivers within the current LTC processes through mechanisms that

- augment opportunities to alleviate the dependency of individuals after a functional loss, through self-care or appropriate support/replacement of the defective functions;
- improve safety and detect potential problems in a timely manner, by monitoring the environment and reducing the effects of inappropriate behaviour on the part of the care recipient or informal carers;
- support the care recipient or informal carers in collateral activities, e.g. administrative procedures and education about lifestyles; and
- orchestrate collaboration among formal carers, and with the patient and the informal carers.

Among the ways technologies indirectly influence LTC processes, through activities not involving actual care provision but nevertheless performed within the LTC environment, are the following:

- activities to support the adoption of technologies, e.g. through portals with a description of the available devices or services, showrooms and orientation centres to assist consumers in selecting appropriate devices;
- ICT solutions to assist with managerial tasks, e.g. to support managers in setting up an organisational model and in the governance of the system;
- ICT services to support matching between families and family-paid informal carers; and
- e-learning services for voluntary and family-paid informal carers.

Further indirect influences acting in other sectors, which may nevertheless have an impact on LTC in the medium to long term, include the following:

- prevention of the events or processes that may give rise to long-term conditions, efforts to slow their progression and mitigate their (permanent) effects on daily life, e.g. assistance in the care of chronic conditions and prevention of their predictable consequences;
- improvements in the effectiveness of ICT solutions, e.g. work to produce and maintain a body of coding schemes and structured knowledge (termed 'info-structure') in a format suitable for computer processing, to assure semantic interoperability during the care process and to perform the timely calculation of quality indicators for managers and policy-makers; and
- support for research and field experiments on the requirements for technological support, the optimisation of the related services, the evaluation of their effectiveness and the development of new technological solutions.

According to the analysis provided in this deliverable, each kind of technological solution will have a different strategic and practical influence, depending also on the regulatory and organisational context.

It should be noted that interventions in the design of buildings and *in the production* of technologies – e.g. to obtain more effective or cheaper versions of a device, to develop new materials, to set up new production processes and to improve design – are beyond the scope of this deliverable.

2.3 Influence of technologies on home care

Home care involves self-care by the individual, care provided by an informal carer and care provided by formal carers, for just a few hours or 24 hours a day; it can be on a temporary, intermittent or long-term basis. It helps the individual to maintain personal independence, comfort and contact with friends and family in the local community. The tasks of formal carers may also include training and the provision of a break for informal carers.

Technologies are currently used to assist the performance of some tasks, but human intervention is often not yet replaceable. In the future, some direct effects could be envisaged, in particular on training and remote advice, remote shopping and remote monitoring (Table 3).

Table 3. Assessment of the influence of technology on the tasks performed in home care

Tasks	Now	Future
Personal care: Getting out of bed, getting dressed and undressed, going to the toilet, managing continence, emptying a commode, mouth care, care of the terminally ill, colostomy/stoma care, hair care, assistance with medication, washing, bathing/showering, skin care, getting into bed	**	*
Nutritional care: Preparation of drinks as well as breakfast, light meals and hot meals, assistance with eating and food hygiene	*	*
Practical care: Light housework, washing up, cleaning the toilet/bathroom, making a bed, emptying a commode, shopping	**	**
Mobile night help: Assistance for clients who need monitoring or personal care throughout the night	*	**
Respite care: Respite provision for family carers, which can be day-time care in blocks of hours, a waking night service or night-sitting service	—	*
Family carer training programme: Supporting family carers by equipping them with the knowledge and skills to carry out their caring role more effectively and helping them to improve their health and social wellbeing	*	***

Now = current status of the meaningful use of technology for the tasks

Future = potential to increase the direct support for the tasks

* = negligible effect, ** = slight effect, *** = strong effect

Source: Authors' cumulative assessment.

2.4 Influence of technologies on residential care

Residential care should be considered in principle for people who cannot continue living in their own home, even with support from home care services, because they are too frail or are unable to care for themselves. An individual can stay in residential care for a short time (known as respite care), over a longer period or permanently. The staff is usually available 24 hours a day. The residential care may involve registered nurses, experienced care assistants, rehabilitation services and speech or pain therapists. Most of the tasks require the physical presence of a carer if the individual is not able to be independent. At present, technologies may be used for some specific tasks, but are far from having a crucial impact.

In the future, an advance of expensive but effective smart equipment could be envisaged for clinical tasks, telemedicine services, administrative services, social networking and safety in the environment, which may be justified in residential care if used for several care recipients. In addition, other solutions to assist mobility and the preparation of meals could be deployed extensively (Table 4).

Table 4. Assessment of the influence of technology on the tasks performed in residential care

Tasks	Now	Future
Accommodation and hotel services , including laundry and bed changing	*	*
Food and diet , including preparation of meals and fulfilment of dietary requirements and assistance with eating	*	**
Personal hygiene , including help with washing, bathing, shaving, oral hygiene, skin care and nail care	**	*
Personal care , such as assistance in getting up or going to bed, eating, dressing, walking and using the toilet	*	**
Simple treatments , including assistance with taking medications (including eye drops), applications of simple dressings, lotions and creams and oxygen therapy	*	**
Health monitoring , e.g. blood pressure, food or liquid intake, weight	**	***
General medical services	*	**
Specialist medical services	*	***
Exercise activities , neuromotor and cognitive behavioural rehabilitation services	*	**
Alzheimer's or dementia care , mental stimulation	*	**
Counselling and support , including behaviour management, psychological support and reminding devices	*	**
Safe and secure environment	*	***
Transportation to a facility and activities	*	**
Social entertainment activities and integration with local services	*	***
Social secretarial and personal assistance services	*	***

Now = current status of technology penetration and meaningful use for the tasks

Future = potential to increase the direct support for the tasks

* = negligible effect, ** = slight effect, *** = strong effect

Source: Authors' cumulative assessment.

2.5 Self-care – The care recipient's perspective

An important element of a care model is its integration of the overall process, with the care recipient and the informal carers playing a proactive role.

People with long-term conditions become experts themselves in how their condition affects them and their lives; they progressively learn how to manage their conditions. People should be supported and helped to care for themselves, and technological solutions are able to contribute to this objective.

2.6 Role of the care manager in an innovative care model

The costs of managing care for the frail elderly and the elderly with chronic diseases have been spiralling. Various organisational models have been developed to reduce costs while improving quality and satisfaction, which allocate activities to specific professional profiles and roles in relation to the applicable environment. A new profile, that of a ‘**care manager**’, is emerging in different contexts, to assist the recipient of care and the informal carer in routine management of a long-term condition, with a special emphasis on support for self-care. The care manager should be the interface between the care recipient and the various actors in the care system, and should help the care recipient (and the informal carers) in the implementation of a predefined, stable care plan and in the recognition of situations that require alert and potential adaptation/extension of the plan.

The National Health Service (NHS) in the UK calls a similar profile a “community matron” (NHS Careers, 2010). According to the job description outlined by the NHS, a community matron, as well as providing nursing care, acts as a care manager – a single point of contact for care, support or advice, typically for a caseload of around 50 high-intensity users. It should be noted that in section 3.5 we introduce another role, the (clinical) ‘**case manager**’, i.e. a role mostly taken by a physician who coordinates the care plans for the most complex patients with multiple conditions. In the presence of this other figure, a single care manager could offer support to a number of stable patients – between 100 and 200.

The adoption of the job profile of care manager is a consequence of the design of a new model of care. As an example, the process followed by Evercare (a subsidiary of United Healthcare Group, which provides health and well-being services to more than 70 million Americans) implies developing an organisational model of care based on the introduction of a care manager, who is able to cope proactively with the main issues in long-term conditions (Evercare, 2004).

Although it is difficult to isolate the specific quota of benefits coming from the mere use of technology, it is clear that an optimal use of ICT and home equipment opens the doors to an effective and pervasive deployment of these kinds of organisational models, i.e. to the provision of innovative care services.

The “Whole System Demonstrator” programme in England – the largest randomised control trial of tele-health and telecare services in the world – is an attempt to quantify the impact of the more effective organisation that is enabled by this technology. It makes the claim that “if used correctly tele-health can deliver a 15% reduction in A&E visits, a 20% reduction in emergency admissions, a 14% reduction in elective admissions, a 14% reduction in bed days and an 8% reduction in tariff costs” (Department of Health, 2011). More detailed data on this trial will be released in a few months.

2.7 Influence of information services on healthy ageing

The novelty of our approach lies in the systematisation of any available technological solution in a comprehensive framework. Through the case studies of three chronic conditions, we stress the need for a comprehensive review of the requirements for the different phases across the various health and social care processes, looking for similarities among the patterns of care tasks involved in these processes and the consequent systemic impact of information-related technologies.

This approach is complementary and more comprehensive than the usual “symptomatic” approach looking at the immediate needs within social care (e.g. Tak et al., 2010), and is concentrated on the direct impact of each technological solution on the care recipient or on the individual formal and informal carers.

Appropriate national and regional planning, also involving insurance systems and care providers, with the corresponding adaptation of the regulations and specific organisational changes, is very likely to induce a dramatic transformation of LTC within that integrated environment.

A common substrate of data, information and knowledge

Up to ten years ago, in most European countries the market and the initiatives of each health care facility were spontaneously adopting an attitude centred on issues related to the diffusion of advanced technological solutions (mainly e-health and home devices) and trying to comply with the resulting organisational changes (Rossi Mori et al., 2007).

That process of change management stems from many independent local decisions; it is completely different from the process usually involved in health care policies, which tends to be centred on specific target populations in a particular situation (e.g. elderly people or individuals suffering from cancer or diabetes). These policies call for large-scale programmes for the systemic dissemination of innovation, which should be implemented using an approach centred on innovative care models, with technology as a consequent enabling tool. Hence nowadays, careful coordination is required, according to national and regional policies that promote new organisational models and which call for the cooperation of all stakeholders.

This is particularly true when the objective is to create integrated ‘care networks’ (to connect people, not only to connect systems) on health and wellness, also including aspects of LTC. Indeed, to achieve the maximum of benefits and a more sustainable evolution of the health and social care system, all the technological resources that are needed to integrate social and health care should be developed with an appropriate coherence across a wide jurisdiction.

All the actors should rely on a common substrate for the **management of information, communication and knowledge** (MICK) (Rossi Mori et al., 2012). In principle, this substrate will hold all the data, information and knowledge in a unique context, and it may be able to propagate ‘instantaneously’ any modification in the informative resources of the care system to the properly authorised actors.

The adoption of a coherent substrate in a large jurisdiction, across all the entities that contribute to the provision and the governance of long-term care within a global environment, including health and social care, should be an essential component of the appropriate implementation of the regulatory, organisational and cultural changes.

It may have a potentially huge impact on the role and the responsibilities of all the stakeholders and thus on the provision of long-term care.

The feasibility and the effectiveness of the integrated substrate depends on the organisational coherence among all the entities in the health and wellness ecosystem, which in turn depends on the regulations and on the cultural context within each jurisdiction.

This substrate should be designed to take into account the framework provided by the MICK landscape, as determined by the new organisational models being promoted in the care system.

It should make extensive use of standards and reference material in a computable format (the info-structure), including the definition of reference care plans, datasets and governance indicators, earmarked subsets of coding schemes, guidelines for producing each kind of documentation on the activities performed and the conditions of the individual.

3. Direct and indirect influence of technologies on LTC

In this section we deal with the systemic impact of technology systems, including not only ICT but also home equipment that captures clinical data or generates reminders and alarms. We first

discuss the issues related to the potential direct impact of the technologies on LTC processes, then the indirect influences that may involve a modification of the LTC milieu.

3.1 Scenarios involving technologies related to activities of daily living and instrumental activities of daily living

The recipient of care may present a reduction of autonomy in daily activities, perhaps up to the point that s/he becomes completely dependent for certain kinds of functions.

From a practical point of view, technological solutions – in particular domotic equipment and telecare (already discussed in the previous deliverable) – may be able to alleviate the dependency of the care recipient and thereby reduce the burden for informal carers. This would provide a major improvement in the (quality of) daily life of the care recipient and the informal carers, thus facilitating the move from an institution to home. The meaningful use of information technologies is often limited to notifications of activities and to coordination among the actors.

The devices to support most **functions for the activities of daily living (ADLs)** are highly specialised, i.e. each of them produces a very circumscribed impact and usually evolves independently from the others. A general theory is not feasible, as each device can be described only in relation to a particular case study (i.e. in the context of diabetes, obesity and dementia). Several basic technologies already assist efforts to cope with the Katz basic ADLs (i.e. bathing, dressing, toileting, transferring, continence and feeding). Most of them are currently in use in residential care as well at home. Dramatic progress has already been made, e.g. on stair elevators and diapers for incontinence (a product based on highly technical solutions); yet human assistance will remain essential to support the most severe limitations in ADLs. The basic ADLs appear unsuitable for *further dramatic advances* in technologies – the additional direct effect from the development of technology will probably be modest.

The direct effect on **instrumental ADL (IADL) functions** (as defined by Lawton and Brody, i.e. the ability to use a telephone, shopping, food preparation, housekeeping, laundry, transportation, medications and handling finances) will perhaps be relatively important, especially if combined with indirect changes in the modalities for performing these same activities. Significant achievements have seen massive diffusion, e.g. in (industrial) food preparation and storage, special telephone sets and web-based remote shopping. IADL activities are more suitable than ADL activities for future technological enhancements because they can benefit from alternative ways of being performed and thus be assisted by technology.

Particular attention should be given to domotic devices (monitoring and alarms, especially for dealing with cognitive degenerative disorders), to a register of contacts and to indicators for proper governance of the system.

As a consequence, the most relevant future impact of technologies seems not to come from the market for ADL devices, but from the changes for individuals and organisations assisted by the technologies across the entire health and social ecosystem, especially those changes dealing with chronic conditions, which will involve new laws and regulations. As the sustainability of the health system is becoming an issue in most countries, it is possible to foresee a change in the regulations to facilitate home stays, even without a proper evidence base on the future development of technology and new organisational models.

The roles of home care and residential care will change,

- by expanding the range of opportunities for home care;
- by increasing the efficiency and effectiveness of residential care; and

- thus by increasing the choices for the care recipient, for the family and for the care system (concerning the most appropriate kinds of services/facilities that are offered and how these can be regulated).

An improvement in the *organisation* of social care services, and hence in their effectiveness, could greatly affect this phenomenon. In other words, the indirect effect of technologies on the organisation and governance of services, as well as the prevention of LTC needs – e.g. by improving the effectiveness of health care for chronic conditions – could be expected to have a dramatic influence on the roles in LTC, more than the direct effect on specific aspects of ADLs and IADLs.

Building a scenario is not straightforward, because it is influenced by several variables to be explored and schematised:

- which technology will actually spread (spontaneously or supported by policy plans), at what cost, providing which functions and how friendly it is (usability);
- which regulatory changes, ‘aware’ of the technological opportunities, are likely to intervene in the medium to long term (e.g. laws concerning informal carers);
- which organisational models will be adopted in a region/country (and when); what will be the impact of the modified care models (assisted by technologies) on labour productivity and costs in LTC; and
- what will be the role of the family as consumers (as they are buying complementary services and devices, which are not provided by the public system or by insurance), with consequences for the equity of care provision.

3.2 Indirect influences of technologies on LTC

Within a jurisdiction, the health and social system should make available an ample spectrum of technology-assisted services and facilities for LTC, in order to manage in real time all the tasks (care-related and administrative) and the staff activities related to the care recipient.

For example, an online catalogue of the available interventions, with their precise definitions, could be a crucial tool for staff making referrals and planning care, for all the meta-scenarios just described.

The catalogue should have the following features:

- be accessible to all referrers and commissioners of care;
- provide details of all commissioned services;
- describe access and referral requirements; and
- give details of the relevant, integrated care pathways and other protocols, as both reference material and the particular care plan adapted to the recipient of care.

Probably the most cost-effective investment in ICT for long-term care could be the electronic management of the contacts of each care recipient with the long-term care providers, by a shared repository (possibly a component of a longitudinal electronic health record managed at the level of a wide jurisdiction).

In an ideal situation, the repository should also consider the notification of activities of self-care performed by the care recipient and her/his informal carers.

Each ICT application should be able to register the most significant data about all the steps involved in triggering a contact within the system (the intents, the orders, the schedule and a synthesis of the actual event), for all the kinds of professional interventions:

- support
- social care
- psychological care
- medication
- preventive care
- palliative care
- therapies
- surgery, and
- monitoring and supervision.

The appropriate use of ICT, together with the other technological solutions specific for each meta-situation, could produce the following benefits:

- a single (virtual) point of access for care recipients, carers and clinicians;
- integrated health and social care plans for people receiving LTC;
- a case management process to ensure that the needs of care recipients are effectively planned, controlled and escalated across all aspects of the individual's social and health needs; and
- support for a mix of roles and skills to deliver the care model and individualised care plans, including new and revised roles.

3.3 Optimising the use of resources and the quality of care

Another aspect to be considered is the influence of technologies on the quality of care.

Three major benefits for quality have been demonstrated: increased adherence to guideline-based care, enhanced observation and monitoring, and decreased medication errors. The primary domain of improvement is preventive health. The key efficiency benefit shown is decreased utilisation of care. Data on another efficiency measure, time utilisation, have been mixed. Empirical cost data are limited. Available quantitative research is limited and has been done by a small number of institutions. Systems are heterogeneous and sometimes incompletely described. Available financial and contextual data are limited. Four benchmark institutions have demonstrated the efficacy of health information technologies in improving quality and efficiency. Whether and how other institutions can achieve similar benefits, and at what costs, are unclear.

Based on the review of the literature in WP5, the ANCIEN project has identified four dimensions of quality in LTC. Further studies are needed, however, to develop a robust and comparable set of indicators in order to attain an adequate level of accuracy in the measurements of the different dimensions. The quality dimensions are outlined below. The first three are based on the conceptual framework for OECD Health Care Quality Indicators by the OECD (Arah et al., 2006). The fourth dimension has been added because of its importance in LTC.

- 1) **Effectiveness.** Effectiveness has been defined as a combination of concepts (Legido-Quigley et al., 2008):
 - Effectiveness of care refers to the extent to which the intervention achieves the desired outcomes. Donabedian (1980) defines effectiveness as the extent to which attainable improvements in health are, in fact, attained; the IOM (1990) refers to health outcomes; and the Council of Europe (1997) talks about increasing the chances of achieving desired results and avoiding undesired results.
 - Appropriateness, as a performance dimension, is the degree to which the health care provided corresponds to the clinical needs, given the current best evidence. This dimension is most often presented as part of effectiveness.
 - The competence of the health system personnel assesses the degree to which health system personnel have the training and abilities to assess, treat and communicate with their clients. This dimension, in terms of its assessment, is assumed to be included in effectiveness.
- 2) **Safety.** This goal has been defined as “the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the process of care” (National Patient Safety Foundation, 2000).
- 3) **Patient value responsiveness.** This is also the combination of different concepts (Legido-Quigley et al., 2008) aimed at representing the patient’s point of view:
 - Patient value responsiveness refers to “how a system treats people to meet their legitimate non-health expectations” (WHO, 2000) and their preferences and values – emotional well-being, personal development, self-determination, interpersonal relations, social inclusion and social networks. Responsiveness is closely related to patient-centredness, that is, the extent to which care elicits each patient's expectations, feelings and fears about the illness.
 - Satisfaction considers how the treatment and the improvement in the patient’s health meet his/her expectations.
 - Acceptability concerns how humanely and considerately the treatment is delivered.
- 4) **Coordination.** Coordination has been defined as the combination of the following organisational issues (Legido-Quigley et al., 2008):
 - Timeliness refers to the degree to which patients are able to obtain care promptly. It includes both timely access to care (people can get care when needed) and coordination of care (once under care, the system facilitates the movement of people across providers and through the stages of care).
 - Continuity addresses the extent to which health care for specified users, over time, is coordinated across providers and institutions.
 - Integration concerns that of primary and secondary care, and between health care and social care.

In collaboration with WP5, data were collected on the use of technology in selected countries across the four dimensions (see Table 5). The goal was to identify examples of good practices in the use of technology for enhancing the quality of LTC.

Table 5. Examples of initiatives supporting the development and diffusion of technology to improve the LTC quality dimensions

Country	Project
Comprehensive experiences (all of the following technology projects have an impact on the four quality dimensions)	
Sweden	<p><i>Technology and Dementia Project.</i> Managed by the Swedish Institute of Assistive Technology (SIAT), this project stimulated increased use of new technologies and tools that can provide support in daily life to help individuals to be active, safe and secure. The three-year project on engineering and dementia was completed in autumn 2008.</p> <p><i>Assisting Carers using Telematics Interventions to meet Older People's Needs (Action).</i> The Action service was initially and primarily developed to provide support to family caregivers, but with time and at the request of the users and participating municipalities, it evolved to become a self-care support service as well. The service is connected through an ordinary TV screen. The Action service is currently active in 25 municipalities in Sweden and has approximately 300 users. It is composed of</p> <ul style="list-style-type: none"> • information and education programmes on health care in daily lives, and programmes on how family members and older people can more easily cope with daily life, what help and support is available in the community and technical aids; • gymnastic and relaxation programmes; • programmes for stimulation of the cognitive functions; and • programmes in which users can enter their life story, illustrated with photos, along with recorded lectures on care, help and support. <p><i>IPPI.</i> This tool has been developed to facilitate and include older people in the modern information society. The concept of IPPI is that everyone can use a TV to communicate in the digital world. IPPI enables people to receive movies and pictures from camera phones. Service users can also obtain a photo and the name of the carers who will visit them from the home-care provider. Relatives can provide text, voice and video messages.</p> <p><i>AMIGO.</i> The Amigo Service merges three different services, one of which is IPPI. The other two are a digital 'manual' for informal carers and access to a call centre. The AMIGO service is used in approximately 20 municipalities.</p> <p><i>Technology in apartments (Malmö).</i> This project seeks to develop a demonstration environment that is built as an apartment, where everyday technology can be tested and used by older persons, their relatives and nursing staff.</p> <p><i>Creation of a resource centre on smart everyday technology for the elderly (Dalarna).</i> This project includes setting guidelines for the resource centre's organisation, creating a display environment and mobile showrooms, conducting workshops and training, and developing sales activities in the resource centre.</p>

Table 5. *cont'd*

	<p><i>Artemis II.</i> The Multicultural Association of Pensioners has received funds to further develop methods to prevent accidents and raise awareness about the security of elderly people and various facilities for the elderly and their dependents from other countries.</p> <p><i>Technologies for the elderly in Kramfors.</i> The principle underlying this project is that technology in everyday life for people over 80 should be included as part of the municipality's Prevention Centre, where interaction takes place with support for relatives and other actors involved in prevention. The aims are to promote greater knowledge of and interest in the technology of everyday life through the opportunity to test technical solutions.</p>
Germany	<p><i>Financial support.</i> People can receive financial support for home adaptations, telecare, fire alarms and so on. The attribution of this service to one of the quality dimensions in this table is not possible.</p>
Italy	<p><i>eHealth/telemedicine services.</i> According to the e-Care Observatory (http://www.onecare.cup2000.it), there are about 80 eHealth projects in Italian health organisations providing care for elderly patients. While these telemedicine services are available in some organisations, there is no national strategic plan for telemedicine or eHealth. Nor are there any DRGs focused on telemedicine services, so organisations are not incentivised to adopt them. In conclusion, there are some excellent examples but there is no plan or coordination being undertaken at the regional or national level. There are two national commissions on eHealth (which include decision-makers and representatives from industry and care providers), but still no strategic decision has been implemented.</p>
UK	<p><i>Whole Systems Demonstrator project.</i> This project is subject to a large-scale trial funded by the Department of Health (Department of Health, 2011).</p>

1) Effectiveness

Estonia	<p><i>Renovation and building of new nursing care institutions.</i> This effort is being supported by the European Regional Development Fund during 2007–13, which aims at increasing not only the accessibility, but also the quality and effectiveness of the utilisation of LTC resources all over the country.</p>
Italy	<p><i>eHealth/telemedicine service projects.</i> According to the e-Care Observatory (http://www.onecare.cup2000.it) there are about 80 eHealth projects in Italian health organisations devoted to elderly patients. Although telemedicine services are available in some organisations, there is no national strategic plan for telemedicine. Nor are there any DRGs focused on telemedicine services, so organisations are not incentivised to adopt them. In conclusion, there are some excellent examples but there is no plan or coordination being undertaken at the regional or national level.</p>
Hungary	<p><i>Monitoring system for human resources in health care.</i></p>

Table 5. cont'd

Latvia	<i>Self-care supporting technologies.</i> The state lends for free a wide variety of different self-care supporting technologies, also to elderly people, to ease their stay at home and in performing ADLs. These technical devices are lent for different periods, usually two to three years at a time.
The Netherlands	<i>Telecare services.</i> Telecare services involve the use of ICT to deliver care to clients located elsewhere. For example, one such project has started as the collaborative efforts of an insurer, a patient organisation and a telecommunication provider (the Koala project in the Groningen province, covering telecare and telecure). The clients can contact a nurse or a medical service centre at any time (24/7) through their own TV. This project has initially focused on patients with chronic conditions, but it is seen as the basis for future tele-services for long-term care in general.

2) Safety

Estonia	<i>Emergency buttons.</i> These buttons are provided to the elderly and other persons in need, with financial support from municipalities. Also, many other safety-oriented devices are provided to people with support from the state budget, such as ramps.
Latvia	<i>'Safety button'.</i> Organised by the Latvian Samaritans Association, this initiative involves provision of an electronic device – a button that is in use 24 hours a day – through which the client can reach an operative unit that will react to his/her health or other problems immediately.
Italy	<i>Fascicolo Sanitario Elettronico (FSE).</i> This national effort seeks to integrate care at all levels, by sharing patient information in an online, organised database. Half of the regions have developed their own versions of FSE, still to be integrated with one another. The project is supposed to include a patient summary, which could be key to avoiding risks in emergencies (see “Alloggi domotici” [Home automation], Prato, http://www.mobiserv.eu/index.php?lang=it).
Austria	<i>'Benefit'</i> is a technology programme aimed specifically at elderly people.
The Netherlands	<i>Domotic applications.</i> Different domotic applications are used by most formal care institutions, such as bell mats, sensors, door blockers and cameras (on average, three applications per nursing home). Many nursing homes also use cameras and listening devices. Some use radio frequency identification as well. The Dutch Health Care Inspectorate especially promotes their use in order to reduce strong limitations on the freedom of movement of patients. One example is the introduction of 'Remote Care', also known as screen-to-screen care, to communicate with clients through a screen. Screen-to-screen is deployed for clients who are not eligible for institutional care, but eligible for nursing or personal care at home.

3) Responsiveness

Italy	<i>AAL-HOPES (Help and social interaction for elderly on a multimedia platform with e-Social best practices,</i> http://www.hopes-project.org/) is an EU-funded project that aims at developing a web-based platform for supporting the social integration of elderly people with and without disabilities (e-Social Best Practices®). The platform is being tested in the Emilia Romagna and Lazio regions.
-------	---

Table 5. *cont'd*

Austria	<i>'Benefit'</i> is a technology programme aimed specifically at elderly people.
Hungary	<i>Minimum standards in social care (2010–11)</i> . These standards are under development by the Institute of Social Policy. The indicator set has been developed and published, and is currently being tested in a pilot project.
The Netherlands	<i>Domotic applications</i> . The domotic applications described above also increase quality of life by increasing the client's independence. Telecare has also been used. This includes monitoring, consulting and treatment. For example, a nurse can monitor the client through a video network or address the client's psychic problems. In care outside institutions, there are possibilities for financing such care, e.g. in special housing zones and complexes.
4) Coordination	
Estonia	<i>Electronic assessment tools for LTC</i> . Development is underway on electronic assessment tools for LTC applying the inter-RAI system for Estonia, which enables the assessment, planning and evaluation of LTC services, as well as of needs and results, for all LTC institutions. Work is also underway to develop the Estonian Electronic Health Record System (e-health system), which is to be accessible for all the connected health institutions with a view to promoting coordination among providers of health and LTC services.
Italy	<p><i>'Mattoni' (Building Blocks) Project</i>. This national project is aimed at standardising the semantics of several health care-related issues, including residential care information. Its results may be the basis for development of regional and local systems, but it has not produced significant effects so far.</p> <p><i>SINA (Sistema Informativo per la Non Autosufficienza)</i>. This national-level information system will periodically collect information about the multidimensional assessment of dependent patients (including the elderly) and will integrate data from other sources about the costs and activities of social care. The system has been developed and tested in some regions (Liguria, Piemonte, Val D'Aosta, Veneto, Friuli Venezia Giulia, Provincia di Bolzano, Toscana, Marche, Abruzzo, Molise, Campania and Puglia) but it is still without real use for decision-making.</p> <p><i>Fascicolo Sanitario Elettronico (FSE)</i>. This national effort seeks to integrate care at all levels, by sharing patient information in an organised, online repository. Half of the regions have developed their own versions of FSE, which are still to be integrated. It will become a key tool for coordinating LTC.</p> <p><i>Telemedicine services</i>. These are available in some hospitals in Italy (e.g. San Giovanni Addolorata in Rome, San Filippo Neri in Rome, INRCA hospital in Ancona) and they integrate the assistance of different professionals.</p>
Hungary	<i>ISZER</i> . A Hungarian initiative, ISZER (the Hungarian acronym for integrated social and health care) promotes coordination between health and social care.

Table 5. cont'd

The Netherlands	<i>Telecare services to support coordination.</i> The telecare project by the firm Novay (www.novay.nl) aims at improving care by means of communication and information exchange among the various care providers and institutions, using integrated fixed and mobile ICT applications. Another example is the Koala project (see above), where the medical service centres also perform the external coordination of services for their clients, such as calling for a nursing team, making appointments and sending faxes to contact persons.
-----------------	--

Source: Data collected by ANCIEN partners.

3.4 Preventing and delaying the consequences of chronic conditions

A second indirect mechanism is also linked to an increase in the quality of care, by progress in medicine and in care provision models. Such progress is increasingly able either to prevent long-term conditions, to slow their advance or to reduce their effects, e.g. by less invasive and more effective procedures, more accurate diagnostic devices and modern organisational models (e.g. the chronic care model). Other advances include new drugs, more effective rehabilitation procedures, risk management and the reduction of medical errors, along with more timely governance and a more appropriate allocation of resources.

In principle, the progress towards new models of care for chronic conditions tends to shift the care from hospitals to home or LTC facilities, without affecting the quality of the care provided. Thus care recipients will usually be more frail (also bearing in mind their chronic conditions and related repercussions) and the burden of health care will be increasingly transferred from formal carers to the patient and informal carers.

In addition, the better management of acute events (e.g. fractures and strokes) is not solving the health or social consequences, but is sending more frail people back home or to LTC facilities.

The pervasive use of modern technologies might enhance the above process of change in the organisational model pertaining to long-term conditions.

In this context, the contribution of health-related technologies is often crucial to facilitate the above achievements and eventually may have a potentially large, indirect impact on LTC. Indeed, a number of achievements are either not possible or have little effect without an adequate adoption of technological solutions.

Often a dramatic cultural change is required, which is closely linked to organisational and technological changes. On the whole, the management of change usually involves explicit action by top decision-makers (government or managers of health maintenance organisations (HMOs) or both).

Ultimately, sometime in the future, ICT and other technologies will necessarily be present behind the scene and their massive use will be considered 'natural' and given as understood. Currently there is an excess of focus on ICT, which will be replaced by a more correct focus on health issues. In the last decades, we have experienced a trend moving from 'medical informatics' to 'health care informatics', to 'ICT for health' and recently to 'e-health' and 'connected health'. Each term has reflected the evolution in the way of thinking (i.e. awareness) of decision-makers and the driving forces behind it. Today it is time to 'drop the e-', from 'e-health' to just 'health'.

Certainly, it is difficult to assess, for each region, which level of cultural and organisational change has already occurred in that direction, when the big bang (if any) will occur, and where the driving forces of the governments, the consumers and the health care providers will meet.

By order of magnitude, the impact on LTC of technology-enabled organisational changes related to ‘health’ promotion and maintenance (in the holistic meaning involving both health care and social care) is far greater than the magnitude of the impact stemming from the ‘spontaneous’ deployment of the mere technology. Furthermore, it is greater than the ‘sum of the impacts’ of each individual kind of domotic or medical device. In other words, it is not possible to isolate LTC from the phenomena of the health care transformation occurring worldwide, i.e. from the development of the organisational models forced by the need for economic sustainability of the care plus the increasing awareness of citizens about their rights to holistic health care.

In turn, the growing scale of the transformations, no longer limited to a few facilities but involving all the facilities within entire regions, requires the intervention of the top decision-makers in governments and insurance firms/HMOs and new regulations/rules of the game.

The situations in which current technological solutions can be more smoothly utilised and may provide the most benefits are those that are more stable and repetitive, especially those involving multiple actors who belong to different teams yet need to synchronise their objectives, roles and activities.

Therefore the most appropriate context of use concerns frail people and those in the early stages of chronic conditions, where the patient learns to manage the condition and adapt his/her lifestyle. On one side, the social and health care professionals are better able to cooperate among themselves, while on the other side the patient (and the informal carer) is trained to become an ‘expert’ in the tasks and responsibilities to be handled, at least able to cooperate proactively within the limits stated by the professionals.

The house or the LTC facility could become more safe thanks to domotic devices, and some equipment may assist in preventing bedsores or performing fitness exercises. Moreover, through the Internet, the care recipient could interact more effectively with professionals and with other individuals with similar conditions, in addition to the communication channels already available today, as well as be monitored at a distance by devices for observation and (clinical) measurements.

The influence on informal care will be mainly due to an improvement in the health status of the care recipient, i.e. a reduction in functional limitations. This achievement will enable an increasing number of care recipients to be reasonably independent or to receive assistance at home (thus to increase the absolute number of cases that require the presence of informal carers at home). It will also prevent a number of admissions (and the length of stay) in hospitals and residential facilities, reduce the contacts with GPs and in general with professionals, and support informal carers by diminishing their burdens in coping with a particular functional limitation of the care recipient.

3.5 Requirements for the management of information

The MICK for a recipient of long-term care may be influenced by the following factors:

- the clinical and social (chronic) conditions of the care recipient;
- the actors involved in the care and the level of autonomy required by the care recipient and respective informal carers; and
- the actual organisation of the care system (locally and in the wider jurisdictions) with regard to the specific condition.

As mentioned above, we characterise the requirements of the MICK for a set of meta-situations, with each meta-situation generically describing a particular phase in the development of the situation of a care recipient (Rossi Mori et al., 2012).

We claim that the key criterion for gathering together the clusters of technological solutions should be the similarity of the pattern of care tasks; the dimensions that strongly influence the care tasks are the severity of the conditions and the complexity of managing care (e.g. beyond the possibilities of the patient and the informal carers).

As the starting point of the MICK landscape, below is a description of four possible high-level combinations of meta-situations, care tasks and clusters of solutions, perhaps to be further subdivided into more specific homogeneous subclasses. The generic analysis presented here may be further refined by any particular jurisdiction to comply with the actual local context.

Generally speaking, the meta-situations that are stable and regular are also predictable enough to be effectively described in a structured way; therefore the equipment and the information technology may be used in a systematic way.

In this section we divide the health care context into three stereotypical meta-situations for risk stratification and population management for chronic diseases (inspired by the so-called ‘Kaiser Pyramid’), plus a meta-situation to cope specifically with the LTC issues. These meta-situations involve **organisational models and information management** that are similar for different conditions.

To discuss the technological phenomena applied to LTC, we first identify the factors that influence the evolution of this sector, either as a set of bottom-up, autonomous decisions, or as coordinated actions suggested or supported by the authorities of a large jurisdiction (e.g. by legislation, economic incentives or common infrastructure).

3.5.1 Meta-situation 1 – ‘Regular attention’ with predictable MICK needs

In this meta-situation, the clinical state of the care recipient requires systematic attention for a long period, because either s/he is at risk of (a complication of) a disease or in an early, uncomplicated phase of a chronic condition, or is undergoing follow-up to control the effects of previous treatment.

With the right support many people can learn to be active participants in their own care, living with and managing their conditions. This can help them to prevent complications, slow down deterioration, and avoid getting further conditions. The majority of people with chronic conditions fall into this category – so even small improvements can have a huge impact. (Department of Health, 2004, Annex 4)

This meta-situation requires intermittent, sporadic monitoring by the health system. The patient and the informal carers may have a relevant role in changing the patient’s lifestyle and preventing dangerous behaviours. Only a minimal number of the care recipients will require social services for the direct consequences of their clinical state.

Apparently, systematic use of any relevant technological infrastructure or service (according to our current criteria for considering it in the context of a LTC condition) is not required. Yet the use of such an infrastructure (if available within a jurisdiction) will facilitate the integration between LTC – if any – and the other processes of care provision.

3.5.2 Meta-situation 2 – ‘Stable care tasks’ with additional, systematic MICK needs

In meta-situation 2, the clinical state of the care recipient requires synchronisation among health and social professionals, and with the care recipient and the informal carers, according to a stable plan with precise mutual roles.

The progression of the health condition is predictable, and usually an authoritative, reference care pathway is available. The latter describes the classes of clinical situations and provides guidance, for each class, about the ideal tasks to be performed by each actor (including the patients and their informal carers). Thus it fixes a priori each actor's roles and responsibilities.

Disease/care management, in which multidisciplinary teams provide high quality evidence based care to citizens, is appropriate for the majority of people at this level. This means proactive management of care, following agreed protocols and pathways for managing specific diseases. It is underpinned by good information systems – patient registries, care planning, shared electronic health records. (Department of Health, 2004, Annex 4)

In principle, the **routine activities** performed by all the actors should be orchestrated by a 'care manager', i.e. by a care professional (preferably a suitably trained nurse), who in particular should help the patient to manage the relationships with all the clinical actors and with the care system (booking, reimbursement, provision of goods and services). The care manager should also coordinate the activities involved in managing self-care and train informal caregivers, as well as promote self-care.

All the technological services may involve the systematic use of a suitable infrastructure. The appropriateness of the activities assisted by the technological solutions may be determined by the managers through suitable indicators, and the services may therefore be optimised.

3.5.3 Meta-situation 3 – 'Continuous adaptation of variable care tasks' involving unpredictable MICK needs

The state of care recipients in this meta-situation involves multiple chronic conditions, with severe complications and acute co-morbidities. It requires multiple activities with 'parallel responsibilities' among various actors, perhaps operating in different facilities.

The course of action is strongly dependent on the 'daily' development of the situation: it is difficult to orchestrate all the assessments and decisions by all the actors into a coherent and comprehensive care process. Therapy is complex (often requiring a hospital stay) and should be continually adjusted according to its actual effects. This situation suggests an opportunity for ICT solutions to support the organisational aspects of shared care and cooperative decision-making.

As people develop more than one chronic condition (co-morbidities), their care becomes disproportionately more complex and difficult [for] them, or the health and social care system, to manage. This calls for case management – with a key worker (often a nurse) actively managing and joining up care for these people. (Department of Health, 2004, Annex 4)

The coherent management of the complete care process requires a 'case manager', i.e. a professional (a skilled nurse or – in more complex cases – a GP or specialist) who should support the health 'system', to properly involve and synchronise health professionals, providers, the patient and informal carers. The management of information, communication and knowledge is more demanding of professional skills and less foreseeable, i.e. less suitable for a structured representation for further systematic processing.

All the above technological solutions may involve the systematic use of an infrastructure or service. The assessment of technological services by the managers is limited to the issues of efficiency; appropriateness and quality may hardly be controlled given the overall complexity of the situation in which they are embedded.

3.6 Adaptation of the generic situations to the actual contexts

Even in apparently simple cases, the above generic schema based on three clinical and social meta-situations needs accurate adaptation to the local context and specialisation for the particular care recipient and his/her environment.

Indeed, let us consider for example the early stages of diabetes, where the main objective is to ensure that a few tests and visits by GPs and diabetologists are performed every year, in addition to support for a change in the lifestyle of the patient. In a given jurisdiction, the reminders and the scheduling of contacts may be foreseen within an explicit care plan. They may be managed, respectively, by the GP or the diabetologist, care manager, a primary care service or by the patient.

The actual care context for each of the above actors is different, and this influences the cluster of ICT and telemedicine solutions most appropriate to cope with their requirements.

More specifically, each of the actors defines the composition of the target group of patients for which s/he has the main responsibility. For example, the mandate of a diabetologist is limited to a small target group of patients with diabetes in various stages, while the target group seen by a GP involves patients with diverse chronic conditions and the group seen by a nurse acting as a care manager will include a selection of patients from a set of GPs.

Analogously, the modalities for contacting the patient are very different, especially where the activities relating to diabetes have to be synchronised with other ongoing contacts for the same patient with respect to other health issues.

Technology could be an important catalyst for the introduction of more effective care services and the deployment of new organisational models. There is evidence that the collaboration among health professionals and with the patients themselves, based on innovative organisational models (integrated disease management, chronic care model) is able to slow down the development of disease, diminish complications and sequelae, improve the quality of life and reduce the number of hospital admissions. In other words, it positively impacts on the satisfaction of the patients and on the sustainability of the system.

The practical deployment of these models is hindered, however, by the dispersion of professionals and individuals in the territory, the fragmentation of care activities, insufficient communication among the professionals and with the care recipients, and inadequacies in the capture of clinical data. Moreover, health professionals demonstrate difficulties in the transfer of know-how from their theoretical education to daily practice.

As a consequence, the quality of integrated care cannot be optimal without the crucial support of ICT solutions and devices for monitoring and measurement, at home or in residential facilities.

Technologies could represent an enabling component for the diffusion of new care models, with significant improvements in the quality and appropriateness of care, through various innovative mechanisms that

- improve the capture of the most relevant data for each condition, with an immediate check on their quality and on their relation to available data and knowledge;
- offer the possibility to exchange structured administrative, organisational and clinical data among all the actors involved with the same care recipient;
- facilitate data analysis and comparison among care recipients for self-audit by professionals and for the optimal management of care plans;
- produce the proper routine data needed to generate timely governance indicators; and

- enable tailored educational programmes – also based on case-specific data – for all the professional and non-professional actors.

4. Framework for the detailed comparison of case studies

Chronic conditions are seen in this deliverable as part of the predictable factors that lead to the provision of LTC. More compensatory management of the disease in the early stages and the reduction/delay of complications may postpone or reduce the need for LTC in later years. In line with progress of the disease, the needs for LTC may evolve in different ways, according to the nature of the condition considered.

To cope effectively with the needs of a patient with a long-term condition and to manage the cure and care activities for the patient in an optimal way, close cooperation is crucial among the formal carers, as well as with the patient and his/her informal carers.

In most cases, with evolution of the stages of the condition, the number of professionals involved increases, along with the number of different health and social activities performed (with related planning, appointments, provision, reporting, reimbursement, etc.).

The integrated management of information and communication (by ICT solutions and equipment that generate information) is an essential component for the success of the organisational model adopted within each jurisdiction.

In this section, we present the results of the methodology used in WP4 to systematically describe the main aspects of the LTC activities for a given long-term condition. We set up a framework with detailed criteria and we apply it to three case studies: diabetes, dementia and obesity. Descriptions of the specific features of each case study are provided in the appendices.

Here we provide a set of tables with subjective assessments that characterise the influence of each long-term condition on LTC, categorised at three levels: an initial stage, a mild stage of the disease with the application of a stable care plan and a severe stage with a complex combination of multiple diseases and complications.

An assessment of the effect on each stage of the condition has been made, to establish a comprehensive framework for the three case studies. The degree is expressed in points, as either 'null' (*feature not relevant or not applicable*) or as one (*negligible effect*), two (*slight effect*) or three points (*strong effect*). At the end of each section, the assessments are then also rendered as colours in a synthetic table.

This approach is new and no previous data exist. It needs familiarisation by field experts, in order to produce a more consolidated and repeatable assessment.

Therefore the present judgments are intended as just a step towards qualitative appraisals, to provoke questions and guide comparisons of the three case studies. They give a first indication of the variety of effects that appropriate usage of the technology could give rise to in different situations, which should be explored in subsequent, deeper studies.

We first present the tables regarding needs (denoted as type 'a' tables), and then the tables on the solutions (type 'b').

4.1 LTC needs, from the perspective of technological solutions

In this section, the needs for LTC are compiled and characterised from the perspective of the potential use of some technological solutions. First, in Tables 6-9, the main stages of each condition are considered. Then in Tables 10-13, an assessment is made of the ADLs and IADLs affected by each condition. Finally, in Tables 14-17, the roles of the formal and informal carers are taken into account.

4.1.1 Main features and stages of each condition

The feature we consider in this subsection is the relation between the prevalence of each stage of a particular condition and age.

It should be noted that in all the tables in section 4.1, the triplet of numbers in the first column refers respectively to the three stages of the condition (initial, mild or severe, I-M-S), with the interpretation of their values as follows: x = not relevant, 1 = negligible, 2 = low and 3 = high. These figures are then rendered as colours in a short comparative table at the end of each subsection, and are finally summarised altogether in Tables 46 and 47 in section 4.3.

Table 6. Diabetes – Prevalence with age (a)

Prevalence increases with age 1-1-2	Type 1 diabetes mellitus displays a steady increase in the incidence rate with age up to around 10-15 years old and a second rise in incidence after the age of about 25-30. Meanwhile, type 2 diabetes mellitus is one of the most common forms of chronic disease globally. The number of people with diabetes is expected to increase dramatically in European countries during the next two decades.
--	--

Table 7. Obesity – Prevalence with age (a)

Prevalence increases with age 1-1-1	The condition is not directly age-related.
--	--

Table 8. Dementia – Prevalence with age (a)

Prevalence increases with age 2-3-3	The increase of prevalence with age is confirmed by both epidemiological studies and data from health insurance for long-term care to people suffering from Alzheimer's disease (Alzheimer Europe, 2009).
--	---

The three case studies involve different correlations, mainly owing to the diverse pathology behind them.

Actually, obesity is strongly related to lifestyle, while dementia is closely connected with age. Diabetes (type 2) has an intermediate association.

Table 9. Main feature of each condition – Prevalence with age (a)

	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

4.1.2 Limitations in ADLs/IADLs that may require LTC

This subsection focuses on the ADL and IADL limitations and on the limits of self-care. It first considers whether there is a loss of function that cannot be overcome by the individual alone or with the support of an informal carer.

Then it assess the burden for the informal carers: first, whether the carer is in a work situation and whether the care interferes with the ability to work; and second, whether an elderly partner is present and whether s/he could perform either all or a subset of the tasks required of an informal carer.

Table 10. Diabetes – Limitations in ADLs/IADLs that may require LTC (a)

When the patient lives alone x-x-1	There are limitations in cases with complications. Diabetes is associated with the development of a specific microvascular complication of retinopathy, which can lead to blindness, nephropathy with potential renal failure and neuropathy. The latter carries the risk of foot ulcers and amputation, and also autonomic nerve dysfunction.
Despite support by the informal carer x-x-1	There are limitations in cases with complications. Diabetes is associated with the development of a specific microvascular complication of retinopathy, which can lead to blindness, nephropathy with potential renal failure and neuropathy. The latter carries the risk of foot ulcers and amputation, and also autonomic nerve dysfunction.
Incompatible with the work of the informal carer x-x-x	There is no need for continuous assistance, even in cases with complications.
Incompatible with an elderly informal carer (the partner is unable to cope with the care for the loved one) x-x-x	There is no need for continuous assistance, even in cases with complications.

Table 11. Obesity – Limitations in ADLs/IADLs that may require LTC (a)

When the patient lives alone x-2-3	Limitations increase in the advanced stages. Class III individuals are completely dependent (see ‘Doris’ and ‘Emma’ in Appendix 3).
Despite support by the informal carer x-1-3	Class II individuals may recover some ability if the individual is assisted; however, care is physically demanding for the carer.
Incompatible with the work of the informal carer x-x-2	Class III individuals are completely dependent.
Incompatible with an elderly informal carer (the partner is unable to cope with the care for the loved one) x-1-2	Care is too demanding for an elderly partner or relative.

Table 12. Dementia – Limitations in ADLs/IADLs that may require LTC (a)

When the patient lives alone x-2-3	For ADLs, at the first stage patients do not have any problem. At the intermediate stage, patients lose their spatial and temporal references and do not recognise the objects surrounding them. Their environment can lead to accidents. Yet they can still eat alone and are able to move on their own.
---------------------------------------	--

Table 12. cont'd

	<p>At the last stage, the patient suffers from severe memory loss, degradation of oral and written expression and very serious physical problems. It is no longer possible to leave the patient alone. Some people are bedridden and must be supported for all ADLs; they are still able to move on their own and to eat occasionally, but they are unable to take a complete meal; all other tasks (dressing, toileting and ensuring hygiene) cannot be accomplished alone.</p> <p>Concerning IADLs, the limitations depend on the type of activity, as follows:</p> <ul style="list-style-type: none"> • <i>Using the phone.</i> At the first stage of the disease, the patient can use the phone on his/her own initiative. The patient can find and dial a number. At the intermediate stage, the patient gradually loses the ability to use the phone. At first s/he may answer the phone but cannot call and gradually stops responding. In the final stage, the patient no longer uses the phone. • <i>Shopping.</i> At the first stage of the disease, the patient goes shopping alone, but begins to make some mistakes that draw attention and soon needs to be accompanied to shop. The speed of degradation depends on the old habits of the patient (shopping very repetitively or not). In the final stage, the patient is completely unable to go shopping. • <i>Meal preparation.</i> At the first stage, the patient can prepare and serve meals independently. At the intermediate stage, the patient can participate, from time to time, in preparing meals if someone assists. In the final stage, the patient requires meals to be prepared and served. • <i>Household tasks.</i> At the first stage, the patient can clean the household alone or with occasional assistance. At the second stage, the patient can still perform light tasks like washing dishes and making a bed, from time to time. At the final stage the patient does not participate in household tasks. • <i>Laundry.</i> At the first stage the patient continues to do his/her own laundry. Then others are needed to do the laundry. • <i>Use of public transport.</i> At the first stage, especially if the disease has not been diagnosed, the patient continues to travel independently using public transport, taxis or driving his/her own car. Once the disease is diagnosed, the patient's movements are restricted to taxis and car with the assistance of another person, up to an advanced stage of disease. • <i>Medication.</i> At the first stage, the patient is able to take medication alone but occasionally forgets it. At the second and third stages, the patient is unable to take medication on his/her own. • <i>Managing a budget and finances.</i> At the first stage, the patient manages his/her finances independently but sometimes forgets to pay rent or bills and the bank account is overdrawn. From the second stage of the disease onwards, the patient is unable to manage a budget and finances. <p>To summarise, in terms of IADLs, the patient may continue for some time to perform repetitive tasks that do not require much memory.</p>
--	--

Table 12. *cont'd*

Despite support by the informal carer x-2-3	At the first stage of Alzheimer's disease, an informal carer may help the patient to stabilise his/her cognitive functions, through the use of different cognitive stimulation methods on a daily basis.
Incompatible with the work life of the informal carer x-2-3	The time of care increases with the evolution of the disease. The presence of a caregiver becomes ever more vital for managing daily life and incompatible with the work of an informal carer if no formal carer is available.
Incompatible with an elderly informal carer (the partner is unable to cope with the care for the loved one) x-2-3	As the disease evolves, the partner may have a lot of problems: the partner may be in bad health and not have the energy to cope with the care; the partner may not accept that his/her spouse has Alzheimer's disease; and the partner may have financial difficulties with the cost of professional carers. For all these reasons, s/he may not cope with the care for the loved one.

While diabetic patients are normally able to cope with the therapy and the minor consequences of the disease (if there are no severe complications), persons in a severe stage of obesity or dementia are unable to perform self-care and remain completely dependent. In the intermediate stages, dementia is more demanding than diabetes.

Table 13. *Limitations on ADLs/IADLs requiring formal LTC (a)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
When the patient lives alone		2	3		2	3			1
Despite support by the informal carer		2	3		1	3			1
Incompatible with the work life of the informal carer		2	3			2			
Incompatible with an elderly informal carer		2	3		1	2			

4.1.3 Required activities by formal and informal carers

This subsection deals with the need for care activities by the diverse health care professionals, for social activities and for the continual presence of another person (formal or informal carer).

Table 14. *Diabetes – Need for formal and informal care activities (a)*

Multidisciplinary health care activities x-1-2	<p>The need increases in advanced stages.</p> <p>The person living with diabetes will spend the vast majority of his/her time managing diabetes and only an estimated 1% of his/her time in contact with health care professionals.</p> <p>The diabetes care team involves a multidisciplinary group of health care professionals who are available to support the patient, with the patient being at the core of the team. The multidisciplinary group involves the following persons: a diabetes physician, personal caregivers and family members, other specialists (e.g. renal physician or cardiologist), psychologist, podiatrist, pharmacist, dietician, primary care nurse, family doctor, diabetes educator, etc.</p>
---	---

Table 14. cont'd

Medical specialist activities (& geriatrician) x-1-2	Most routine diabetes care initially takes place in a primary care setting. At advanced stages, people with additional or complex needs may require management and support in a specialist setting for some or all of their care.
GP activities 2-1- x	Most routine diabetes care initially takes place in a primary care setting. The role of primary care decreases as the disease stages advance, because people with additional or complex needs may require management and support in a specialist setting for some or all of their care.
Nursing and other associated activities, including education x-x-1	Nursing activities are required after major complications, such as end-stage renal disease, blindness or pancreatitis, which drastically affect the performance of self-care tasks.
Rehabilitation activities (& occupational therapy) x-x-x	These are not particularly relevant.
Social service activities x-x-1	These are relevant in cases with severe complications.
Continual presence of another person x-x-1	The continual presence of another person is required after major complications, e.g. end-stage renal disease, blindness or pancreatitis, which drastically affect the performance of self-care tasks.

Table 15. Obesity – Need for formal and informal care activities (a)

Multidisciplinary health care activities x-1-2	The need increases in advanced stages.
Medical specialist activities (& geriatrician) x-1-2	The need exists in advanced stages, mainly for cardiac complications.
GP activities 1-1-1	The disease per se has a very slow evolution. The 'clinical' role of the GP in relation to obesity is mainly to promote a healthy diet and lifestyle; the other needs should be satisfied by the various health professionals.
Nursing and other associated activities, including education 1-1-3	Encouraging a healthy lifestyle and an appropriate diet are the major objectives of the initial stages. Support for functional mobility is one of the major goals of the advanced stages.
Rehabilitation activities (& occupational therapy) 1-2-x	Stimulation of the fading abilities is the major goal of the initial and intermediate stages.
Social service activities x-1-2	The need increases in advanced stages.
Continual presence of another person x-1-2	The need increases in advanced stages.

Table 16. Dementia – Need for formal and informal care activities (a)

Multidisciplinary health care activities x-x-x	These services are not relevant for long-term care.
Medical specialist activities (& geriatrician) x-x-x	The medical specialists (neurologists and geriatricians) diagnose Alzheimer's disease and propose medical treatments, with limited effect on the loss of cognitive functions. Yet their daily role in long-term care is limited.
GP activities x-1-x	<p>The GP plays an important role at the middle stage of Alzheimer's, when the situation becomes very difficult to manage for the informal caregiver. The GP can give helpful advice to the informal caregiver and help in making good decisions.</p> <p>At the severe stage, supporting people with Alzheimer's to stay at home becomes very complicated and transfer to an institution becomes more or less obligatory. The GP stops taking care of the patient.</p>
Nursing and other associated activities, including education 1-1-x	<p>At home, patients with Alzheimer's at the initial and moderate stages need daily nursing help with toileting and other health care tasks if they suffer from other pathologies in addition to Alzheimer's.</p> <p>In the French context, for example, patients at home do not receive help from nursing for educational and training tasks, except if they take part in the activities of a daycare centre for sufferers of Alzheimer's.</p> <p>At the severe stage, patients move to institutions.</p>
Rehabilitation activities (& occupational therapy) 1-1-x	Rehabilitation activities and occupational therapy are desirable at the two first stages of Alzheimer's. Their effectiveness differs, depending on the stage of the disease: stimulating and maintaining the cognitive functions at the onset of the disease or slowing the rate of deterioration in the second phase of Alzheimer's.
Social service activities x-x-1	The intervention of social services is necessary at the severe stage, when an institutional facility must be found. Informal carers may need counselling and information from social services to help them select a nursing home and to complete all the formalities for the patient's entrance into the facility.
Continual presence of another person x-2-3	The evolution of Alzheimer's involves the need for the continual presence of a formal or informal carer near the patient, because of the risk of accident if the patient is left alone.

At the initial and moderate stages, diabetes requires regular, periodic follow-up by a GP and a specialist. At the severe stage, the complications of diabetes require good coordination among the various specialists. In relation to obesity, at the first stage the GP in conjunction with a nurse may be able to manage the care plan, including education of the individual about a healthy diet and lifestyle. At later stages, more professionals will be involved. As to dementia, the clinical problems are not the most relevant.

Table 17. Required activities by formal and informal carers (a)

	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 associated activities, incl. education	1	1		1	1	3			1
Rehabilitation activities (& occupational therapy)	1	1		1	2				
Social activities			1		1	2			1
Continual presence of another person		2	3		1	2			1

4.2 Potential influence of technological solutions

In the following subsections, several types of technology impacts are analysed for patients with diabetes, obesity and dementia: the role of technology in facilitating different types of care, in enhancing ADLs and IADLs, in supporting informal care and self-care, and in integrating care.

4.2.1 Opportunities increased by technologies

This subsection analyses the role of technology in enabling or preventing diverse types of services: hospitalisation, nursing care, home care, informal care and self-care (Tables 18-21).

Table 18. Diabetes – Role of technology (b)

Delaying progress of the condition 2-2-1	The new technologies in diabetes treatment are mostly useful in new approaches to diabetes management, as notably revealed in integrated care, prevention and early detection of the disease. The most important health technology in diabetes is hence the support for systematic screening programmes at the initial stages, for identifying those persons whose risk of developing diabetes type 2 is higher than usual.
Reducing hospitalisations x-1-2	Appropriate management, assisted by home-based technologies and enhanced communication devices, may be able to compensate for deterioration in some functions (especially at the more advanced stages) and thus to avoid hospitalisation.
Staying in a facility with nursing care x-x-x	The decision to stay in a facility is not significantly influenced by technology.
Staying at home with informal carers x-x-x	An informal carer is not needed at the early stages. Technology could be relevant for the last stage, however, in cases with severe complications.
Staying at home alone x-x-1	Technology is relevant in cases with severe complications.

Table 19. Obesity – Role of technology (b)

Delaying progress of the condition 2-2-1	Technology is relevant for assisting education, rehabilitation and mobility. It is also relevant for more effective coordination among the formal carers.
Reducing hospitalisations x-1-2	Hospitalisations may be reduced as a consequence of improved health care provision.
Staying in a facility with nursing care x-1-2	At advanced stages, technologies can provide an opportunity to remotely assist effective multi-professional care.
Staying at home with informal carers x-1-2	With technological support, the patient can stay at home, assisted by an informal carer (also at advanced stages) as a consequence of improved health care provision and as the opportunities to remotely provide effective home care increase.
Staying at home alone 1-2-x	Technology can assist the performance of ADLs, IADLs and health maintenance tasks, reducing the effects of fatigue. Morbidly obese patients are totally dependent and cannot stay at home alone.

Table 20. Dementia – Role of technology (b)

Delaying progress of the condition 1-x-x	At the first stage of Alzheimer's disease, some information sites can provide training and coaching for patients and caregivers. Screen savers, videophones and conversation prompters may produce good results in memory stimulation, assistance and the creation of a virtual community of patients and caregivers. A series of games explicitly designed for cognitive stimulation are available on the market. Cameras have been used to improve the memory of persons with Alzheimer's. Many technologies contribute to delaying (for some months) the progress of Alzheimer's disease in the first phase.
Reducing hospitalisations x-x-x	The hospitalisation of people with Alzheimer's disease results from falls or the consequences of different pathologies. Often the hospitalisation occurs when the caregiver is exhausted. No technological solution specific to Alzheimer's exists to reduce hospitalisations.
Staying in a facility with nursing care x-x-x	Nursing care is targeted at physical care and does not require specific technologies for people with Alzheimer's disease.
Staying at home with informal carers x-1-x	Many technologies are available to assist the patient with geolocation, through a device worn as a bracelet, necklace or badge, or carried as a card in a wallet. The device sends an alarm if the person with Alzheimer's leaves a given perimeter or falls. Some bracelets trigger the door lock of the house. The aim of these geolocation devices is to give more freedom of movement to patients at the middle stage of the disease, when they get lost and must be found quickly. At the first stage, these techniques are not necessary because the patient understands s/he needs to stay at home. At the last stage, these techniques are no longer necessary because the patient reduces his/her activities and does not move around much.

Table 20. *cont'd*

Staying at home alone 1-2-x	The patient cannot stay at home alone at the last stage of Alzheimer's disease. A number of technologies, not specific to Alzheimer's, can be used at the two first stages and make it easier to stay at home alone: clocks with large figures, telephones that put the patients in contact with an operator able to link up with the main caregivers and remote support. Recent improvements allow the tool to be adjusted to the characteristics of the disease.
--------------------------------	--

At the initial and moderate stages of diabetes and obesity, technology may play a positive role in delaying the progress of the condition by enhancing prevention and integrating carers. In the most severe cases, technology helps in reducing the need for hospitalisation. The medium and severe stages of obesity may be treated in nursing facilities or at home with an informal carer, if adequately supported by technology. Technology cannot help much in keeping the patient at home in severe cases of dementia and diabetes – more professional care is needed.

Table 21. *Opportunities increased by technology (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Delaying progress of the condition	1			2	2	1	2	2	1
Reducing hospitalisations					1	2		1	2
Staying in a facility with nursing care					1	2			
Staying at home with informal carers		1			1	2			
Staying at home alone	1	2		1	2				1

4.2.2 Potential impact of domotics, equipment and home devices

This subsection describes the potential impacts of technology on the acquisition of data and on monitoring the environment and patients with dementia, diabetes and obesity (Tables 22-25).

Table 22. *Diabetes – Potential impact of domotics, equipment and home devices (b)*

For monitoring (sensors: position, movement) x-x-1	These are relevant in cases with severe complications.
Avoiding environmental risks (sensors: gas, fire, etc.) x-x-1	These are relevant in cases with severe complications.
Improving adaptation to the environment (automatic functions, robots, etc.) x-x-1	These are relevant in cases with severe complications.

Table 22. cont'd

Undertaking remote vital sign measurements x-x-1	These are relevant in cases with severe complications.
Undertaking remote clinical measurements x-2-3	The need to provide more frequent self-monitoring of blood glucose measurement, to document glucose excursions and guide insulin therapy – in the most advanced stages – has led to the development of innovative technologies that can provide nearly 300 measurements a day. Efforts are currently underway to develop an integrated system with glucose meters and insulin pumps. Mobile phones have also been linked to blood glucose meters to allow easy review of charted data, real-time feedback of support and integration of the data with medical records.

Table 23. Obesity – Potential impact of domotics, equipment and home devices (b)

For monitoring (sensors: position, movement) x-1-x	These are solely relevant in the case of class II patients living alone. Otherwise, at the initial stage there is no particular need for monitoring and for class III patients, the continuous presence of another person cannot be replaced by environmental sensors.
Avoiding environmental risks (sensors: gas, fire, etc.) x-x-x	There is not a particular need.
Improving adaptation to the environment (automatic functions, robots, etc.) x-2-3	All the automatic functions and robots that allow control of the house (e.g. lighting and opening doors) and for things to be moved (e.g. from a bed or chair) are relevant.
Undertaking remote vital sign measurements x-x-2	There is not a particular need at the early stages. For class III patients, they are useful for monitoring cardiac complications.
Undertaking remote clinical measurements x-1-2	There is not a particular need in relation to the disease itself. At later stages, they are useful for monitoring cardiac complications.

Table 24. Dementia – Potential impact of domotics, equipment and home devices (b)

For monitoring (sensors: position, movement) 1-2-3	Equipment that is relevant at home and in nursing homes, at the different stages of the disease, includes the following: a movement-sensitive mattress, a cushion that detects the prolonged absence of the elderly person, and numerous sensor devices enabling the detection of sleepwalking, total inactivity by the patient, abnormal events requiring emergency action, etc.
Avoiding environmental risks (sensors: gas, fire, etc.) 2-3-3	Environmental risks are not well understood by patients who are able to live at home (at the first stage of the disease and for the most part at the second stage). It is important that sensors inform the caregiver of risks whenever s/he is not present with the patient. At the last stage, almost all patients are in nursing homes, which are always equipped with sensors.

Table 24. *cont'd*

Improving adaptation to the environment (automatic functions, robots, etc.) 1-2-1	The home and nursing homes may be equipped with sensors to automatically switch off lights, close shutters, open doors selectively, etc. The objective is that such equipment can help people with Alzheimer's disease to revive certain sensations affected by the disease. It is assumed that the environment reactivates memory and orientation, reassures the patient and helps him/her to be less confused in performing IADLs.
Undertaking remote vital sign measurements x-x-x	The evolution of the disease does not involve this kind of measurement.
Undertaking remote clinical measurements x-x-x	The evolution of the disease does not involve this kind of measurement.

Data acquisition is nicely improved by technology in cases of obesity and diabetes, where patients may collaborate in the process. Technology may have a great impact on dementia in terms of monitoring the patient and managing the environment.

 Table 25. *Potential impact of domotics, equipment and home devices (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
For monitoring (sensors: position, movement)	1	2	3	1					1
Avoiding environmental risks (sensors: gas, fire, etc.)	2	3	3						1
Improving adaptation to the environment	1	2	1	2	3				1
Undertaking remote vital sign measurements					2				1
Undertaking remote clinical measurements				1	2		2	3	

4.2.3 Impact of domotics, equipment and (remote) devices on ADLs

This subsection analyses the impact of various technologies on each ADL for patients with diabetes, obesity and dementia (Tables 26-29).

 Table 26. *Diabetes – Impact of domotics, equipment and (remote) devices on ADLs (b)*

Bathing (sponge bath, tub bath or shower) – Receives either no assistance or assistance in bathing only one part of the body x-x-x	Not specifically relevant
Dressing – Gets clothes and dresses without any assistance except for tying shoes x-x-x	Not specifically relevant
Toileting – Goes to toilet room, uses toilet, arranges clothes and returns without any assistance (may use a cane or walker for support and may use bedpan/urinal at night) x-x-x	Not specifically relevant

Table 26. cont'd

Transfers – Moves in and out of bed and chair without assistance (may use a cane or walker) x-x-x	Not specifically relevant
Continence – Controls bowel and bladder completely (without occasional ‘accidents’) x-x-x	Not specifically relevant
Feeding – Feeds self without assistance (except for help with cutting meat or buttering bread) x-x-x	Not specifically relevant

Table 27. Obesity – Impact of domotics, equipment and (remote) devices on ADLs (b)

Bathing (sponge bath, tub bath or shower) – Receives either no assistance or assistance in bathing only one part of the body x-2-x	Special bathing equipment is needed for class II patients. A sponge bath is usually used for class III patients.
Dressing – Gets clothes and dresses without any assistance except for tying shoes x-1-1	Some support may be given by low-tech tools.
Toileting – Goes to toilet room, uses toilet, arranges clothes and returns without any assistance (may use a cane or walker for support and may use a bedpan/urinal at night) x-1-x	Some support may be given by low-tech tools.
Transfers – Moves in and out of bed and chair without assistance (may use a cane or walker). x-1-2	For class II patients, some support may be given by low-tech tools. Transfers for class III patients could be problematic even with earmarked tools.
Continence – Controls bowel and bladder completely (without occasional ‘accidents’) x-1-2	Low-tech tools and advanced materials (e.g. diapers) may be relevant.
Feeding – Feeds self without assistance (except for help with cutting meat or buttering bread) x-x-x	The overall impact of technology is irrelevant.

Table 28. Dementia – Impact of domotics, equipment and (remote) devices on ADLs (b)

Bathing (sponge bath, tub bath or shower) – Receives either no assistance or assistance in bathing only one part of the body x-x-1	In nursing homes, people with Alzheimer’s at the last stage could benefit from the same domotic equipment and remote devices as those without the disease, e.g. adapted bathrooms. This equipment makes the tasks of formal carers easier.
Dressing – Gets clothes and dresses without any assistance except for tying shoes x-x-x	The contribution of technologies is irrelevant.

Table 28. *cont'd*

Toileting – Goes to toilet room, uses toilet, arranges clothes and returns without any assistance (may use a cane or walker for support and may use a bedpan/urinal at night) x-x-1	In nursing homes, those with Alzheimer's at the last stage could benefit from the same domestic equipment and remote devices as those without the disease, e.g. an adapted toilet. This equipment makes the tasks of formal carers easier.
Transfers – Moves in and out of bed and chair without assistance (may use a cane or walker) x-x-1	In this regard, there are no technologies earmarked for dementia.
Continence – Controls bowel and bladder completely (without occasional 'accidents') x-1-2	In this regard, there are no technologies earmarked for dementia.
Feeding – Feeds self without assistance (except for help with cutting meat or buttering bread) x-1-x	In this regard, there are no technologies earmarked for dementia.

The technologies, especially low-tech devices, in general play a marginal role in improving and supporting ADLs. Notable exceptions are the tools for supporting mobility and controlling continence in patients suffering from dementia and obesity.

 Table 29. *Impact of domotics and devices on ADLs (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Bathing (sponge bath, tub bath or shower)			1	2					
Dressing – Gets clothes and dresses without assistance				1	1				
Toileting – Goes to toilet room, uses toilet, etc.			1	1					
Transfers – Moves in and out of bed and chair			1	1	2				
Continence – Controls bowel and bladder by self	1		2	1	2				
Feeding – Feeds self without assistance (except cutting)	1								

4.2.4 Impact of domotics, equipment and (remote) devices on IADLs

This subsection describes the impact technology may have on each IADL for people suffering from obesity, diabetes and dementia (Tables 30-33).

 Table 30. *Diabetes – Impact of domotics, equipment and (remote) devices on IADLs (b)*

Ability to use a telephone x-x-x	Not an issue
Shopping x-x-x	Not an issue
Food preparation x-x-x	Not an issue
Housekeeping x-x-x	Not an issue
Laundry x-x-x	Not an issue

Table 30. *cont'd*

Mode of transportation x-x-x	Not an issue
Responsibility for own medications -1-2	Support with reminders
Ability to handle finances x-x-x	Not an issue

Table 31. *Obesity – Impact of domotics, equipment and (remote) devices on IADLs (b)*

Ability to use a telephone x-x-x	Overall impact of technology is irrelevant
Shopping x-1-2	Shopping by Internet
Food preparation x-x-x	Overall impact of technology is irrelevant
Housekeeping x-x-x	Overall impact of technology is irrelevant
Laundry x-x-x	Overall impact of technology is irrelevant
Mode of transportation x-x-x	Overall impact of technology is irrelevant
Responsibility for own medications x-x-x	Overall impact of technology is irrelevant
Ability to handle finances x-x-x	Overall impact of technology is irrelevant

Table 32. *Dementia – Impact of domotics, equipment and (remote) devices on IADLs (b)*

Ability to use a telephone x-x-x	There is not a relevant improvement owing to specific technological aids. See also subsection 4.2.2.
Shopping x-1-x	Geolocation devices give more freedom of movement to patients at the middle stage when they get lost and must be found quickly.
Food preparation 2-3-x	Environmental sensors (e.g. gas) improve safety. See also subsection 4.2.2.
Housekeeping 1-1-x	Environmental sensors improve safety, but the risk is not high. See also subsection 4.2.2.
Laundry 1-1-x	Environmental sensors improve safety, but the risk is not high. See also subsection 4.2.2.
Mode of transportation x-1-x	Geolocation devices give more freedom of movement to patients at the middle stage when they get lost and must be found quickly.
Responsibility for own medications 1-1-x	Reminders may be useful for the patient and the informal caregiver, at the initial stage.
Ability to handle finances x-x-x	There is not a relevant improvement owing to specific technological aids.

A large number of mature technological solutions related to IADLs are already in use. Apart from some specific activities for each case study, the additional impact will generally be moderate or irrelevant.

Table 33. *Impact of domotics and devices on IADLs (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Ability to use a telephone									
Shopping		1		1	2				
Food preparation	2	3							
Housekeeping	1	1							
Laundry	1	1							
Mode of transportation		1							
Responsibility for own medications	1	1					1	2	
Ability to handle finances									

4.2.5 Impact of devices allowing remote communication: Role of formal carers

Technology permits remote monitoring and remote visits that can be beneficial to patients in terms of increased clinical effectiveness, patient-centeredness and efficiency. Here we assess the impact in light of potential future changes in the roles of the formal carers. In this subsection we consider the same solutions from the point of view of the reason for contact (Tables 34-37).

Table 34. *Diabetes – Reasons for remote communication by formal carers (b)*

Remote medical visit x-1-2	Home tele-health (and other kinds of remote medical visits) is a service that gives the clinician the ability to monitor and measure patient health data and information over geographical, social and cultural distances, and provides assistance and guidance.
Remote nursing visit x-1-2	Home tele-health gives the clinician the ability to monitor and measure patient health data and information over geographical, social and cultural distances, and provides assistance and guidance.
Remote monitoring of rehabilitation exercises x-x-x	Not an issue.

Table 35. *Obesity – Reasons for remote communication by formal carers (b)*

Remote medical visit x-x-1	In advanced stages, the reason main relates to cardiac consequences.
Remote nursing visit x-1-1	Remote communication could be useful for instructions to the caregiver.
Remote monitoring of rehabilitation exercises 1-1-2	In advanced stages, remote communication could also support the activities of the caregiver.

Table 36. *Dementia – Reasons for remote communication by formal carers (b)*

Remote medical visit x-1-1	The remote medical visit reduces the transfer of patients and the risk of disturbance when the patient leaves his/her usual environment.
Remote nursing visit x-x-x	There is no impact in this regard.
Remote monitoring of rehabilitation exercises 1-2-x	These devices are really effective in the diagnostic phase (often at the second stage) and when the programmes can be used by patients with the assistance of an informal caregiver. At the first stage, the patient does not think always s/he needs this kind of exercise. At the last stage, the patient is no longer able to practice rehabilitation exercises.

Technology plays a good role already in supporting remote monitoring and remote visits across all the pathologies. We envisage some further advances in the future for remote visits by formal carers in complex cases of diabetes, which will have some indirect influences on LTC and give rise to opportunities for tele-rehabilitation with a direct impact on LTC.

Table 37. *Impact of remote communication (role of carers) (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Remote medical visit		1	1			1		1	2
Remote nursing visit					1	1		1	2
Remote monitoring of rehabilitation exercises	1	2		1	1	2			

4.2.6 Impact of devices allowing either the care recipient or informal carer to communicate remotely: Reasons for contact

This section likewise analyses the home technology discussed above from the point of view of the goals to be achieved, i.e. as a means of communication enabling the patient to be educated, trained and informed by carers, and to keep in contact with his/her own social network (Tables 38-41).

Table 38. *Diabetes – Reasons for remote communication by care recipients and informal carers (b)*

Education about LTC and lifestyle 2-2-1	Diabetes education continues to be cited as a cornerstone of effective diabetes care and supports the philosophy of chronic care models. It is well established that the practice of education in diabetes self-management is critical to the care and management of people with diabetes, and that measurable behaviour change is the unique outcome of working with a diabetes educator.
Instructions & training 1-2-3	Web-assisted e-learning modules foster learning about self-management. The patient learns gradually how to manage the technologies for self-management, as the stages of the disease advance. There is no need for further training at the severe stage. Still, informal carers change their role at the severe stage, and thus need instructions and training.

Table 38. *cont'd*

Advice 1-1-2	Reasons for remote communication include web-assisted suggestions and advice at the early stages about physical activity, healthy eating, monitoring, etc. Professional, earmarked remote advice may be given at later stages.
Company (by formal carers) x-x-1	There is no particular need for professional support, except in cases of limitations from severe complications.
Company, leisure and support (social network) x-1-1	The literature suggests that social media has very little influence on the current mobile applications for diabetes. Most applications that claim to include social media features only provide a link to their groups on well-known social networking sites, such as Facebook and Twitter.

Table 39. *Obesity – Reasons for remote communication by care recipients and informal carers (b)*

Education about LTC and lifestyle 2-3-1	Education is a crucial factor for changes in lifestyle.
Instructions & training 1-1-2	Instructions may be directed at the caregiver.
Advice 1-2-1	Advice for coping with new and subsequent issues may also be directed at the caregiver.
Company (by formal carers) x-x-2	For class III patients, such communication may take place during the period of absence of a caregiver or to assess the state of the patient.
Company, leisure and support (social network) x-2-3	Remote communication is an additional way to take part in the life of the community when mobility is increasingly compromised.

Table 40. *Dementia – Reasons for remote communication by care recipients and informal carers (b)*

Education about LTC and lifestyle 1-1-x	The communication devices for education about LTC and lifestyle are useful for the caregiver at stages 1 and 2 of the disease, for organising care at home.
Instructions & training 1-2-x	When the diagnostic is made and when the disease is accepted by the family, human communication devices for instructions and training are useful.
Advice 1-1-1	During all the stages of the disease, the patient and caregivers need advice and may accept some external advice.
Company (by formal carers) x-1-1	At the second and the last stages, the informal carer needs to manage the relationship with formal carers and human communication devices can help. Formal carers should discourage the patient and the informal carer from withdrawing and should encourage some degree of the informal carer's socialisation.
Company, leisure and support (social network) x-1-x	Human communication devices can increase the social network of the caregiver during the period when s/he needs to give extensive support to the patient at home in the second phase and can facilitate the possibility of respite periods.

Technology as a communication medium works to a significant extent in most stages and for all three of the pathologies (except severe stages of dementia).

Table 41. Impact of remote communication (reason) (b)

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Education about LTC and lifestyle	1	1		2	3	1	2	2	1
Instructions & training	1	2		1	1	2	1	2	3
Advice	1	1	1	1	2	1	1	1	2
Company (by formal carers)		1	1			2			1
Company, leisure and support (social network)		1		2	3		1	1	

4.2.7 Impact of information systems

This final subsection explores the role of information systems in improving care, administration and quality control processes (Tables 42-45).

Table 42. Diabetes – Impact of information systems (b)

Organising care provision 2-2-3	The integrated register may be a fundamental component of a strategic programme on diabetes. The primary goal of the register is to provide a tool for daily management of the cooperation among all the actors and timely feedback to the decision-makers, to be applied in the routine activities of public health.
Synchronising care activities 1-2-3	Systems used to assist practitioners in the management of diabetes should offer ‘just-in-time’, evidence-based support for decision-making and preserve provider autonomy while promoting the transformation of clinical information into action.
Simplifying the administrative procedures x-1-2	Similar to the effect of an integrated register, the addition of administrative data fills the gaps in follow-up and enhances both the compliance rate and resource use, although these data are not as rich as the clinical information.
Increasing the patient’s compliance (reminders, diet advice) 1-2-3	Outcomes can be improved if the primary care team works within a structure that provides reminders and recall for metabolic control and complication risk assessment. Electronic medical records can search for ‘overdue’ interventions when patients have not shown up and might get lost to follow-up in a paper-based system.
Facilitating self-assessment (by the care recipient or informal carer) 1-2-2	The need increases as the disease develops. Patients generally comply with expectations to collect and upload clinical data; however, clinicians do not always respond with timely review and feedback. In this regard, programmes have been found to work best when staff is specifically assigned to support web-assisted interventions.
Documenting the assessments and the care procedures 1-2-2	The need increases as the disease develops. Comprehensive systems that link medical management to self-management with the electronic medical record have consistently shown significant improvements in clinical outcomes and cost savings.

Table 42. *cont'd*

Evaluating quality and appropriateness; planning and allocating resources (by managers) 1-2-2	Managers and policy-makers need timely indicators to govern changes in the management process (towards integrated care) and then to keep the system effective. The function is relevant mainly at the advanced stages, when the organisation of care is more complex.
--	--

 Table 43. *Obesity – Impact of information systems (b)*

Organising care provision x-1-1	Information systems allow each actor (formal as well informal carers and the patient) to be aware of the goals and the tasks of the other actors.
Synchronising care activities x-1-2	Information systems mainly help to orchestrate the activities of multiple formal carers.
Simplifying the administrative procedures x-1-2	The issues are significant for class II and class III patients, who require more goods and services from an insurance or public system.
Increasing the patient's compliance (reminders, diet advice) 1-2-2	The issues are particularly significant for class II and class III patients, when care becomes more complex.
Facilitating self-assessment (by the care recipient or informal carer) 2-1- x	At the beginning the patient (and the caregivers) should learn how to perform the assessment.
Documenting the assessments and the care procedures 1-1-2	Information systems have an indirect effect on the quality of care. Without imposing a very heavy task, it is important to regularly record the main activities that are performed and the state of the patient, as reported by the formal carer and with reference to the care plan.
Evaluating quality and appropriateness; planning and allocating resources (by managers) 1-1-2	Information systems have an indirect effect on the quality of care. The capture of quality data during the process of care provision allows timely and accurate quality indicators to be identified and the use of resources to be monitored.

 Table 44. *Dementia – Impact of information systems (b)*

Organising care provision 1-1-x	If the information system improves, the organisation of care at home (stages 1 and 2) will improve too, but the importance of this improvement has not been demonstrated.
Synchronising care activities 1-1-1	A better transmission of information between formal carers allows better synchronisation of their activities, but the importance of this improvement has not been demonstrated.
Simplifying the administrative procedures x-1-2	The impact of information systems in simplifying administrative procedures is particularly important if the disease is severe. In this case, a proper flow of information among professionals is crucial.

Table 44. *cont'd*

Increasing the patient's compliance (reminders, diet advice) x-x-x	Information systems are not particularly relevant in this regard.
Facilitating self-assessment (by the care recipient or informal carer) x-x-x	The role of technology in allowing the caregiver to assess the patient's state is not particularly relevant.
Documenting the assessments and the care procedures 1-1-1	Better information opens the way for the evaluation of professional practices and the better definition of procedures.
Evaluating quality and appropriateness; planning and allocating resources (by managers) 1-1-2	The individual care plan should be decided after a multidisciplinary assessment is undertaken of dependency and the family situation. Every improvement in the organisation and the availability of information will accelerate the process and facilitate the allocation of the various services.

Information systems play a critical role in supporting work processes in care organisations, across all pathologies. Their role is irrelevant for dementia only in those processes where the patient needs to collaborate. ICT has a role in the chronic care model for diabetes, with an indirect influence on LTC.

Table 45. *Impact of information systems (b)*

	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Organising care provision	1	1		1	1		2	2	3
Synchronising care activities	1	1	1	1	2		1	2	3
Simplifying the administrative procedures		1	2	1	2		1	1	2
Increasing the patient's compliance (reminders, diet advice)				1	2	2	1	2	3
Facilitating self-assessment (by the care recipient or informal carer)				2	1		1	2	2
Documenting the assessments and the care procedures	1	1	1	1	1	2	1	2	2
Evaluating quality and allocating resources (by managers)	1	1	2	1	1	2	1	2	2

4.3 Consolidated tables on the need for and influence of technologies

Tables 46 and 47 present a complete comparison of needs and potential solutions.

Table 46. Comparative assessment of the care needs for the different phases of the three case studies (a)

(a) 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
(a) Limitations on ADLs/IADLs									
When the beneficiary lives alone		2	3		2	3			1
Despite support by the informal carer		2	3		1	3			1
Incompatible with the work of the informal carer		2	3			2			
Incompatible with an elderly informal carer		2	3		1	2			
(a) Required activities by formal and informal carers									
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 associated activities, including education	1	1		1	1	3			1
Rehabilitation activities (& occupational therapy)	1	1		1	2				
Social activities			1		1	2			1
Continual presence of another person		2	3		1	2			1

Notes: 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

Table 47. Comparative assessment of the potential technological solutions for the different phases of the three case studies (b)

(b) Opportunities increased by the technologies	Dementia			Obesity			Diabetes		
	I	M	S	I	M	S	I	M	S
Delaying progress of the condition	1			2	2	1	2	2	1
Reducing hospitalisations					1	2		1	2
Staying in a facility with nursing care					1	2			
Staying at home with informal carers		1			1	2			
Staying at home alone	1	2		1	2				1
(b) Impact of domotics and remote devices									
Monitoring (sensors: position, movement)	1	2	3		1				1
Avoiding environmental risks (sensors: gas, fire, etc.)	2	3	3						1
Improving adaptation to the environment	1	2	1		2	3			1
Undertaking remote vital sign measurements						2			1
Undertaking remote clinical measurements					1	2	2	3	

Table 47. *cont'd***(b) Impact of domotics and devices on ADLs**

Bathing (sponge bath, tub bath or shower)		1		2	
Dressing – Gets clothes and dresses without assistance				1	1
Toileting – Goes to toilet room, uses toilet, etc.		1		1	
Transfers – Moves in and out of bed and a chair			1	1	2
Continence – Controls bowel and bladder	1	2		1	2
Feeding – Feeds self without assistance (except cutting)	1				

(b) Impact of domotics and devices on IADLs

Ability to use a telephone									
Shopping			1			1	2		
Food preparation	2	3							
Housekeeping	1	1							
Laundry	1	1							
Mode of transportation			1						
Responsibility for own medications	1	1						1	2
Ability to handle finances									

(b) Impact of remote communication (role of carers)

Remote medical visit		1	1			1		1	2
Remote nursing visit					1	1		1	2
Remote monitoring of rehabilitation exercises	1	2		1	1	2			

(b) Impact of remote communication (reason)

Education about LTC and lifestyle	1	1		2	3	1	2	2	1
Instructions & training	1	2		1	1	2	1	2	3
Advice	1	1	1	1	2	1	1	1	2
Company (by formal carers)		1	1			2			1
Company, leisure and support (social network)		1			2	3		1	1

(b) Impact of information systems

Organising care provision	1	1			1	1	2	2	3
Synchronising the care activities	1	1	1		1	2	1	2	3
Simplifying the administrative procedures			1	2		1	2		2
Increasing the patient's compliance (reminders, diet)					1	2	2	1	3
Facilitating self-assessment (by care recipients, informal carers)				2	1		1	2	2
Documenting the assessments and the care procedures	1	1	1	1	1	2	1	2	2
Evaluating quality and allocating resources (by managers)	1	1	2	1	1	2	1	2	2

Notes: I = prevention and initial stages, M = moderate conditions, S = severe conditions (complex situation), null = not relevant; 1 = negligible; 2 = low; 3 = high

Even at this preliminary stage, the relevant differences among the three case studies seem able to stimulate the starting hypotheses for carrying on further activities in the field.

5. Recommendations

The studies performed in WP4 of the ANCIEN project, as described in the two deliverables, have given rise to recommendations that fall under four themes:

- 1) improving the assessment of technological services and the criteria for selecting them in the context of deploying innovative organisational models;
- 2) promoting the growth of awareness in a given country about the issues at stake and the opportunities offered by technology;
- 3) setting a favourable context that will include technological support as part of a well-defined path of organisational change; and
- 4) progressively producing a corpus of reference information (info-structure) to foster the pervasive and interoperable development of the sector.

The recommendations are discussed in detail in the following subsections.

The ‘technical’ topics, for example those related to infrastructure, security and privacy, are already addressed in most e-government plans and are thus outside the scope of this deliverable.

5.1 Improving the outcomes of the assessment methodologies

The mechanisms and the degree of influence of technologies on each long-term condition are extremely varied across the stages of its progression and among the assorted conditions.

Valid technological solutions already exist and their benefits have been demonstrated in a number of projects (e.g. Department of Health, 2011); 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 better assess the technologies, from economic and organisational points of view, to enable them to take more informed decisions about how to reorganise and enhance the care models. Further studies are needed not only to improve the evidence of the benefits and their cost-effectiveness (e.g. Renewing Health, 2011) but also to put them into practice, in order to best use the limited resources available for LTC.

Comprehensive methodologies should be able to assist decisions (in the various settings, notably those of the public system, insurance system, voluntary organisations and families) by comparing different complementary components to build complex strategies.

In this vein, the activities carried out in WP4 of the ANCIEN project have developed a systematic scheme with a grid of criteria for analysing the potential influence of technologies on a series of features (related to ADLs, IADLs and the mutual roles of the care recipient, the informal carers and the formal carers). It enables the specifications for technological solutions to be systematically worked out for each stage of a long-term condition. As part of validating the concepts, the framework has been applied to three stages of a long-term condition in three case studies – respectively dementia, diabetes and obesity – to show the extreme differences in the requirements of each scenario (see section 4 above).

5.2 Increasing awareness of the opportunities offered by technology

A major factor that hinders the development of technology in the LTC sector is the mere lack of awareness of all the opportunities offered by technology.

One form of intervention is the set-up of a coordinated network of intra- and interregional information centres providing individuals with assistance concerning their rights, choosing the most suitable devices, information on social and health care organisations (including volunteer organisations) and on their available services.

The centres could also produce and distribute (multilingual) material for comparing different types of devices, and manage showrooms offering the opportunity to test them. The network of centres could have a web portal, through which documents could be made available to people in an electronic format and where discussion of problems in the LTC sector could take place.

The set-up of pre-competitive ‘living labs’ may also be recommended. These facilities would entail a space for innovation, where industries, authorities and organisations could gather experience, 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 the intermediate-level decision-makers who cope daily with organisational issues and the supervision of care processes, for example managers in municipalities, local health authorities and voluntary organisations.

This activity would have two complementary goals:

- to prepare them to design a roadmap and to monitor its progress; and
- to create a network among the intermediate-level managers, who can then exchange information and updates, and in turn support the top-level policy-makers in setting priorities and strategies.

5.3 Setting the right context for developing technology

Many of the technological solutions now available are recognised as 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 a strong **leadership commitment** to drive the change process.

Without an implementation plan clearly redefining the responsibilities, roles and behaviours of each actor, there is a great risk of resistance to change, which hampers the opportunity to get the feeling of 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 the technological change has a positive return, not necessarily in the form of an economic incentive, but rather in a strategic and organisational development that will become part of a coherent, accountable system.

Industry involvement in LTC is still underdeveloped, partly because of inadequacies on the demand side, which is highly fragmented and has specific difficulties in entering into long-term programmes. Technologies are often an issue left directly to the patient-consumer.

The outsourcing of some components of the services to external public or private organisations can be better addressed with the establishment of a regional or national pricelist.

5.4 Developing and maintaining the info-structure for semantic interoperability

The coherent, future application of technologies in the LTC sector may be accelerated by the production and maintenance of a robust info-structure in a computable format, i.e. a systematic definition of the details about the content shared among applications, made coherent at the regional, national or international level.

The info-structure, specific to the social and health sectors, includes the following:

- a systematic description of relevant care processes (with a precise definition of the actors typically involved and their communication needs) and related exchanges of documentation among the actors, with the criteria for selecting 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 the set of allowed values and their respective codes;
- a definition of each indicator of process and outcome, which is useful for building 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; and
- the modalities of interaction between the home equipment and the rest of the information system.

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

The content can be built gradually, starting with well-selected target populations and the processes and data considered most appropriate by policy-makers in each jurisdiction. The content can then be steadily extended in accordance with local development plans, also considering the relationship with efforts to implement an electronic health record (EHR) system, which is to be implemented in several countries and regions. Notably, the infrastructure of the EHR may also be used for social care processes other than those related to health care.

In addition, a topic certainly useful to managers is the definition of detailed professional profiles for technology managers and related training plans. The successful exploitation of technologies within the innovative care models needs innovators who are able to understand how to integrate them into the care processes and how to manage the relationships among all the stakeholders and players.

6. Conclusions

We have described *multiple mechanisms* by which the application of technology, intended as the complementary use of equipment and ICT solutions, can influence the evolution of LTC from within the sector, including through the following ways:

- changing the mutual roles of professionals and informal carers, allowing them to perform tasks currently performed by more skilled individuals (and thus moving the burden from specialised facilities to less specialised ones and eventually to the home). This phenomenon also includes the potential creation of new professional profiles, e.g. care managers, and new jobs (e.g. increasing the number of non-medical professionals in the field);
- optimising the organisation of LTC, by better synchronising the activities of the different formal and informal carers involved, increasing their awareness of one another, reducing

the time required for their communication (and thus providing better care with fewer resources, with a positive influence on the status of care recipients); and

- optimising the accuracy of the LTC processes by better monitoring and more timely reactions to events in relation to the care recipient (again improving the quality of care and the care recipient's status).

In a more indirect way, two more mechanisms – external to the actual LTC processes – should be considered in studying the future evolution of LTC, namely

- improvements in the health care outcomes, e.g. in the case of diabetes; and
- support for the industry to provide more effective solutions (e.g. by promoting the set-up, verification and diffusion of the info-structure).

The three case studies in this report show the extreme differences in the possible influence of various technologies on each stage of a long-term condition. It is impossible to generalise without considering the classification of individuals with respect to the stage of the disease.

The final effect in the years to come will be to reduce the burden of LTC on the formal care system, in two major ways: by increasing the efficacy and quality, but also by transferring the burden to individuals (the recipients of care and informal carers).

There is also, however, the potential of benefits for the recipients of care and informal carers, who may use the current low-tech tools to alleviate the effects of existing impairments and advanced technologies to improve the effectiveness of self-management. These mechanisms may enable them to return to an active life or to take up a suitable position in a working environment.

We are all accustomed to a large amount of equipment (and more is going to appear) that 'interacts' with the most common human activities, including cars to facilitate transportation and glasses to alleviate defective vision. Some equipment is general purpose in nature – tools that may be used either for defective functions (perhaps after some adaptation), comfort or efficiency (e.g. cars). Other tools are specifically conceived to address missing or defective functions (e.g. glasses and wheelchairs).

Information technology is having a pervasive impact on all dimensions of our lives, mainly through communication devices and infrastructure (the Internet, mobile phones, smartphones, etc.) and through selective access to information and knowledge.

In addition to the above-noted devices and to information technology, a new generation of devices is emerging, which can be placed at home or in LTC facilities and which is able to perform measurements, generate alarms and capture videos. These devices can be remotely controlled and can send data to remote places for appropriate interpretation by skilled people.

We envisage in the medium to long term a revolution in the organisation of care provision, facilitated by the adoption – perhaps on a massive scale – of technology. This will have a major impact on the management of long-term conditions: slowing down consequences, allowing effective organisational changes from hospitals to facilities across the territory and from long-term facilities to home.

More frail people with stable long-term diseases (that need to be cured) will live well outside hospitals, i.e. at home or in long-term facilities, perhaps for a longer period; an increased percentage of recipients of care will be able to stay at home (i.e. not in long-term facilities).

Each actor will be able to perform additional activities related to care that are presently being performed by more skilled people:

- frail care recipients will have the opportunity to become more autonomous in their routine activities (including in ADLs and IADLs);
- care recipients will require less support by the non-professional people around them (mostly informal carers);
- a number of these care recipients will move under the threshold of LTC needs that require the intervention of a formal carer; and
- a number of tasks will be passed from professionals to non-professionals, including the care recipients themselves, perhaps under the (remote) supervision of more skilled people.

For example, the usual telephone device can be replaced by a specialised, friendly display with a webcam for video-communication with a remote care manager or with a specific relative (a modern version of this device is just appearing on the market, produced by Intel and other big companies).

As noted above, several devices are purpose-specific, i.e. they are conceived for a specific defective function; therefore, they produce a very circumscribed impact and a general theory is not possible. Still, a small number of them have been selected in the context of the case studies (i.e. obesity and dementia), and have been considered in detail in the ANCIEN project.

More generally, the effects of most defective functions (beyond ADLs and IADLs) may be alleviated by specific devices or the processes involved may be replaced by suitable alternate processes with similar objectives, assisted by appropriate technological solutions.

Organisational issues (involving the recipient of care as well as formal and informal carers) could often be more relevant than the direct effects of defective functions.

Other significant impacts could be envisaged on the governance of the care system and on the optimisation of LTC provision. Particular attention should be paid to the effects of domotic devices (monitoring and alarms), a register of contacts and indicators for proper governance of the system.

Finally, one should also consider the use of indirect mechanisms, e.g. the education of care recipients and caregivers as well as their access to knowledge (on such topics as management of the long-term condition, patient's rights and administrative issues).

Therefore the effects that could be interesting to policy-makers may perhaps be more related to the systemic organisational changes than to the increase of the market for devices or the ability to cope better with defective functions (by independently assisting each care recipient to perform daily activities).

The main focus of the analysis should not be on the technology but on the organisational changes in the entire health and social care system (facilitated/allowed by the technologies), in particular those dealing with chronic conditions, which will in turn be related to new laws and regulations and will influence the future of LTC.

The above scenario about the future can be seen as mainly qualitative; it is very hard to define for each country or region and for each kind of technological solution the potential speed of adoption of technology, the incentives in place and the benefits/cost ratio of new technologies that will be in the market in the coming years.

In other words, studies about the past are of limited use here: look for example at the speed of the diffusion of the Internet or at the increased speed of diffusion of mobile phones and – more recently – of smartphones. Nevertheless, it is possible to work out a reasonable range of values for the main indicators of the evolution of the sector.

References

- Ali, M.K., M.B. Weber and K.M.V. Narayan (2010), “The Global Burden of Diabetes”, ch. 5, in R.I.G. Holt, C.S. Cockram, A. Flyvbjerg and B.J. Goldstein (eds), *Textbook of Diabetes*, 4th Edition, Oxford: Wiley-Blackwell.
- Almudevar, A., A. Leibovici and A. Tentler (2008), “Home monitoring using wearable radio frequency transmitters”, *Artificial Intelligence in Medicine*, Vol. 42 No. 2, February, pp. 109-20.
- Alwan, M. and J. Nobel (2008), “State of technology in aging services according to field experts and thought leaders”, CAST (LeadingAge Center for Aging Services Technology), Washington, D.C., March.
- Alzheimer Europe (2009), “Prevalence of dementia in Europe” (<http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia/Prevalence-of-dementia-in-Europe>).
- AlzheimersTreatment.org (2010), “The Hazards of Alzheimer's Home Care” (www.alzheimerstreatment.org/care/home-care.html).
- American Association of Homes and Services for the Aging (2010), “CAST – Center for Aging Services Technologies”, Washington, D.C. (<http://www.agingtech.org>).
- ANCIEN Consortium (2009), “A short introduction to ANCIEN – Assessing Needs of Care in European Nations”, CEPS, Brussels (<http://www.ancien-longtermcare.eu/>).
- Arah, O.A., G.P. Westert, J. Hurst and N.S. Klazinga (2006), “Conceptual framework for the OECD Health Care Quality Indicators project”, *International Journal for Quality in Health Care*, Vol. 18, No. 5, pp. 5-13.
- ArjoHuntleigh (2011), “Bariatric Gallery”, ArjoHuntleigh, Houghton Regis, Bedfordshire (<http://www.arjo.com/ukah/Page.asp?pagenumber=3598>).
- Austin, M.M. (2005), “Importance of self-care behaviors in diabetes management: Business briefing”, *US Endocrine Review 2005*, September, pp. 16-21.
- Bharucha, A.J., V. Anand, M.A. Dew, J. Forlizzi, C.F. Reynolds, S. Stevens and H. Wactlar (2009), “Intelligent assistive technology applications. Current capabilities, limitations and future challenges”, *American Journal of Geriatric Psychiatry*, Vol. 17, No. 2, February, pp. 88-104.
- Brownsell, S. (2008), “Supporting Long Term Conditions and Disease Management through Telecare and Telehealth: Evidence and challenges”, Care Services Improvement Partnership – Telecare Learning and Improvement Network, Department of Health, London, January (http://www.icn.csip.org.uk/_library/Resources/Telecare/Support_Materials/Briefing_-_Telehealth_SB_Final2.doc).
- Bu, D., J. Adler-Milstein, D.W. Bates, C.M. Cusack, J.M. Hook, D. Johnston, E. Pan, D. Kendrick, B. Middleton and J. Walker (2007a), *The Value of Information Technology-Enabled Diabetes Management*, Center for Information Technology Leadership, Healthcare Information and Management System Society, Charleston, M.A. (http://www.partners.org/cird/pdfs/CITL_ITDM_Report.pdf).

- Bu, D., J. Adler-Milstein, D.W. Bates, C.M. Cusack, J.M. Hook, E. Pan, D. Kendrick, B. Middleton and J. Walker (2007b), “Benefits of Information Technology-Enabled Diabetes Management”, *Diabetes Care*, Vol. 30, No. 5, May, pp. 1137-42 (<http://care.diabetesjournals.org/content/30/5/1137.full>).
- CAST (LeadingAge Center for Aging Services Technologies) (2011), *A Look into the Future: Evaluating Business Models for Technology-Enabled Long-Term Services and Supports*, LeadingAge, Washington, D.C. (www.leadingage.org/uploadedFiles/Content/About/CAST/CAST_Scenario_Planning.pdf).
- Cebolla, B. and A. Björnberg (2008), *Euro Consumer Diabetes Index 2008*, Health Consumer Powerhouse, Danderyd, Sweden.
- Cheshire and Merseyside Strategic Health Authority (2005), “Long Term Care”, Stakeholder briefing, Issue 1, Liverpool, July (<http://www.cmtpt.nhs.uk/documents/workprogrammes/LTCbriefing1.pdf>).
- Chiu, T., A. Carswell, A. Colantonio, A. Carswell, G. Eysenbach, M. Gruneir, E. Marziali and M. Tang (2009), “Internet-based caregiver support for Chinese-Canadians taking care of a family member with Alzheimer’s disease and related dementia”, *Canadian Journal of Aging*, Vol. 28, No. 4, December, pp. 323-36.
- Clement, M. (2008), “Organization of Care: Key elements from the CDA 2008 Clinical Practice Guidelines”, Canadian Diabetes Association, Toronto (<http://www.diabetes.ca/for-professionals/cpg/ooc/>).
- Cook, D.J. and M. Schmitter-Edgecombe (2009), “Assessing the quality of activities in a smart environment”, *Methods of Information in Medicine*, Vol. 48, No. 5, May, pp. 480-85.
- Council of Europe (1997), Recommendation on the development and implementation of quality improvement systems (QIS) in health care and explanatory memorandum, 41st meeting, 24-25 June, Strasbourg.
- Council of the European Union and European Commission (2007), *Joint Report on Social Protection and Social Inclusion*, Directorate-General for Employment, Social Affairs and Equal Opportunities, European Commission, Brussels (http://ec.europa.eu/employment_social/social_inclusion).
- Demers, L., M. Depa, F. De Ruyter, M.J. Fuhrer, J. Jutai and J. Lenker (2009), “A conceptual framework of outcomes for caregivers of assistive technology users”, *American Journal of Physical Medicine & Rehabilitation*, Vol. 88, No. 8, August, pp. 645-55.
- Department of Health (DHS) (2004), “Improving Chronic Disease Management”, DHS, London (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4075213.pdf).
- (2005), “Self Care, a Real Choice, Self Care Support – A Practical Option”, DHS, London (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4100717).
- (2006a), White Paper on “Our health, our care, our say”, DHS, London (http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4127453).
- (2006b), *Supporting people with long term conditions to self care: A guide to developing local strategies and good practices*, DHS, London (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4130725).

- (2007), *Research Evidence on the Effectiveness of Self Care Support*, DHS, London (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080689).
- (2009), “Whole Systems Demonstrators – An Overview of Telecare and Telehealth”, DHS, London (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_100947.pdf).
- (2011), “Whole Systems Demonstrator Programme: Headline Findings – December 2011”, DHS, London (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131684).
- Donabedian, A. (1980), *The Definition of Quality and Approaches to Its Assessment*, Ann Arbor, MI: Health Administration Press
- Donnelly, M.P., D. Craig, M. Mulvenna, C.D. Nugent and P. Passmore (2008), “Development of a cell phone-based video streaming system for persons with early stage Alzheimer’s disease”, *Conference Proceedings of the IEEE (Institute of Electrical and Electronics Engineers) – Engineering in Medicine and Biology Conference*, Vancouver, 20-25 August.
- Dröes, R.M., F.J.M. Meiland, S. Sävenstedt, M. Hettinga, F. Moelaert, D. Craig and H. Holthe et al. (2009), “Assistive technology for people with mild dementia: Results from the COGKNOW project”, *Neurologie Psychiatrie Gériatrie*, September.
- Edelman, D., L.J. Edwards, M.K. Olsen, T.K. Dudley, A.C. Harris, D.K. Blackwell and E.Z. Oddone (2002), “Screening for Diabetes in an Outpatient Clinic Population”, *Journal of General Internal Medicine*, Vol. 17, No. 1, pp. 23-28.
- Evercare (2004), *Implementing the Evercare programme – Interim report 2004*, Evercare (<http://www.natpact.info/cms/186.php>).
- Gerontological Society of America (GSA) (2010), “Formal Interest Group on Technology & Aging”, GSA, Washington, D.C. (<http://faculty.cua.edu/tran/gsa-tag/>).
- Goldman, D.P., B. Shang and J. Bhattacharya (2005), “Consequences of Health Trends and Medical Innovation for the Future Elderly”, *Health Affairs*, online version (September) (<http://content.healthaffairs.org/content/early/2005/09/26/hlthaff.w5.r5.full.pdf>).
- Hanson, E., H. Arvidsson, A. Claesson, E. Hanson, J. Keady, L. Magnusson and M. Nolan (2007), “Working together with persons with early-stage dementia and their family members to design a user-friendly technology-base support service”, *Dementia*, Vol. 6, No. 3, August.
- Hinder, S. and T. Greenhalgh (2012), “‘This does my head in.’ Ethnographic study of self-management by people with diabetes”, *BMC Health Services Research*, 12:83.
- Hoeksma, J. (2008), “MiBand personal activity monitor launched”, *EHealth Insider*, London (http://www.ehealthurope.net/news/4259/miband_personal_activity_monitor_launched).
- Holt, R., C. Cockram, A. Flyvbjerg and B. Goldstein (eds) (2010), *Textbook of Diabetes*, 4th Edition, Oxford: Blackwell Publishing.
- Horwitz, C.M., M. Bocko, L. Chen, A. Leibovici, M. Mueller, A.P. Pentland, J. Quinn, A. Shar, A. Tentler and D. Wiley (2008), “Is home health technology adequate for pro-active self care?”, *Methods of Information in Medicine*, Vol. 47, February, pp. 58-67.

- Huijnen, C., E. De Wit and A. Van Berlo (2009), “Technology can definitely support the well-being of people who live at home with (mild) dementia”, Communication PB7088, “19th IAGG World Congress of Gerontology and Geriatrics”, Paris, 5-9 July.
- Institute of Medicine (IOM) (2000), *Improving the quality of long term care*, Washington, D.C.: National Academy Press.
- International Diabetes Federation – Europe (IDF-E) and Federation of European Nurses in Diabetes (FEND) (2006), *Diabetes, the Policy Puzzle: Towards Benchmarking in the EU 25*, IDF-E and FEND, Brussels (http://ec.europa.eu/health/major_chronic_diseases/docs/policy_puzzle_benchmarking_eu25.pdf).
- Kennard, C. (2006), “Alzheimer’s Safe Return Program” (http://alzheimers.about.com/od/givingsupport/a/safe_return.htm).
- King’s Fund (2011a), Reading List on “Electronic patient records”, King’s Fund, London (http://www.kingsfund.org.uk/library/reading_lists.html).
- King’s Fund (2011b), Reading List on “Technology in health and social care: Telemedicine, telehealth and telecare”, King’s Fund, London (http://www.kingsfund.org.uk/library/reading_lists.html).
- Klein, R., M.D. Knudtson, K.E. Lee, R. Gangnon and B.E. Klein (2008), “The Wisconsin Epidemiologic Study of Diabetic Retinopathy: XXII the twenty-five-year progression of retinopathy in persons with type 1 diabetes”, *Ophthalmology*, Vol. 115, No. 11, pp. 1859-68.
- Kolitsi, Z. and J. Roca (eds) (2009), “Special Issue on eHealth and Beyond”, *European Journal of ePractice*, No. 8, 23 December (<http://www.epractice.eu/en/editorial/301991>).
- Lancioni, G., A.L. De Bari, G. Cassano, F. De Vanna, M. Minervini, K. Pinto, N. Singh and N. Zonno (2010), “Persons with Alzheimer disease perform daily activities using verbal-instruction technology: A maintenance assessment”, *Developmental Neurorehabilitation*, Vol. 13, No. 2, pp. 103-13.
- Lancioni, G., M. La Martire, M. Megna, M. Minervini, M. O'Reilly, K. Pinto, M.T. Pangrazio, J. Sigafoos, N. Singh and N. Zonno (2009), “Persons with moderate Alzheimer’s disease improve activities and mood via instruction technology”, *American Journal of Alzheimer’s Disease and Other Dementias*, Vol. 24, No. 3, pp. 246-57.
- Landau, R., G.K. Auslander, J. Heinik, N. Shoval and S. Werner (2009), “Attitudes of family and professional care-givers towards the use of GPS or tracking patients with dementia: An exploratory study”, *British Journal of Social Work*, Vol. 39, No. 4, June, pp. 670-92.
- Lauriks, S., R.J. Davies, R.M. Dröes, F.J. Moelaert, M.D. Mulvenna, C.D. Nugent, A. Reinersmann and H.G. Van der Roest (2007), “Review of ICT-based services for identified unmet needs in people with dementia”, *Ageing Research Reviews*, Vol. 6, pp. 223-46.
- Legido-Quigley, H., M. McKee, E. Nolte and I. Glinos (2008), *Assuring the quality of health care in the European Union*, Observatory Study No. 12, World Health Organisation on behalf of the European Observatory on Health Systems and Policies, Copenhagen.
- Lindgren, H. (2008), “Decision support system supporting clinical reasoning process – An evaluation study in dementia care”, *Studies in Health Technology and Informatics*, Vol. 36, pp. 315-20.

- Mahoney, D.F., R.N. Jones and B.J. Tarlow (2003), “Effects of an automated telephone supports system on caregiver burden and anxiety: Findings from the REACH for TLC intervention study”, *Gerontologist*, Vol. 43, No. 4, pp. 556-67.
- Marshall, S.M. (2004), “Recent advances in diabetic nephropathy”, *Postgraduate Medical Journal*, Vol. 80, No. 949. pp. 624-633.
- Ministry of Health and Long-Term Care (Ontario) (2007), *Preventing and Managing Chronic Disease: Ontario’s Framework*, Toronto (<http://thefirstcanadianhealthcare.referencelibrary.ca/documents/>).
- Ministry of Health for Slovenia (2010), “Together in reducing the burden of diabetes”, Diabetes Prevention and Care Development, Programme 2010–2020, Ljubljana, April.
- Monfort, E., P. Alain, F. Etcharry-Bouyx and D. Le Gall (2010), “Apport d’une aide imagée à la compréhension de prescriptions médicales chez des sujets âgés et des patients atteints de maladie d’alzheimer”, *Psychologie & Neuropsychiatrie du Vieillissement*, Vol. 8, No. 1, pp. 65-75.
- Mulcahy, K., M. Maryniuk, M. Peeples, M. Peyrot, D. Tomky, T. Weaver and P. Yarborough (2003), “Diabetes self-management education core outcomes measures”, *Diabetes Educator*, Vol. 29, No. 5, pp. 804-16.
- Must, A., J. Spadano, E.H. Coakley, A.E. Field, G. Colditz and W.H. Dietz (1999), “The disease burden associated with overweight and obesity”, *Journal of the American Medical Association*, Vol. 282, No. 16, pp. 1523-29.
- National Patient Safety Foundation (2000), *Agenda for Research and Development in Patient Safety*, National Patient Safety Foundation, Chicago, IL.
- NHS Careers (2010), “Community matron”, NHS, London (<http://www.nhs.uk/details/Default.aspx?Id=1904>).
- Nijhof, N., D.A.J. Dohmen, J.E.W.C van Gemert-Pijnen and E.R. Seydel (2009), “Dementia and technology: A study of technology interventions in the healthcare for dementia patients and their caregivers”, *Tijdschrift voor Gerontologie en Geriatrie*, June.
- Nygard, L. (2008), “The meaning of everyday technology as experienced by people with dementia who live alone”, *Dementia*, Vol. 7, No. 4, November, pp. 481-502.
- Odetti, L., G. Anerdi, M.P. Barbieri, P. Dario, D. Mazzei, S. Micera, E. Rizza and G. Rodriguez (2007), “Preliminary experiments on the acceptability of animaloid companion robots by older people with early dementia”, *Conference Proceedings of the IEEE (Institute of Electrical and Electronics Engineers) – Engineering in Medicine and Biology Conference*, Lyon, 23-26 August.
- Parentgiving.com (2010), “Caring for an Alzheimer’s Patient at Home” (<http://www.parentgiving.com/elder-care/caring-for-alzheimers-patient-at-home/>).
- PRNewswire (2006), “The Columba Bracelet Permits the Localisation of an Alzheimer Patient in the Event of their Getting Lost or Becoming Disoriented”, 16 November, Madrid (<http://www.prnewswire.co.uk/cgi/news/release?id=184581>).
- Renewing Health (2011), “REgioNs of Europe WorkINg toGether for HEALTH”, European project (<http://www.renewinghealth.eu/>).

- Rialle, V. (2007), "Technologie et Alzheimer : appréciation de la faisabilité de la mise en place de technologies innovantes pour assister les aidants familiaux et pallier les pathologies de type Alzheimer", Thèse d'Etat sous la direction du Professeur C. Hervé, Université René Descartes Paris 5, 12 September.
- Rialle, V., C. Hervé, C. Guigui and C. Ollivet (2008), "What do family caregivers of Alzheimer's disease patients desire in smart home technologies", *Methods of Information in Medicine*, Vol. 47, No. 1, February, pp. 63-69.
- Rigaud, A.S. (2008), "Nouvelles technologies et stimulation cognitive", *Soins Gériatrie*, No. 74, November-December.
- Riley, P., N. Alm and A.F. Newell (2009), "An interactive tool to promote musical creativity in people with dementia", *Computers in Human Behavior*, Vol. 25, No. 3, pp. 599-608.
- Rossi Mori, A. and R. Dandi (2012), *The Influence of Technology on Long-Term Care Systems*, ENEPRI Policy Brief No. 10, CEPS, Brussels, February.
- Rossi Mori, A., G. Mercurio and R. Verbicaro (2012), "Enhanced policies on Connected Health are essential to achieve accountable social and health systems", *European Journal of ePractice*, No. 15.
- Rossi Mori, A., G. Mercurio, W. Palumbo, I. Paolini and L. Ruotolo (2008), "Focused Profiles for Chronic Patients in Integrated Care and Clinical Governance", paper presented at the "9th International HL7 Interoperability Conference – IHIC", Crete, 8-11 October, (http://www.hl7.org.gr/ihic2008/9o_congress/ihic_2008.html).
- Rossi Mori, A., P. Agnello and N. Fantini (2007), RIDE D4.3.1 – "Policies and strategies", Deliverable of the EU Coordination Action "RIDE – A Roadmap for Interoperability of eHealth Systems in Support of COM356 with Special Emphasis on Semantic Interoperability" (<http://www.srdc.metu.edu.tr/webpage/projects/ride/modules.php?name=Deliverables>) and (<http://www.srdc.metu.edu.tr/webpage/projects/ride/deliverables/RIDE-D4.3.1%20policies%20final%20v06a.doc>).
- Rossi Mori, A., S. D'Auria and M. Mazzeo (2009), "Deploying Connected Health among the Actors on Chronic Conditions", *European Journal of ePractice*, No. 8, December (http://www.epractice.eu/files/European%20Journal%20epractice%20Volume%208_1.pdf).
- Rowe, M.A., J. Campbell, C. Horne, M. Keller, A. Kelly, S. Lane, B. Lehman, A.P. Benito and C. Phipps (2009), "Reducing dangerous night-time events in persons with dementia by using a night-time monitoring system", *Alzheimer's and Dementia*, Vol. 5, No. 5, September, pp. 419-26.
- Sinclair, A.J. (2000), "Diabetes in old age: Changing concepts in the secondary care arena", *Journal of the Royal College of Physicians of London*, Vol. 34, No. 3, pp. 240-44.
- Smith, G.E., J.C. Hathaway, A.M. Lunde and K.S. Vickers (2007), "Telehealth home monitoring of solitary persons with mild dementia", *American Journal of Alzheimer's Disease and Other Dementias*, Vol. 22, No. 1, pp. 20-26.
- Tak, S.H., L.E. Benefield and D.F. Mahoney (2010), "Technology for Long-Term Care", *Research in Gerontological Nursing*, Vol. 3, No. 1 (<http://www.geronurseresearch.com/view.asp?rid=50887>).
- Sydney Morning Herald* (2010), "Technology the new tool in war on obesity", 7 January (<http://www.smh.com.au/digital-life/hometech/technology-the-new-tool-in-war-on-obesity-20100107-lva3.html>).

- Tracy, J.I., N. Ahmed, W. Khan and M.R. Sperling (2007), “A test of the efficacy of the MC Square device for improving verbal memory, learning and attention”, *International Journal of Learning Technology*, Vol. 3, No. 2, pp. 183-202.
- Visser, T.L. and S.C. Seidell (2001), “The public health impact of obesity”, *Annual Review of Public Health*, Vol. 22, pp. 355-75.
- Wild, K., D. Howieson, J. Kaye, A. Seelye and F. Webbe (2008), “Status of computerized cognitive testing in aging: A systematic review”, *Alzheimer's and Dementia*, Vol. 4, No. 6, November, pp. 428-37.
- Wong, J. (2010), “The future of wireless medical devices”, Cambridge Consultants, Cambridge (UK) and Cambridge, MA (<http://www.docstoc.com/docs/28543647/The-future-of-wireless-medical-devices>).
- World Health Organization (WHO) (2007), *The challenge of obesity in the WHO European Region and the strategies for response*, WHO, Geneva.
- (2000), *The World Health Report 2000. Health Systems: Improving Performance*, WHO, Geneva.
- (1999), “Part 1: Diagnosis and classification of diabetes mellitus”, *Definition, diagnosis and classification of diabetes mellitus and its complications, Report of a WHO consultation*, WHO, Geneva.
- Wu, Y.H., J. de Rotrou, V. Faucounau, A.-S. Rigaud and M. Riguet (2009), “Intervention psychosociale auprès d'aidants familiaux de patients atteints de la maladie d'Alzheimer et technologies de l'information et de la communication : une revue de la littérature”, *Psychologie & Neuropsychiatrie du Vieillessement*, Vol. 7, No. 3, September, pp. 185-92.

Websites

- “Alloggi domotici” [Home automation] (<http://www.mobiserv.eu/index.php?lang=it>).
- Alzheimer's Society (<http://www.alzheimers.org.uk>)
- [AlzheimerTreatment.org](http://www.alzheimerstreatment.org) (<http://www.alzheimerstreatment.org>)
- Caisse Nationale de Solidarité pour l'Autonomie, CNSA (<http://www.aides-techniques-cnsa.fr>)
- Craegmoor (<http://www.craegmoor.co.uk>)
- Diabetes.co.uk: The global diabetes community (<http://www.diabetes.co.uk>)
- Fondation Médéric-Alzheimer, “Review of the national and international press” (http://www.espace-ethique-alzheimer.org/ressourcesdocs_revuedeepresse.php?r=5)
- Help and social interaction for elderly on a multimedia platform with e-social best practices, HOPES Project (<http://www.hopes-project.org/>)
- National Institute on Aging (<http://www.nia.nih.gov/>)
- NHS-UK Diabetic Eye Screening Programme (<http://diabeticeye.screening.nhs.uk/>)
- NHS-UK Diabetes – National Guidance (http://www.diabetes.nhs.uk/national_guidance/)
- Novay (<http://www.novay.nl>)
- Observatory on e-Care in Italy (<http://www.onecare.cup2000.it/>)
- Parentgiving: The Ultimate Senior Care Resource (<http://www.parentgiving.com>)
- Third French plan 2008-2012 on Alzheimer's disease (<http://www.plan-alzheimer.gouv.fr/>)
- Worldometers: Real time world statistics (<http://www.worldometers.info/obesity/>)

Appendices. Main features of the three case studies

In these appendices we provide a description of the main features of the three specific conditions (namely diabetes, dementia and obesity) given as case studies in section 4.

Each of the respective presentations in the three appendices has a different focus, depending on the main features of the condition relevant for using the technologies in LTC:

- diabetes presents several kinds of complications and involves the diffusion of the chronic care model, with organisational issues playing a notable role;
- dementia is a field of intense research on technologies to help individuals cope with cognitive deterioration, exercise and adaptation of the house, to support informal carers and to help individuals face the geolocation issues; and
- obesity is one of the most serious public health problems in developed countries, where technologies may have a role in preventing and alleviating the consequences.

Appendix 1. Technology-assisted LTC for the diabetic patient

Diabetes is renowned as a ‘silent epidemic’. The slow progression and lack of symptoms in the early stages of disease preclude seeking medical attention and preventive care. As such, reported prevalence reflects an underestimate of the number of cases because it does not account for undiagnosed cases. Population studies estimate that numerous diabetes cases are as yet unrecognised, even in the most advanced countries, e.g. a screening for an outpatient clinic population in the US found that diabetes was unrecognised in 4.5% of the population (Edelman et al., 2002).

Health-seeking and health utilisation behaviours are influenced by a number of individual, provider and system-level factors. In the case of diabetes, ill health and morbidity as well as preventive care motives result in incrementally more health service utilisation. Various studies have shown that having diabetes doubles one’s risk of hospitalisation compared with not having diabetes, and this risk is amplified by the development of diabetes-related complications.

Aside from the medical or biologic dysfunction caused by disease, there are implications of ill health for individual and interactive functioning in society. This concept of ‘disability’ is distinctive from simple biomedical models of disease and signifies that psychosocial illness or physical deviations from generally accepted norms of anatomical structure or physiologic function may impair one’s ability to perform domestic and occupational activities, and assume societal roles. As a result, diabetes may inhibit one’s general utility and ability to integrate fully in society. Adults in the workplace may have lower work performance by virtue of any number of symptoms (impaired fine motor skills and concentration, grogginess, urinary frequency) or even decline in cognitive functioning. Less tangible, but no less severe, are the psychosocial burdens that may accompany diabetes and affect functioning.

Around 80% of individuals will have developed micro-vascular complications by the time they have had diabetes for 20 years (Klein et al., 2008). Many complications will remain asymptomatic until they have catastrophic consequences. The management of micro-vascular complications involves measures to prevent, detect and treat. General measures such as optimal glycaemic and blood pressure control lead to a reduction in the incidence and progression of micro-vascular complications but specific preventive measures are also needed and are discussed below.

Eyes

Diabetic retinopathy is the most common cause of blindness in people of working age. It is almost invariably asymptomatic until there is a catastrophic sight-threatening haemorrhage. For this reason it is important to screen regularly for retinopathy to allow treatment before haemorrhage and visual loss occur. Distal symmetrical polyneuropathy is the most common form of neuropathy seen in diabetes and is addressed in the following section on the diabetic foot.

Diabetic foot

Around 10–15% of all people with diabetes develop a foot ulcer as a result of the combination of peripheral neuropathy and vascular insufficiency to the foot. Prevention of ulceration is an important goal and requires education of the person with diabetes so that s/he is aware of this possibility. It is important to inform people that they should not delay obtaining professional help if problems ensue.

Kidneys

Diabetic nephropathy is characterised by a progressive increase in urinary albumin excretion, accompanied by increasing blood pressure and decline in the glomerular filtration rate, ultimately culminating in end-stage renal disease. Micro-albuminuria, the earliest stage of nephropathy, affects around 50% of people with diabetes after 30 years, while frank proteinuria affects a quarter of people with type 1 diabetes after 25 years (Marshall, 2004).

Management of diabetes

The person living with diabetes will spend the vast majority of his/her time managing diabetes and only an estimated 1% of his/her time in contact with health care professionals (Hinder and Greenhalgh, 2012).

Therefore, the person with diabetes needs to be supported to take much of the responsibility for the management of his/her diabetes.

The diabetes care team involves a multidisciplinary group of health care professionals who are available to support the person with diabetes. This means that the person with diabetes should work together with the health care professionals as an equal member of the diabetes care team.

This relationship should provide the information, advice and education to support the empowerment of the individual with diabetes to enable him/her to take control of the condition and ensures that the care offered is made appropriate for the individual and his/her circumstances.

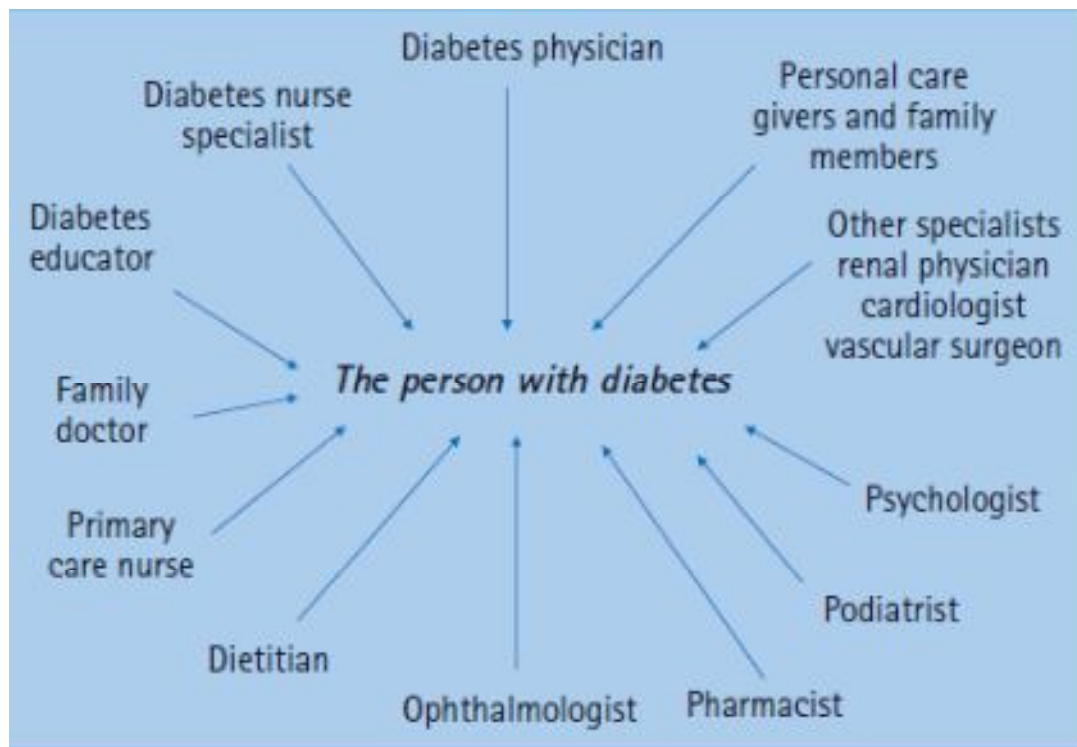
The large number of health professionals involved in the care team on diabetes (see Figure A1) means that the roles and responsibilities of all must be clearly presented and agreed. It is often helpful for the person with diabetes if the key members of the diabetes care team are identified, as they will have more contact with some health care staff than others. Most routine diabetes care takes place in a primary care setting but some people with diabetes with additional or complex needs will require management and support in a specialist setting for some or all of their care (e.g. see Diabetes.co.uk).

Given the chronic nature of diabetes, continuity of care is essential. Ideally, this should be provided by the same doctors and nurses at each visit, but where this is not possible, the health care team should have access to previous records so that the team members are fully aware of the medical history and background of the person with diabetes.

In Slovenia, a National Plan for Health Care 2008–13 was adopted in which one of the priority areas is prevention and early detection of chronic non-communicable diseases, among which is diabetes. The Plan defines measures and specific programmes for health promotion among the elderly and their education in coping with diabetes (Resolution on the National Plan for Health Care, 2008–13).

Slovenia also adopted a national programme for diabetes management that brings forward activities complementary to previously adopted health care policies on such topics as nutrition, movement and sport promotion, and prevention in primary health care. Prevention and early detection can avoid the possible side effects and complications connected to diabetes that present a large burden for the individual as well as for his/her relatives, the health care system and society as a whole. New health care technologies bring new management and integrated approaches to care that can prevent complications through early detection and treatment.

Figure A1. The actors potentially concerned with care for people with diabetes



Source: Holt et al. (2010).

Innovative care models for treating diabetes in Europe

When planning health care policies for diabetes, it is very difficult to find a balance between developments, inventions and new expensive technologies on the one hand, and on the other hand higher frequencies of diseases, population ageing, restricted health care budgets and changes in organising treatment and in quality standards for managing diabetic patients.

New technologies are needed to help achieve professional and financially sustainable management of diabetic patients in a way that will improve their health status. The new technologies in diabetes treatment mostly entail a new way of organising diabetes management through integrated care, prevention, early detection and diagnosis of the disease. Although there are also new technologies being developed in the treatment of diabetes (organisational as well and new information and communication devices, new medical equipment and instruments for glucose level measurement), these cannot lead to long-term, financially sustainable management of the disease.

The most important health care technology in diabetes is hence the introduction of systematic screening programmes to help detect persons whose risk of developing type 2 diabetes is higher than usual. Among them, those who already have the disease need to be identified, while among others additional measures are needed to prevent the disease. Special attention in screening programmes is needed for pregnant women and youngsters.

For effective management of the disease, under the guidance of WHO and the International Diabetes Federation (IDF) (Europe), the St Vincent Declaration was internationally adopted 20 years ago. Unfortunately it has not been fully implemented yet. By adopting the Declaration, European countries confirmed the goal of trying to prolong the survival and improve the quality

of life of diabetic patients, reduce the complications due to diabetes and develop research activities in the field of diabetes prevention and treatment.

The Declaration includes guidelines for diabetes management that promote preparation of integral programmes for detection and management of diabetes and its consequences, which include patient self-care, support within the environment, education of the public about diabetes and its consequences, and the organisation of education for diabetic patients, their relatives and health care teams providing care to diabetic patients. The Declaration gives high priority to establishing an information system for data collection and management and to international cooperation in research.

Special attention in the Declaration is given also to the integral care and inclusion of all health care levels (mostly primary) in the management of diabetic patients as well as the inclusion of all medical and some non-medical professions in the management of the disease. The active participation and engagement of the patient is likewise anticipated.

During the Austrian presidency of the EU Council in 2006, the Vienna Declaration was adopted, through which the EU member states obliged themselves to prepare national strategies for diabetes cost management, to improve cooperation and to exchange good practices in the field.

According to the report by IDF–E and FEND (2006), only 11 out of 25 member states have a national framework or a plan for diabetes that includes prevention at the primary level and of the complications. In addition, in these countries very little data are available on the implementation of national programmes and assessment against the planned goals. Three countries that prepared national programmes according to the guidelines of the St Vincent Declaration are presented below: Austria, Finland and the Great Britain. The state of play in Slovenia is presented as well.

Austria

The management and prevention of diabetes has been one of the priorities of Austrian health care policy since 2005. In 2006, diabetes was among the key topics of the Austrian presidency of the European Union. In 2005, a national programme for diabetes management was adopted as well as guidelines for treating patients with diabetes. Special attention is given in the programme to preventing obesity in children by promoting a healthy way of life, and to the management of diabetes in pregnancy. A disease management programme was introduced, along with the promotion of self-care by diabetic patients, an information system for diabetes, education and research. Preventive screenings have been carried out to reduce the incidence of diabetes cases by 30% by 2020. Given that the responsibility for carrying out the national programme lies with regional authorities, the differences in the success of the programme at that level are very large.

Finland

Since Finland introduced its development programme for prevention and treatment of diabetes (2000–10), it has become a case of good practice in the European region. The DEHKO programme was confirmed by the Ministry of Social Care and Health Care, with coordination and implementation in the hands of the Finnish Diabetic Patients Association. The priority areas in the DEHKO programme are preventing diabetes type 2, improving health care for all diabetic patients and promoting self-care.

The role of primary care in the management of health care and education within the health care system is strongly stressed, as well as informatisation, the establishment of a national diabetes registry and integrated care with close cooperation in care provision across the various care levels.

Another case of good practice is the Finnish programme on prevention of diabetes type 2 (2003–10). It included three approaches: a population-wide approach (preventing obesity, healthy nutrition, healthy physical activities and other activities for health promotion), a programme for high-risk individuals (screening programmes, additional diagnostics and information on lifestyles of high-risk individuals) and a strategy for early detection and disease management.

For the purposes of screening for diabetes type 2, the ‘Finnish Diabetes Risk Score’ has been developed, in which a questionnaire, ‘T2D Risk Assessment Form’ is used. On this basis, the presence of risk factors for diabetes type 2 is determined. The questionnaire represents the first phase of screening, which is a starting point for medical diagnostic procedures and further management. Many of the procedures in the screening are carried out by certified medical nurses, and the entire team active in managing care for the patient has access to data in an electronic file, which makes cooperation easier.

Great Britain

Diabetes prevention and treatment is a high priority in Great Britain. In 2001, a national programme for the management of diabetes was adopted. It concentrates on obesity prevention and healthy lifestyle promotion. In 2007, a report evaluating the national programme was presented, which reviewed the achievement of the many goals set by the programme. The main finding is that the empowerment of the patient and inclusion of the population in prevention activities are necessary for the success of the programme. To prevent diabetes complications, a special programme was financed in 2003 that enabled diabetic retinopathy screening for 78% of diabetic patients.¹ Many guidelines were published, including on diabetes type 1 management, elevated levels of blood sugar management (2002), diabetic foot (2004), high blood pressure and high cholesterol management (2002), kidney transformations (2002), obesity (2006) and diabetes in the course of pregnancy (2008).²

Slovenia

In diabetes prevention, Slovenia is among those countries that adapted their health policies to fast-growing trends of obesity among adults and children. Slovenia outlined a nutrition strategy for 2005–10, with the stated objective of reducing the incidence of chronic diseases, including diabetes. A national programme for physical activities for health promotion was adopted for the period 2006–11. A national programme for diabetes was launched in 2010, which promotes prevention and early detection, integrated care, the role of primary health care and that of other health care workers besides physicians.

According to data of the Health Consumer Powerhouse in the publication *Euro Consumer Diabetes Index* in 2008 (Cebolla and Björnberg, 2008), which are based on a questionnaire among diabetic patients, Slovenian patients think that the accessibility of medical devices and medicines is good. On the other hand, the patients were not happy with the availability of information about the quality of care by providers, preventing obesity, check-ups on blood sugar levels or the availability of certified nurses.

¹ See the (UK) NHS Diabetic Screening Programme (<http://diabeticeye.screening.nhs.uk/>).

² See the (UK) NHS Diabetes National Guidance (http://www.diabetes.nhs.uk/national_guidance/).

There are many possibilities to improve the organisation of treatment for diabetic patients in Slovenia. Numerous therapeutic possibilities are not used, the treatment is not intensive enough and is not optimally organised, and the education of patients is not satisfactory. In 2007, the guidelines for diabetes type 2 were prepared for more uniform treatment of patients and for greater professional knowledge of all stakeholders in the process. A national registry of diabetes is not available in Slovenia.

Although the first priority in diabetes management is prevention and promotional activities in different areas, also important is the promotion of new technologies, organisational methods and medical devices in the process of treating diabetes. Among the latest technologies that have been suggested for introduction into the publically financed system are the VACO diaped and VACO diaped plus (a vacuum system for diabetic foot), pharmacological treatment for diabetic macular oedema and proliferative diabetic retinopathy (Ministry of Health for Slovenia, 2010).

Use of technological solutions in treating diabetes

Citizen-oriented approaches to technological services appear to have the least effect based on the data available today. Whereas citizen-oriented technologies do enhance diabetes management, they only have an indirect influence on important care processes, which are largely under the control of providers, such as referrals for ophthalmologic exams. Still, more effective citizen-centred approaches may be developed in the future (Bu, 2007b).

Actually, appropriate ICT solutions are able to capture the patient's data and to share in a timely and safe manner the proper information among all the actors involved; in principle, such solutions are able to ease the complexity of the clinical pathway for the integrated management of diabetes.

The most obvious solution is an integrated patient register to hold the history, diagnosis, assessment and individualised care plans. Such a register can make selected information available to all authorised persons involved in managing and supporting the patients, i.e. to make available to each professional a shared synthetic medical record of his/her long-term care patients, with the minimal relevant information for his/her role. It may also send reminders to the point of care and to the patient's home. The primary goal of the register is to provide a tool for the daily management of cooperation among all the actors and for timely feedback to the decision-makers, to be applied in the routine activities of public health.

Altogether, technologies may offer an opportunity to improve quality of life by facilitating reductions in the rates of consequences, such as blindness, lower-extremity amputations and end-stage renal disease, even if their actual effect strongly depends on the organisational issues.

Current research is focusing on a number of non-invasive methods to enable continuous monitoring (infrared, electric currents and ultrasound). The continuous monitoring systems available require calibration, but are then able to record blood glucose levels at 5-minute intervals for up to 72 hours. Efforts are being made to develop integrated systems with glucose meters and insulin pumps. Computerised algorithms for controlling insulin pumps on the basis of blood glucose levels have been developed and have already been evaluated in the setting of intensive care. Mobile phones have also been linked to blood glucose meters to allow easy review of charted data, real-time feedback of support and the integration of data with medical records.

Diabetes education continues to be cited as a cornerstone of effective diabetes care and supports the philosophy of chronic care models. It is well established that in the practice of diabetes self-management, education is critical to the care and management of people with diabetes, and that measurable behaviour change is the unique outcome of working with a diabetes educator (Mulcahy et al., 2003; Austin, 2005).

In Table A1.1, we synthetically represent our assessments of the potential influence of technologies (ICT and home devices) on the care tasks for diabetes, based on the tasks listed by the Canadian Diabetes Association (Clement, 2008).

Table A1.1 Potential influence of technologies on the care tasks for diabetes

Task	Influence
Good outcomes for people living with diabetes depend on...	
Daily commitment to self-management	***
Support by their proactive interdisciplinary team	***
A system that links these two together	***

* = negligible effect,

** = slight effect,

*** = strong effect

Sources: Authors' cumulative assessment; list of tasks extracted from Clement (2008).

A systematic approach to diabetes care will improve outcomes. The key components of a systematic strategy for diabetes care are shown in Table A1.2.

Table A1.2 Components of a systematic strategy for diabetes care

Task	Influence
Identify patients with diabetes	*
Have a diabetes registry	***
Have a systematic recall process	***
Use clinical flow sheets	**
Consider diabetes-focused visits/group visits	*

* = negligible effect,

** = slight effect,

*** = strong effect

Source: Authors' cumulative assessment.

The assessments are then explained in the subsequent Table A1.3, with a comparison between paper charts and the electronic medical record (EMR) system.

Table A1.3 Key components of a systematic strategy for diabetes care

Identify patients with diabetes

When seeing patients, ordering medication or arranging investigations, it is helpful for professional and support staff to know who in the practice has diabetes.

Paper charts

- Use stickers on the outside of the chart or colour code charts.
- Include a problem list on the front sheet of the chart and highlight diabetes.
- Include a clinical diabetes flow sheet at the front of the chart.

EMRs

- Most EMRs have a summary section or patient profile that lists diagnoses, and when opened identifies patients with diabetes.

Have a diabetes registry

It is important to know the patient population of the practice to manage them well. A diabetes registry is a list of people with diabetes in the practice.

Paper charts

- Can be created from billing information.
- Can help primary care physicians keep track of their patients and create a practice registry.
- Diabetes education centres may be able to generate a list by primary care provider.

EMRs

- EMRs can be a very helpful tool for tracking the number of patients with diabetes and demographic information.
- Lists can be generated and sorted by age, type of diabetes or other criteria.
- Can track the number of patients achieving targets and whether any changes made improved control.
- Can help identify patients for group visits who have similar needs.

Have a systematic recall process

Outcomes can be improved if the primary care team works within a structure that provides reminders and recall for metabolic control and complication risk assessment.

Paper charts

- Once a registry is in place, a recall system can be established.
- The system can be simple – such as recalling patients by their birth month or allocating certain last name (and first initials) to specific months for recall.
- A three-month prescription can serve as a basis for reminding patients of their next visit.
- A recall visit can be booked at the time of the current visit.
- A laboratory can book the patient for his/her next lab test at the time of the current blood work; a physician can recall a patient once blood work is received.

EMRs

- EMRs can generate ‘tasks’ to automatically recall patients for lab work and visits.
- EMRs can search for ‘overdue’ interventions for patients who have not shown up and might get lost from follow-up in a paper-based system.

*Table A1.3 cont'd***Use clinical flow sheets**

A clinical flow sheet is a one- or two-page form that gathers all of the important data regarding a patient's disease. Outcome studies show that their use is associated with increased adherence to guidelines. It is useful to have an easy and accessible method to track metabolic parameters and ensure timely assessment of complications and risk factors. A flow sheet also becomes a convenient tool for explaining to patients the meaning of various tests, complications and need for ongoing follow-up.

Paper charts

- These are available on some websites for chronic disease management.
- Flow sheets can be filled in by the staff when paper lab results and consults are filed.
- Flow sheets should be kept at the front of the charts.

EMRs

- Can automatically populate lab values into the EMR flow sheet.
- Care elements that are overdue or not on target are often highlighted.
- EMRs can display results in a longitudinal fashion to highlight trends.

Consider diabetes-focused visits/group visits

Diabetes-focused visits can help both patients and physicians deal with this complex disease. If the patient and the physician understand that the visit is to address issues surrounding diabetes, this allows time to discuss lab test results, complications, risk assessment, adherence and follow-up.

Group visits may not only potentially increase capacity, but also may allow a meaningful exchange of information to occur among people with diabetes and help patients to self-manage.

Source: Clement (2008).

The above table was conceived for the physician and the support staff in the practice. For the patient and the informal carers, it is also possible to list a series of tools to support care management:

- web-assisted suggestions and advice about physical activity, avoiding smoking and staying healthy;
- web-assisted e-learning modules to learn about self-management;
- devices to measure the blood glucose, blood ketone meters, continuous glucose monitors (which now can be connected to the Internet via a smartphone); and
- insulin pumps.

Of course, the patient and the informal carers should also be able to manage a very friendly ICT application, with reminders of the activities to be undertaken, records of activities performed and annotations, and the possibility to communicate with different formal carers.

Diabetes in old age

According to Sinclair (2000), the key points about diabetes in old age are the following ones:

- Diabetes affects 10–25% of elderly people (>65 years) worldwide, with particularly high rates in such populations as Pima Indians, Mexican-Americans and South Asians.

- Glucose tolerance worsens with age, the main factor being impairment of insulin-stimulated glucose uptake and glycogen synthesis in skeletal muscle.
- The factors precipitating hyperosmolar hyperglycaemic syndrome include infections, myocardial infarction, stroke and drugs such as thiazides or glucocorticoids.
- Episodes of hypoglycaemia resulting from insulin or sulfonylureas may be severe and prolonged, particularly because counter-regulatory responses are impaired in the elderly.
- High levels of disability are common in older people with diabetes and lead to heavy use of health care resources and premature mortality.
- About 16% of elderly people with diabetes in the UK are registered blind or partially sighted (eight times more than the non-diabetic population), which justifies regular screening for undetected eye disease.
- Risk factors for foot ulceration affect 25% of elderly people with type 2 diabetes.
- Management strategies for many elderly people with diabetes are as for the younger population, with similar lipid-lowering and antihypertensive treatment schedules and aspirin or clopidogrel for patients with increased cardiovascular risk.
- Effective delivery of diabetes care depends on close cooperation between the hospital and the community, the involvement of diabetes specialists and practice nurses, and attention to all causes of disability and ill health.
- Elderly people with diabetes in care homes are particularly vulnerable and require greater diabetes specialist input.

The future

The global burdens associated with diabetes are growing rapidly and they are projected to escalate even further in the future. The hypothesised explanations for this trend of increasing burdens include the following (Ali et al., 2010, p. 79):

- the rising prevalence of diabetes and pre-diabetes worldwide;
- ageing and longevity accompanied by costly co-morbidities;
- lowered diagnostic thresholds;
- more attentive detection of cases;
- the availability of newer, more costly treatment methods on the basis of industry research and development; and
- changes in clinical management, especially growth in the use of self-glucose monitoring and medical devices, new therapeutic drugs and increasing demand for paramedical services.

The primary domain where technologies (mostly in the form of new organisational models) can help improve health outcomes in diabetes is prevention and health promotion. The major benefit expected is decreased utilisation of care. Empirical data and evaluation from countries that adopted national programmes and strategies are very limited; however, investing in technologies for prevention seems the most cost-effective option for the financial sustainability of the care system.

Technological capability has increased rapidly. Yet well-designed trials to determine how best to use technology and that address public policy have not progressed at the same rate. Results from randomised controlled trials and carefully designed, nonrandomised trials can provide valuable information. Comprehensive systems that link medical management to self-management with the electronic medical record have consistently shown significant improvement in clinical outcomes and cost savings. These systems, however, have not been adopted widely.

One of the health care technologies believed in the studies to contribute most to the improvement of health outcomes of the diabetic patients is establishment of the EMR and (national) diabetes registries.

Contrary to common beliefs about inertia with regard to patients' adoption of diabetes care technology, according to the study patients generally comply with expectations to collect and upload clinical data. This is consistent in older adults, across countries, socioeconomic levels and ethnicities.

Nevertheless, clinicians have not always responded to uploaded EMR data with timely review and feedback. In this respect, programmes have been found to work best when staff is specifically assigned to support web-assisted interventions.

Improving continuous monitoring devices

Current research is focusing on a number of non-invasive methods to enable continuous monitoring (infrared, electric currents and ultrasound).

Detailed data on the magnitude and duration of glucose fluctuations can be used to guide lifestyle and drug therapy in an attempt to produce a near-physiologic control of glucose levels.

The continuous monitoring systems available require calibration, but are then able to record blood glucose levels at 5-minute intervals for up to 72 hours. Efforts are being made to develop integrated systems with glucose meters and insulin pumps. Computerised algorithms for controlling insulin pumps on the basis of blood glucose levels have been developed and have already been evaluated in the setting of intensive care. Mobile phones have also been linked to blood glucose meters to allow easy review of charted data, real-time feedback of support and the integration of data with medical records.

From an organisational point of view, this and other solutions imply the need for an entity in the health system (e.g. the GP or a service centre) to set up a service for the registration of the data, and to manage a service to monitor and interpret the data.

'Just-in-time' information on diabetes

Systems used to assist practitioners in the management of diabetes systems should offer 'just-in-time', evidence-based support for decisions and preserve provider autonomy while promoting the transformation of clinical information into action. The practice of medicine is an ever-changing landscape with evolving frontline practitioner needs and disease management workflow. By streamlining the informational needs of the busy practitioner, ICT applications have the potential to curb health care costs while significantly improving care for large patient populations.

Appendix 2. Supporting home care: Coping with dementia

Overview of patients with dementia

Alzheimer's disease (AD) is the most common cause of dementia. The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions.

AD is a progressive disease, which means that over time, more parts of the brain are damaged. As this happens, the symptoms become more severe. People in the early stages may experience lapses of memory and have problems finding the right words. As the disease progresses, they may

- become confused, and frequently forget the names of people, places, appointments and recent events;
- experience mood swings. They may feel sad or angry. They may feel scared and frustrated by their increasing memory loss; and
- become more withdrawn, owing either to a loss of confidence or to communication problems.

As the disease progresses, people with AD will need more support from those who care for them. Eventually, they will need help with all their daily activities. Keeping the individual at home requires providing strong support for the informal carers. The most useful tasks may be described as follows:³

- Family support and education – [L]earning how to adjust to personality changes and knowing what to expect can make a big difference in the home care of an Alzheimer's patient. Get involved with local organisations to learn what causes Alzheimer's and how to manage the disease. Also look for temporary programs that can provide the home care support: the caregiver needs to have time away from the person with Alzheimer's.
- The faculties of cognition and perception become compromised in Alzheimer's patients. They may try to cover up these problems and their fear of failure, or avoid embarrassment by becoming withdrawn. The family caregiver can help by being reassuring and providing dependable support that helps the patient overcome anxieties and gain confidence. The caregiver can use memory aids to make up for fading memory and manipulate the home environment to reduce [the] patient's confusion.
- Learning to communicate with an Alzheimer's patient – Often the Alzheimer's patient remembers the past more easily than the present. Learn to communicate on a level that is easy for them to understand. The patient may become repetitious and engage in meaningless behaviour. The family caregiver will need to learn verbal techniques, such as using short sentences, [a] pleasant tone of voice, memory aids and simple messages, as well as effective nonverbal communications, including eye contact and touch.

³ Authors' compilation, mainly derived from AlzheimersTreatment.org (2010) and parentgiving.com (2010).

- Using therapeutic activities – Music therapy, former hobbies, pets, and establishing routines can help to alleviate the stress caused by the behaviour of an Alzheimer's patient.
- Modifying their home – At first, changes may be simple adjustments (such as keeping often used items in a specific place, labelling doors or drawers, or using notes and timers to remind the person to do certain things). As AD progresses, extensive measures may be necessary to ensure the person's safety and help reduce problematic behaviours in their home.
- Care should involve providing a secure home environment to prevent falls, such as having adequate lighting, removing loose rugs, and rearranging the furniture to allow better mobility.
- There should be protected areas for pacing and walking around, walking aids and devices. The patient will need to engage in exercises that maintain posture and enhance muscle strength.
- Caregivers can help the Alzheimer's patient prevent incontinence thanks to safety aids that help patients find the bathroom more quickly.
- Diet and exercise – Reducing the symptoms of Alzheimer's is reliant on good health. Making sure the Alzheimer's patient has a good nutritional diet and gets regular exercise is one of the most important factors in home care.

Home Telecare for the Alzheimer's patient in an early state of disease is an area where wireless-enabled devices can play a significant role. Remote patients can use a monitoring system that connects them to their care providers through a home television and a broadband Internet connection. By interacting with their care providers and receiving personalised feedback, patients become better informed about their condition and can follow a suitable nutritional diet. This in turn gives them the support and motivation needed to become more active in managing their health. Domotic devices (alarms, webcams and sensors for gas, water, smoke, movement, etc.) can increase safety and allow for prompt reaction to unexpected events (e.g. falls).

The education and training of patients and caregivers may be facilitated by the use of computerised tools, notably through the Internet, webcams and specialised, simplified interactive devices, such as

- recorded e-learning modules,
- interactive videogames like Wii for promoting exercise, and
- video-conference and chat.

A lot of AD sufferers experience problems of disorientation and can become lost. In an attempt to offer a solution to this difficult situation, an electronic bracelet, which integrates a mobile telephone system, intelligent alerts and localisation via satellite (GPS), could offer an important service.

If the wearer of the bracelet leaves their habitual geographic area, which has been previously defined by their relatives or carers, the device automatically sends out an alert to advise those responsible for the patient. The wearer of the bracelet can be located immediately – e.g. through a telephone assistance centre that operates 24 hours a day, 365 days of the year – and the patient can be contacted using the device's hands-free function.

When the Alzheimer's sufferer begins to lose their capacity to recognise their family environment or to forget their name and address, episodes of wandering off and disorientation become a reality and bring with them daily anxiety for all those who care for the patient. The bracelet offers an alternative solution. (PRNewswire.co.uk, 2006)

Providing assistance and care to patients affected by dementia⁴

The evolution of dementia consists of several clinical stages:

Mid/early

Characterised by memory loss and behavioural problems, the mid/early phase lasts from two to four years. Problems in short-term or episodic memory (recalling recent events occurring a few hours or days ago) are visible. These memory problems are sufficient to disturb patients' everyday lives. Patients may have problems managing a budget or using transport. Difficulties with language and attention are also symptoms of the onset of Alzheimer's. Patients can forget certain words or have difficulties in expressing themselves. The symptoms of the mid/early phase can sometimes be confounded with depression. Aware of their difficulties, patients often lose interest in their usual activities: gardening, do-it-yourself, shopping or visits to friends.

Moderate/middle (cortical dementia)

Occurring over a period of two to six years, a person passing through the moderate phase exhibits the characteristic symptoms of dementia. Loss of autonomy is significant with worsening memory and behavioural problems. Contrary to the previous phase, patients deny or underestimate their difficulties. They lose their spatial and temporal references (spatial and temporal disorientation). The presence of another person rapidly becomes vital for managing daily life. Patients no longer recognise the objects surrounding them, and thus their environment can lead to accidents.

Articulacy gradually declines. Patients can no longer express themselves spontaneously and their speech becomes incoherent. In addition to memory and behavioural troubles, mood changes and aggression can be observed, with loss of interest, and problems with eating and sleeping. Patients also start having problems recognising the members of their immediate entourage.

Severe/late

The severe phase lasts from two to four years. It is characterised by very severe memory loss. The capacity to memorise is completely degraded. In addition to short-term memory, patients also forget the events occurring throughout their lifetimes. Oral and written expression undergoes severe degradation until dumbness. The capacity to understand is definitively deteriorated. Very serious physical problems also occur. Patients have great difficulty in moving about and falls are frequent. Keeping them at home at this point becomes very complicated for their entourage, making transfer to an institution more or less obligatory. It is noteworthy that not all patients progress to this stage of dementia, nor do they all have the same symptoms within the same periods. Lasting and progressive deterioration do not necessarily mean the loss of competences through the course of the disease. Still, a person with AD will have a shorter life expectancy than someone of the same age without it.

Technologies used for assisting and caring for dementia patients

The descriptions of the technologies applied to elderly persons and those affected by AD use several classifications (Alwan and Nobel, 2008; Lauriks et al., 2007; Rialle, 2007 and Rialle et al., 2008):

⁴ Note: This section is mostly inspired by several articles in the "Review of the national and international press" published by the Fondation Médéric Alzheimer in France (http://www.espace-ethique-alzheimer.org/ressourcesdocs_revuedeepresse.php?r=5).

- as a function of their objectives, more specifically reorganising the home and daily life, enhancing conviviality, improving well-being, etc.;
- by level of complexity;
- as a function of their main user, i.e. the caregiver or the patient; and
- by multiple criteria – Nijhof et al. (2009) distinguishes “symptomatic” aid, social contact and company for the patient, health monitoring and safety, etc.

A description of the different technologies available, including the names of the manufacturers and the prices of the products, can be viewed online.⁵

Many of these technologies use sensors to measure physiological parameters (remote monitoring of weight, pulse, temperature, blood pressure, sweating, oximetry, feeding, drug use, sleeping and hygiene, sleepwalking, electrocardiogram and total inactivity of the patient). They are intended for medical diagnostics and monitoring with a view to detecting abnormal events requiring emergency action.

The installation of physiological sensors is a prerequisite for implementing telemedicine. The TELEGERIA project at the Georges Pompidou Hospital in Paris has set up a remote video consultation service for the patients of an EHPAD (establishment accommodating dependent elderly persons) in which they are in contact with the hospital’s geriatricians and specialists through a wireless handheld camera. The sensors also permit the measuring of environmental parameters in order to improve the quality of life of elderly persons. Fall sensors, for example (sewn into clothes or worn on a belt), alert a tele-monitoring centre and start an emergency procedure. To protect privacy, the images of certain tele-monitoring systems are processed directly by computer to detect abnormal behaviour and emergency situations (Care Link Services) or they substitute the image with data from a large number of sensors (forming a 3D model). Lastly, there are networks of advanced integrated sensors. Home automation provides various combinations of these sensors as a function of the objective set.

Information sites, television and Alzheimer’s disease

There is a wide variety of sites:

- Some are dedicated to AD in general (e.g. the AD information benchmarking site developed by the Lyonnais company Activ’Age).
- Certain interactive sites provide customised information by focusing on the needs of the patient accessing the site (the Alzheimer’s centre of the Free University of Amsterdam).
- Certain sites are devoted to identifying support technologies (e.g. the Alzheimer’s Society in the UK).

The primary objective of these sites is to provide information, although they can also provide training and coaching for patients and caregivers (Hanson et al., 2007).

The homecare project using the Internet (“M@D”, developed in the south of France) uses the elderly person’s television to provide access to the site. The individual simply has to press a button to be directed to homecare services.

The television programme for persons in the process of losing their autonomy, “T-seniority”, currently in its experimental phase, makes a distinction between local and national information

⁵ See the website of the Caisse Nationale de Solidarité pour l’Autonomie, CNSA (<http://www.aides-techniques-cnsa.fr>).

on dependence, and sets up personalised information services for use by the patient's family (photos, messages, possibilities for videoconferences, etc.).

Screen savers, videophones and conversation prompts

Different procedures exist for different objectives, as outlined below.

- *Simple memory stimulation.* A sequence of images, video clips and pieces of music relating to the history of the patient is installed to stimulate the patient's memory (Microsoft Design IT ergonomic, computer-design competition).⁶ Usually, no evaluation is performed on the installation of such systems. The caregiver may be asked to produce the screen saver, by selecting quality media and avoiding over-repetitive discourse.
- *Assistance and creation of a virtual community of patients or caregivers (or both).* A videoconference between patients and senior caregivers, the Attentive Care Internet service, was developed by Caregiver Technologies (Oklahoma City).

Projects have emerged to bring patients together and break through their isolation (in Brittany a platform using televisions as interfaces operates successfully, following multidisciplinary research conducted by an engineer, a geographer, a psychologist and a sociologist, in association with Institut Télécom Bretagne and the Sociology Research Workshop – EA 3149. Videophones give patients easy access to caregivers with friendlier contact thanks to the image transmitted. Consequently, stress is also reduced for informal caregivers (Mahoney et al., 2003; Donnelly et al., 2008).

Tele-monitoring

Through tele-monitoring, the installation of cameras connects the caregiver to a tele-monitoring centre for a limited period. This technology above all concerns isolated patients affected by dementia (Smith et al., 2007).

Cognitive stimulation systems

The systems mentioned below fall within the scope of a well-structured plan, as much with respect to maintaining functional capacities as to stimulating cognitive functions.

Video games for maintaining functional capacities

The player, equipped with sensors, reproduces the movements seen on the screen (Wii, tennis, golf, bowling, etc.). Coordination, stability and strength are supposed to improve. These games are not specific to AD, even though they are used for persons affected by it; it is necessary to check whether these games are adapted.

An experiment carried out in the Hérault region (the Clapiers old people's home) has installed these games in an old people's home and called on young volunteers to participate in order to add an intergenerational dimension.

Combating memory and cognitive stimulation problems

Simple alarms remind the patient about when to take medicine. For example, Neuropage has existed since 1994. More sophisticated medication organisers inform the patient of the time of administration and enter information on a website accessible to caregivers (Life Techniques).

⁶ See the Craegmoor website (<http://www.craegmoor.co.uk>).

Assistance through images on drug prescriptions is aimed at facilitating understanding of prescription instructions and ensures these are assimilated. This approach enables the instructions to be repeated and simplifies the message given. Compliance with help given by images is significantly better among elderly persons and those with Alzheimer's (Monfort et al., 2010). Assistance through images may also postpone intervention by an informal caregiver.

Verbal instructions transmitted through a vocal system can help patients to perform specific activities. This technology provides assistance, reassures the patient and lessens the workload of family caregivers (Lancioni et al., 2009 and 2010).

A series of games explicitly intended for cognitive stimulation are now available on the market. Nintendo has produced different memory games for its portable DS console (including a cerebral training programme), in competition with Mindfit (an Israeli product sold in France), Happy Neuron (a French product from Scientific Brain), Big Brain Academy (an Australian product) and an audio-visual stimulator from the Korean company Daeyang E & C. Cognitive stimulation programmes specifically intended for AD patients generally comprise two parts: one for patients and the other for caregivers (family and professional).

Cameras attached to the patients' necks that take photographs, passively, every 30 seconds have been used to improve the memory of persons with AD. The explanation given is that it mimics the episodic memory of the brain. The Microsoft Laboratory at Cambridge and the memory centre at Addenbrooke University Hospital (UK) developed the SenseCam in 2005. Five hundred models are used by researchers and industrial production should come on-stream in the near future.

In a rather different vein, automated and regular cognitive tests using telephone keypads have been used to monitor the cognitive function of volunteers, initially with no or only slight cognitive deficiency.

Computer programmes developed by French geriatricians can be used by patients with assistance from their caregiver (Rigaud, 2008).

Although related to the stage of the disease, certain games and stimulators have proven effective for patients (Tracy et al., 2007). The impact is immediate on the caregiver, who can observe that certain cognitive functions are being maintained, and on the (potential) patient, who can track his/her cognitive condition. No scientific evaluation of these effects has been performed, however.

Mention must also be made of work in progress regarding the possibility of applying virtual reality technologies to cognitive rehabilitation (Laboratory of Psychology and Neurosciences, University of Paris Descartes).

Musical therapy

Musical therapy is a technique that mainly acts on emotional and psychological factors. Different studies have shown that musical therapy reduces anxiety, depressive phases and aggression; thus it significantly improves patients' humour, communication and autonomy. An interactive tool exists for encouraging musical creativity (Riley et al., 2009) in AD patients composed of a tactile screen capable of generating notes and being used by persons without musical knowledge.

Robots

Persons with AD appear to accept robots with animal-like features well. This aid, while intended for patients, could also have an indirect positive effect on family caregivers and lighten their workload (Odetti et al., 2007).

Geolocation devices

A great deal of literature exists on these devices. There are two main types of systems: the bracelet and the geolocation systems.

Bracelet

A bracelet (or a necklace, a card in a wallet or a badge format) sends an alarm to a monitoring centre if the person with AD either leaves a given perimeter or falls, thereby warning the caregiver. Some bracelets can be manual with a button activated by the patient, while other more efficient ones are automatic and use an array of sensors.

Orange, a French company (through its subsidiary Médical Mobile), has developed an e-bracelet, Colomba, intended for persons with AD, which was first marketed through retailers and then made available by medical prescription. An experiment performed with 12 people over a period of six months took place in Cher, associating Orange with structures providing care to AD patients. Certain bracelets trigger the door lock of a building (a bracelet developed by the Finnish company Vivago; this system was introduced in an old people's home belonging to the Lille City Council in 2003).

Theoretically, the aim is to give more freedom of movement to the person with AD.

Geolocation systems

Geolocation is a more powerful system, used at a clearly determined stage of the disease, when the patient gets lost and must be found quickly. In France, Aloize, a GPS transmitter that can localise a wearer to within 20 meters, is used; several services are offered (with a history of movements, a definition of a safety perimeter and an alarm sent to the caregiver in case of departure from the perimeter). Geolocation can also be ensured by inserting a chip in the patient's shoes (an initiative proposed by the Spanish engineer Isaac Daniel). Yet low cloud cover and very high buildings can reduce the intensity of the signal. Geolocation can use urban wireless networks indifferently (see the European CityBee project, part of the 6th Framework Programme), intended for several segments of the population. Certain systems incorporate both geolocation and fall-detection capacities. These techniques are fairly well targeted at a specific stage of the disease: mobile persons passing through a light-to-moderate stage (about 60% according to the Alzheimer's Society in the UK)⁷ and who get lost regularly. They are efficient for monitoring in the home (Almudevar et al., 2008; Horwitz et al., 2008). Thanks to this kind of device, the "Safe Return" programme of the Alzheimer's Society in the UK has helped 8,000 of its member AD patients to return home (Kennard, 2006).

Nonetheless, the efficiency of geolocation techniques depends on the following aspects:

- the existence of a call centre at the end of the line capable of reacting to emergency situations;
- the acceptance of this technology by the patients and their families. For instance, this acceptance is not obvious at first sight in France, despite the speed of deployment in the UK; and
- the solution of all the ethical issues raised by this technique, which include those of respecting basic rights (the freedom to come and go as one pleases, the social perception of a 'Big Brother' in control) and the obligation to provide medical-social assistance. Should elderly persons be left in peace or pushed to leave the confinement to which AD

⁷ See the website of the Alzheimer's Society (www.Alzheimers.org.uk).

has led them, by using new technologies? Opinions on the subject are divided. These tools have been the subject of reflection and criticism by the Association France Alzheimer, the president of the national commission of information technology and civil liberties (CNIL) and the Société Française de Gériatrie et de Gériatologie, because of the risks of infringing the individual rights to freedom, privacy and integrity, and human rights. Furthermore, patients with AD require psychological support from their entourage and there is a risk that a device might lessen bonds. One of the points put forward in the debate is the possibility being offered to the elderly person to decide on using a technology. The need to provide a framework for such practices appears quite obvious.

The advantages are also quite obvious for the caregivers who are responsible for monitoring and who are thus less worried, as immediately they are informed of abnormal situations. Once again, however, no scientific studies have been conducted to assess the extent of these advantages.

Other assistance technologies

A number of technologies not specific to ageing pathologies can also be used for persons with dementia, for example:

- clocks with large figures;
- simplified MP3 readers;
- telephones with large numbers;
- telephones that put the patient in contact with an operator aware of the patient's situation and able to link up with the main caregivers;
- a tactile computer without a keyboard or mouse, just large icons for accessing email, the Internet and photos (the 'Magui' computer);
- a movement-sensitive mattress, with a cushion that detects the prolonged absence of an elderly person from his/her bed (over a hundred beds equipped in the Cholet region, in 20 old people's homes). The period can be adjusted according to the person's requirements and lifestyle. These devices were first designed for AD patients and are liable to reduce restraints;
- intelligent walking frames that help users to lift themselves up and which offset loss of balance. MONIMAD is equipped with a mobile system for monitoring falls and physiological parameters; and
- storage of medical information on subcutaneous chips, assumed to be very useful for AD patients (authorised in the US since 2004).

Remote support

The UNA (the leading French homecare network, with 1,200 member organisations) has set up its own telecommunication network, UNA Téléassistance. An initial diagnostic is performed to determine whether the remote support is requested for medical or social reasons. In the latter case, all the members of the network providing services to the elderly person share the information immediately through a communication platform (email, SMS and Internet sites).

In Corrèze, there are 4,200 subscribers receiving remote support from the savings fund foundation for solidarity, i.e. ten times the national average.

The ADMR service (homecare in rural areas) combines GPS and mobile phones. In the case of emergency calls, the subscriber's position is displayed immediately and the operator can consult the patient's file. The user or his/her tutor must give prior written consent.

Remote support is also aimed at the early stage of the disease when the patient is still able to call another person, communicate and engage in dialogue. This technology backs up the caregiver, enables the extension of homecare and a certain level of autonomy for the dependent person.

Home automation

This form of technology makes up a large chapter in the literature on new technologies. The general idea is that an apartment equipped with an array of electronic sensors placed in objects, the floor and walls can help an AD patient to live better at home. The sensors remind the individual to accomplish different tasks or automatically switch on lights and electric devices, adjust luminosity, open doors selectively, etc., and possibly allow the caregiver to perform certain tasks remotely.

Initially, information must be collected to learn the specific behaviour of the patient and detect unusual events liable to trigger an alarm (Cook and Schmitter-Edgecome, 2009).

These signal markers installed in the home are also used to revive certain sensations affected by AD and stimulate certain bodily functions. It is assumed that the environment reactivates memory and orientation, and that for AD patients the environment must be used to reassure them and help them be less confused. The use of technology radically changes the approach towards persons affected by AD. The idea is not to take decisions in their place but to facilitate their autonomy by allowing them to do what they are still capable of managing.

Experiments started in 2007. The engineering laboratory TIMC-IMAG in Grenoble has developed intelligent apartments for AD patients. The University of Newcastle has developed an intelligent kitchen, with applications for AD patients.

Home automation packages have been assembled to mark out light paths in the home (“Europe Assistance”, Legrand), especially to the toilet, and to detect leaks, switch off lights or switch them on at nightfall, switch off cooking plates and taps, and pre-record messages for a comprehensive series of difficulties.

The ‘good night button’ can be used remotely by the family caregiver. Once the patient is in bed, all the lights can be switched off remotely and the doors closed and locked. This aid is provided directly to the family caregiver.

Home automation technologies can be linked to cognitive stimulation. The European research project “CompanionAble” conducts research on the contribution of a robot linked to home automation equipment installed in the home of persons affected by AD and to cognitive stimulation programmes.

These technologies linked to home automation are associated with the light and moderate stages of AD, when autonomy can be preserved or restored. Obviously, these developments reassure the caregiver.

Complex products

The international COGKNOW project (2006–09) contributed towards the development of the COGKNOW Day Navigator, which provides personalised support in different areas (reminders of tasks to be done, orientation in time, telephone calls by pressing on an image, a multimedia reader and safety functions). A central server programmes the patients’ preferences and calendars (Dröes et al., 2009).

Diagnostic support

Diagnostic support for cognitive problems has given rise to the application of new technologies:

- construction of a tool to assist medical decision-making in evaluating Alzheimer's disease (Lindgren, 2008), notably investigation strategies for imaging, biology, etc.; and
- computerisation of cognitive tests (see Wild, 2008 et al. for a systematic review) and algorithmic analysis for assisting diagnostics or determining pertinent diagnostic strategies.

Validation of the application of these techniques to determine which populations could benefit from them is still in progress. It is relatively simple to link a given technology to a stage of Alzheimer's.

Impact of technologies on family caregivers

Generally, geriatric technologies have been developing in France since about 2007, through different experiments, a little later than in other European countries. There are few operational products on offer on the market, in contrast with a large number of experiments.⁸ There are a number of reasons explaining this situation (a relatively insolvent market, resistance to the use of technologies, lack of interest from doctors and lack of evaluation of the medical services provided). The third French plan on Alzheimer's⁹ includes a specific measure concerning technologies.¹⁰ By making the market solvent, it has accelerated the development of technologies for AD patients.

Evaluating technologies

A distinction must be made between technologies specific to AD, which are then made generally available to the rest of the elderly population, and the adaptation of new technologies developed for elderly people to AD patients. Whatever the case, one of the main difficulties stems from the inadaptability of certain technologies to the progression of the troubles affecting patients with AD.

All the technologies that have a positive effect on elderly persons immediately have positive repercussions for the caregiver. Thus if a technology designed for night monitoring is efficient, it provides an immediate advantage for the caregiver (based on a sample of 53 patients, Rowe et al. (2009) indicated a reduction of 85% of departures from home and injuries when such technology is used).

Few clinical tests have been performed on the direct impact of technologies on caregivers working with patients with Alzheimer's disease and those tests that have been carried out generally concern insignificant sample sizes (28 participants; see Chiu et al., 2009). Therefore there are not enough results to provide a basis for generalising these experiments and using the technologies concerned.

Little is known about the impact of technologies on family caregivers, apart from a small number of studies on the caregiver/receiver pair. Theoretically, caregivers are assumed to obtain satisfaction through saving time, reducing stress, finding room to breathe and improving their

⁸ See benchmarking memo 158, December 2009 (www.strategie.gouv.fr).

⁹ See Government of France, Alzheimer Plan 2008 > 2012 (<http://www.plan-alzheimer.gouv.fr/>).

¹⁰ See Government of France, Alzheimer Plan 2008 > 2012, Measure No. 7, Improving Support at Home using New Technologies (<http://www.plan-alzheimer.gouv.fr/measure-no7.html>).

own quality of life if their relative with AD maintains cognitive capacities and autonomy, or if his/her decline is slowed down.

An ethnographic and qualitative evaluation of 40 patients and caregivers who had received equipment at home revealed a reduction of the burden on the family caregiver (Huijnen et al., 2009). A relatively recent review of the literature (Wu et al., 2009) mentions positive effects on the psycho-affective state of the caregiver. A general theoretical model of caregiver stress (Demers et al., 2009) introduces technology as a moderating element that reduces the number of stress factors linked to care. Table A2.1 provides a synthesis of the technological solutions that can fit the different contexts of LTC.

Table A2.1 Use of technologies in the initial, mild and severe stages of dementia

Context	Technology	Initial	Mild	Severe
Taking medicine	Assistance through images	*	**	—
Taking medicine	Verbal instructions transmitted through a vocal system	*	**	—
Taking medicine	Local remind/alert equipment	*	—	—
Social contacts		**	***	**
Tele-monitoring		*	**	*
Cognitive stimulation		**	—	—
Musical therapy		*	**	**
Domestic robots		*	**	—
Geolocation	GPS	*	**	***
Fall recognition		**	***	***
Measures of behaviour		*	**	***
Smart home (bathroom)	Thermostatic mixing/shut-off valves	*	**	*
	Flood detectors	—	*	***
	Duress alarm	*	**	*
	Automated home system (e.g. lighting)	*	**	*
Smart home (kitchen)	Gas stove isolation	*	**	—
	Induction cooktop	*	**	—
	Wireless smoke detectors	—	**	***
	Automated home system	*	**	*
Smart home (bedroom)	Emergency call assistance button	*	**	**
	Automated home system	*	**	**
	Good night button	—	*	***
	Chair and bed occupancy sensors	—	*	***
Smart home (outdoor areas)	Automatic gates	*	*	—
Smart home (automated housing)	Sensor lighting	*	—	—
	Watering system	*	—	—

Null = not relevant; * = negligible; ** = low; *** = high

Source: Authors' cumulative assessment.

A problem prior to evaluating the impact of technologies on family carers: Acceptability of the technology

The opinions of caregivers are far from reaching consensus on the use of technologies. Caregivers fall into two very distinct groups: those who are in favour of technology and those who are openly hostile to it (see Rialle et al. (2008), regarding the analysis of 270 families with a patient with AD confronted by 14 innovative technologies for facilitating care at home). There are doubts as to the reliability of the equipment, fears of paying additional costs, the feeling of loss of closeness with the patient (dehumanisation), guilt about 'abandoning' their sick relation, feelings of 'irreplaceability' in comparison to a 'machine', etc.

Regarding geolocation, some family caregivers feel obliged to use new technologies to ensure the safety of their sick family member; others reject this technique out of respect for their family member's autonomy (Landau et al., 2009) and because of the legal and moral responsibility implied (being constantly responsible for the geolocation system). Professionals attach more importance to respecting the patient's autonomy.

The acceptability of the technology by the AD patient and his/her caregiver is therefore an important factor, in the same way as ease of use. If the technology makes a really meaningful contribution and is incorporated in the patient's physical existence through frequent and continuous use, then this use will be carried on by the patient (Nygard, 2008). Therefore testing the apprenticeship and acceptability of tools is a prerequisite to evaluating the installation of new technologies.

As for matching costs and advantages, once again few studies are available given the large number of medical and socioeconomic variables involved. As yet there is no convincing economic model for the adoption of technologies (Alwan and Nobel, 2008).

Whatever the case, the evaluation of the service provided to the community by these techniques, inasmuch as they play a role in care activities, is a necessity and a great deal of research on the subject is in progress. These studies are obviously multidisciplinary by nature (technical, clinical, the service provided and economic). Everything possible must be done to avoid situations in which engineers and actors in the field (families and professionals) function in parallel worlds in which technological solutions fail to match needs.

To make up for these shortcomings, the CNSA (Caisse Nationale de Solidarité pour l'Autonomie in France) will finance five national expert centres dedicated to the following themes for two years:

- mobility,
- cognitive stimulation,
- interfaces functioning in the use of communication and information technologies,
- automated assistance and re-education, and
- the habitat and accommodation.

These centres will link research laboratories, professionals in compensating the effects of disability and loss of autonomy, users and industrial companies. The objective is to assist the development and improvement of new technical aids on the basis of needs analyses and show that the response is adapted to the specific situations of disability and loss of autonomy.

Furthermore, it is necessary to formulate an adequate ethical framework that protects people with AD from inappropriate use of these technologies (dehumanisation of relations, an assistance system better adapted to the technique than the patient and his/her caregiver, etc.). The issue raised is that of recognising the needs, preferences and values of those using these techniques. Indeed, elderly persons do not envisage the future beyond the next four or five years and are ill disposed to paying for, or investing in, technology.

Although these technologies are vital and efficient, they must be overseen by the community and be reimbursed on the basis of recognising the medical nature of these systems. This issue is crucial in France at a time when debate is due to start on the 'fifth risk', that of dependency.

Appendix 3. Role of technology in coping with obesity

Globally there are more than a billion overweight adults, of whom at least 300 million are clinically obese.¹¹ Both of these conditions are major risks in the development of chronic diseases, including type 2 diabetes, cardiovascular disease and certain types of cancer.

One of the first kinds of commercial services to emerge in this field concerns the need to motivate people to become more physically active. For example, MiLife is an online, personalised coaching system that uses MiBand, a wristband containing a three-way accelerometer, to continuously track an individual's activity levels throughout the day.

The user's physical activity data is captured along with weight measurements from a set of Bluetooth-enabled weight scales, and is transmitted wirelessly through a personal computer to the individual's online personal health record. In this way, time-poor individuals are motivated to increase their overall level of activity throughout each day, and to track their progress online at a time that suits them, setting personal goals in relation to a community of other users (Hoeksma, 2008; Wong, 2010).

To obtain an inside look at eating and exercise habits, wearable wireless sensors are being developed to monitor overweight and obese people as they go about their daily lives.

The experimental devices are designed to keep track of how many minutes they work out, how much food they consume and even whether they are at a fast-food joint when they should be in the park. The goal is to cut down on self-reported answers that often cover up what is really happening.

In a lab test, two overweight teenagers helped evaluate the devices by taking turns sitting, standing, lying down and running on a treadmill. As music thumped in the background, wireless sensors on their chests recorded their heart rates, stress levels and amount of physical activity. The information was sent to a mobile phone.

Traditional weight-loss interventions rely mainly on people's memory of what they ate for dinner and how many minutes they worked out. But researchers have long known that method can be unreliable, since people often forget details or lie.

The new devices are being designed in labs or created with off-the-shelf parts. Some similar instruments are already on the market, including a model that tracks calories burned by measuring motion, sweat and heat with armbands.

But the devices in development aim at becoming more sophisticated by featuring more precise electronics and sometimes even video cameras. Many emerging systems also strive to provide instant feedback and personalised treatment for wearers.

The devices are made possible by advances in technology, such as accelerometers that can measure the duration and intensity of a workout. They also use Bluetooth-enabled mobile phones that can take pictures of meals and send information back.

Getting an accurate picture of what people eat and how often they move around will help researchers develop personalised weight-loss advice.

¹¹ See Worldometers: Real time world statistics, "Obesity in the world – Definitions, sources and methods" (<http://www.worldometers.info/obesity/>).

The problem of adults being either overweight or obese is epidemic in developed countries. Obesity is a major health concern for children and adolescents, who are at higher risk of high blood pressure, high cholesterol and diabetes as they grow older.

A federally-funded US pilot project by the Pennington Biomedical Research Center in Louisiana is exploring whether people can lose more weight when tracked by technology.

Participants carry around Blackberry Curve smartphones to take pictures of their meals and leftovers. They also wear a coin-sized device on their shoe that counts the number of steps they take.

Counsellors pore over the incoming data and give individually tailored health advice through e-mail or telephone. Every month, the participants have their weight checked, and their progress is compared against a separate group that receives only generic health tips.

By using technology to capture eating and exercise details, researchers hope to bypass the self-reporting that can sometimes give an incomplete picture (*Sydney Morning Herald*, 2010).

About obesity: Main features and prevalence

Obesity is a medical condition in which excess body fat has accumulated to the extent that it may have an adverse effect on health, leading to reduced life expectancy or increased health problems. Body mass index (BMI), a measurement that compares weight and height, defines people as overweight (pre-obese) if their BMI is between 25 kg/m² and 30 kg/m², and obese when it is greater than 30 kg/m².

Overweight and obesity affect an increasing number of people each year: the World Health Organization (WHO, 2007) further projects that by 2015 approximately 2.3 billion adults will be overweight and more than 700 million will be obese. Once considered a problem only in high-income countries, overweight and obesity are now dramatically on the rise in low- and middle-income countries, particularly in urban settings.

This is one of the greatest public health challenges of the 21st century. Its prevalence has tripled in many countries of the WHO's European Region since the 1980s, and the numbers of those affected continue to rise at an alarming rate, particularly children. Obesity is already responsible for 2–8% of health costs and 10–13% of deaths in different parts of the European Region (WHO, 2007).

Overweight and obesity are associated with an enormous burden of disease, disability and reduced quality of life. Furthermore, the disease adds to the nation's health care spending and imposes an economic burden on employers.

Obesity remains a significant cause of disability and an underlying cause of death, so authorities view it as one of the most serious public health problems of this century. Obesity brings with it illness, disability and economic hardship, which affect individuals, families, communities, employers and nearly all facets of the health system. The health impact of being overweight or obese has been well documented in the scientific literature: 70-80% of obese adults have diabetes, coronary heart disease, high blood pressure, high blood cholesterol or osteoarthritis (Must et al., 1999), in addition to breathing difficulties during sleep and certain types of cancer.

The epidemic now affects all segments of the population regardless of age, gender or ethnicity; however, the following distinctions should be noted:

- Disability due to obesity-related cardiovascular diseases will increase particularly in industrialised countries, as patients survive cardiovascular diseases in these countries more often than in non-industrialised countries.

- Disability due to obesity-related type 2 diabetes will also increase, especially in industrialising countries, as insulin supply is usually insufficient in these countries.

As a result, in these countries disabling nephropathy, arteriosclerosis, neuropathy and retinopathy are expected to rise. Growth in the prevalence of obesity will potentially lead to an increase in the number of years that individuals suffer from obesity-related morbidity and disability (Visscher and Seidel, 2001).

Description of the condition: Initial, moderate and severe stages

For the purposes of our study, we consider three stages of obesity:

- 1) an initial stage at which attention is needed by individuals potentially at risk (those with a predisposition towards being overweight, with related conditions, a family history of obesity, etc.), i.e. patients who warrant selective concern. These patients are autonomous and a healthy lifestyle is usually better for them than any drugs. In this scenario, we include healthy people and those in the early phases of the disease, which just require regular attention by the health system. With the right support, individuals (with the informal carers) can learn to be active participants in their own care, preventing the disease or learning how to live with the condition. This support can help individuals to prevent complications and slow down deterioration;
- 2) a moderate, stable stage of care, for those patients whose BMI is between 30.0 and 40.0, i.e. patients who are considered 'overweight'. Such patients – as recipients of care targeted at prevention – must be monitored by a multidisciplinary team to deal with potential complications that lead to complex clinical issues, such as hypertension, diabetes type 2, vascular problems, respiratory disorders and some cancers. Obese patients with complications often require hospitalisation, because the care offered at home, also for simple activities, may become complicated; however, the presence of a caregiver supported by a range of appropriate equipment may facilitate the management of patients and help to promote their autonomy. Nevertheless, the care environment must be rapidly adapted to the challenges related to bariatric patients. One of these challenges is the widespread perception among caregivers that care for bariatric patients is demanding not only from the physical point of view but also from the psychological one.

The processes in this situation are predictable, as they usually require the proactive management of a (single) condition during its early period. The care ideally follows an authoritative clinical pathway and a multidisciplinary team performs a set of stable care tasks, according to an agreed care plan. Patients and informal carers (family, friends and volunteers) are possibly assisted by a care manager, acting as both an interface with the care facilities and as a coach to promote the patients' empowerment and to improve compliance with the care plan;

- 3) a severe stage in which patients present a BMI equal to or greater than 40.0 and the condition becomes more complex in its management – the patient is a 'morbidly obese'. The management of the morbidly obese is even more linked to patients' homes, because this type of patient can hardly be transported, and even in cases of emergency, operators without special means (e.g. specific stretchers for the transport of the bariatric patient) are forced to intervene on the spot. Also within a facility, the bariatric patient may become disadvantaged, not because of the limits of the carers but because the stretchers for mobilisation are often unable to cope with the excess weight.

Degree of autonomy of the recipient of care

A care recipient in the first stage (class 1) can prevent obesity by limiting energy intake from total fats and shifting fat consumption away from saturated fats to unsaturated fats, limiting the intake of sugars, increasing consumption of fruit and vegetables and increasing physical activity. More activity may be required for weight control.

Patients in the second or the third stages are defined as individuals who have limitations in health and social care owing to physical size, health, mobility and environmental access.

The Bariatric Gallery developed by ArjoHuntleigh (2011) offers an assessment tool to help evaluate individual patient needs. In the Bariatric Gallery (see Table A3.1) people are classified according to their degree of functional mobility, from the most mobile to the most dependent.

The scale may be related to BMI and to the degree of functional mobility, as in Table A3.2.

Table A3.1 Description of the needs related to obesity

	Needs
Albert	<ul style="list-style-type: none"> • Ambulatory, but may use a cane or similar for support • Independent, can clean and dress himself • Can tire quickly • Stimulation of abilities is very important
Barbara	<ul style="list-style-type: none"> • Uses a walking frame or similar • Can support herself to some degree • Dependent on a carer who is present in demanding situations • Physically demanding for a carer • Stimulation of remaining abilities (e.g. ambulation) is very important
Carl	<ul style="list-style-type: none"> • Sits in a wheelchair • Is able to partially bear weight on at least one leg • Has some trunk stability • Dependent on a carer in most situations • Very physically demanding for a carer • Stimulation of remaining abilities is very important
Doris	<ul style="list-style-type: none"> • Sits in a wheelchair • No capacity to support herself • Cannot stand unsupported and unable to bear weight, even partially • Dependent on a carer in most situations • Extremely physically demanding for a carer • Stimulation of remaining abilities is very important
Emma	<ul style="list-style-type: none"> • Passive • Might be almost completely bedridden • Often stiff, contracted joints • Totally dependent • Extremely physically demanding for a carer • Stimulation and activation is not a primary goal

Source: Authors' elaboration based on ArjoHuntleigh (2011).

Table A3.2 Classification of obesity and its relation to the Bariatric Gallery

BMI	Classification	Bariatric Gallery	Prevention	Degree of functional mobility
< 18.5	Underweight	–	–	–
18.5–24.9	Normal weight	–	–	–
25.0–29.9	Overweight	–	Universal	Independent
30.0–34.9	Class I obesity	Albert	Selective	Independent
35.0–39.9	Class II obesity	Barbara, Carl	Targeted	Partially dependent
≥ 40.0	Class III obesity	Doris, Emma	–	Totally dependent

Source: Authors' elaboration based on ArjoHuntleigh (2011).

Evolution of the condition

The evolution of obesity could be spontaneous or as a consequence of appropriate care; in this section we describe the main health and social care tasks involved in facing obesity or delaying its effects.

According to the WHO (2007), the fundamental causes of the obesity epidemic are sedentary lifestyles and high-fat energy-dense diets, both resulting from the profound changes taking place in society and the behavioural patterns of communities as a consequence of increased urbanisation, and industrialisation and the disappearance of traditional lifestyles. There are also a few cases caused primarily by genes, endocrine disorders, medications and psychiatric illness.

There are numerous methods for treating overweight and obesity but the mainstays against obesity are dieting and physical exercise, especially at the initial stage of disease. When the illness becomes more serious, supplementing dietary management, physical activity and exercise are anti-obesity drugs that may be taken to reduce appetite or inhibit fat absorption. Gastrointestinal surgery is reserved for extreme cases.

Prevention programmes will stem the obesity epidemic more efficiently than weight-loss programmes. Yet, only a few prevention programmes have been developed or implemented, and the success rates reported to date have been low. Obesity prevention programmes should be high on the scientific and political agenda in both industrialised and industrialising countries. Overweight and obesity, as well as their related chronic diseases, are largely preventable.

According to the WHO (2007), there are three types of prevention:

- universal prevention, involving measures directed at the entire population, which should aim at stabilising the level of obesity and eventually lowering the incidence and hence the prevalence of obesity. A reduction in weight-related disease by lifestyle modification, including improved diet and physical activity levels, are the objective, as well as reductions in smoking and alcohol consumption;
- selective prevention, for educating sub-groups of the population with a high risk of obesity so they can deal effectively with the risk factors, which may be genetic and predispose them to obesity). Such strategies can be initiated in appropriate setting which allow access to these high risk group, including schools, community centres and primary care venues; and
- targeted prevention, for avoiding weight gain and reducing the number of people with weight-related disorders among those individuals who are already overweight or who have biological markers associated with excess adiposity but are not yet obese. This group has a particularly high risk of becoming obese and suffering from obesity-related disorders. Individuals who have some existing weight-related problems and those with a

high risk of developing obesity co-morbidities, such as cardiovascular disease and type 2 diabetes, should be a key priority in this prevention strategy.

Relevance/role of actors

In this section, we attempt to schematise the relations between the topics and the tools involved in treatment for obesity. In Table A3.3, we also show the generic health issues and the actors involved.

Table A3.3 Potential correlations between health issues and technological solutions

Issues	Topics	Tools	Actors
Pain	Rest	Medications, electric profiling bed, electric height-adjustable couch, pressure reduction mattresses	GP (to prescribe)
	Nocturnal disorders		
	Walking	Aids and appliances, such as a walking stick or walking aid	
ADLs	Elimination	Bedside commode chair, bedpans, bedbaths	Nurse, Caregiver
	Dressing, undressing, shoes	Special shoes and clothes	
	Personal hygiene and grooming	Mobile bariatric shower, commode chair	
	Functional transfers (bed↔chair)	Sliding sheet, mobile sling lifter, bariatric slings, bariatric wheelchair	
	Ambulation	Walking aid, walker with castors	
IADLs	Shopping for groceries, clothing, medications	E-commerce, caregiver	Caregiver, social services
	Mobility/transport	Coordination services	
Health maintenance	Taking medications	Electronic diary, dispenser	Specialist, self
	Nutrition/diet	Food journal, sensors in the fridge	
	Self-monitoring	Calorie meter	
	Remote monitoring	Weight, pressure, blood glucose	
Education	Remote training	Portals, community	Contact centre (counselling)
	Supervision technology	Portals, community	
Prevention	Follow-up nutrition	ICT application for communication and reminders	GP
	Follow-up related pathologies	ICT application for communication and reminders	
	Follow-up psychological state	ICT application for communication and reminders	
Safety	Home environment	Alert systems, sensory	Any
Leisure	Communication	Telephone, computer, television	Self
Physical activity	Rehabilitation	Tele-therapy, Wii console	Therapist, self
	Trainer	Tele-therapy, Wii console	

Source: Authors' elaboration.

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).