



European Network of Economic
Policy Research Institutes

ANCIEN

Assessing Needs of Care in European Nations

LONG-TERM CARE QUALITY ASSURANCE POLICIES IN EUROPEAN COUNTRIES

ENEPRI RESEARCH REPORT NO. 111

WORK PACKAGE 5

MARCH 2012

Roberto Dandi (LUISS)
Georgia Casanova (LUISS)
Roberto Lillini (Università Vita-Salute San Raffaele)
Massimo Volpe (LUISS)
Antonio Giulio De Belvis (LUISS)
Maria Avolio (LUISS)
Ferruccio Pelone (LUISS)

Contributions by: Thomas Czypionka, IHS (Austria), Gerli Paat and Merle Merilain, PRAXIS (Estonia), Edvard Johansson and Tarmo Valkonen, ETLA (Finland), Erika Schulz, DIW (Germany), Róbert Iván Gál, TARKI (Hungary), Kaspar Ilves and Baiba Plakane, PRAXIS (Latvia), Valentina Prevolnik Rupel, Marko Ogorevc and Boris Majcen, IER (Slovenia), Beatrice Fermon and Marie-Eve JOEL LEGOS (France), Stanisława Golinowska and Izabela Styczyńska CASE (Poland). Marek Radvanský, B-IER (Slovakia), Sergi Jimenez and Raquel Vegas, FEDEA (Spain), Thomas Emilsson, Stockholm County Council, (Sweden), Esther Mot, Victoria Shestalova and Ali Aouragh, CPB (the Netherlands), and Juliette Malley, LSE-PSSRU (the UK).



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 3 of the ANCIEN 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 authors and are not attributable to Eurostat, the European Commission or any of the national authorities whose data have been used.

ISBN 978-94-6138-177-4

Available for free downloading from the CEPS website (www.ceps.eu)
and the ANCIEN website (<http://www.ancien-longtermcare.eu/>)

© Copyright 2012 Roberto Dandi, Georgia Casanova, Roberto Lillini, Massimo Volpe, Antonio Giulio De Belvis, Maria Avolio, Ferruccio Pelone

Contents

ABSTRACT	1
1. AIMS AND ACKNOWLEDGEMENTS.....	1
2. QUALITY IN LTC.....	3
2.1 Definition of LTC quality.....	3
2.2 Dimensions of LTC quality	4
2.3 The assessment of quality in LTC	5
2.4 Quality of life in LTC	7
2.5 Quality Policies in LTC	8
2.5.1 Quality of LTC at the international level.....	9
2.5.2 National policies for LTC quality.....	12
2.5.3 Organisational level quality management	21
2.5.4 User-level quality	23
2.5.5 Coordination of LTC providers	24
3. AN ANALYSIS OF EUROPEAN QUALITY POLICIES IN LTC	24
3.1 Data gathering: the survey.....	24
3.2 Analyses	27
3.3 Results	35
4. CONCLUSIONS.....	45
REFERENCES.....	51
ANNEX. COUNTRY REPORTS ON LTC QUALITY POLICIES	53
1. Finland (by ETLA)	54
1.1 LTC quality documents	54
1.2 LTC quality system	54
1.3 Strategies for quality in informal LTC	55
2. Hungary (by TARKI).....	56
2.1 LTC quality documents	56
2.2 LTC quality system	56
3. Slovakia (by B-IER)	58
3.1 LTC quality responsibilities and documents.....	58
3.2 LTC quality system	59
3.3 Strategies for the improvement of quality in informal LTC	60
4. Spain (by FEDEA).....	62
4.1 LTC quality documents	62
4.2 LTC quality system	63
4.3 LTC quality guidelines	64
5. Sweden (by ETLA)	65
5.1 LTC quality documents	65
5.2 Organisational Overview	66

5.3 Laws for LTC	67
5.4 Monitoring, Quality Indicators a Overview.....	67
5.5 LTC quality system	70
5.6 LTC clinical guidelines	70
5.7 Human resources	70
5.8 Strategies for the improvement of LTC informal care.....	71
5.9 Use of technology for LTC quality.....	72
5.10 References on LTC quality in Sweden	74
5.11 References on technology and LTC quality.....	74
6. The Netherlands (by CPB).....	76
6.1 LTC quality documents	76
6.2 LTC quality system	78
6.3 LTC quality guidelines	79
6.4 Strategies for quality in informal LTC	80
6.5 Use of technology for LTC quality.....	80
7. United Kingdom (by LSE)	82
7.1 LTC quality documents	82
7.2 LTC quality system	82
7.3 LTC quality guidelines	83
7.4 Strategies for quality in informal LTC	84
7.5 Use of technology for LTC quality.....	85

Long-Term Care Quality Assurance Policies in the European Union

ENEPRI Research Report No. 111/March 2012

Roberto Dandi, Georgia Casanova, Roberto Lillini, Massimo Volpe,
Antonio Giulio De Belvis, Maria Avolio, Ferruccio Pelone*

Abstract

This report analyses the quality assurance policies for long-term care (LTC) in the following countries: Austria, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Poland, Slovakia, Slovenia, Spain, Sweden, the Netherlands, and the United Kingdom.

First, we discuss quality assurance in LTC by analysing: the dimensions of quality, the policy frameworks for quality in LTC, the different levels of development of LTC quality policies at the international, national, organisational, and individual levels. Second, we describe the methodology for collecting and analysing data on quality policies in the selected countries.

We then report and discuss the results, identifying four clusters of countries based on quality policies and indicators for LTC. These clusters are compared to the clusters identified in WP1 of the ANCIEN project. Policy recommendations are proposed.

Finally, country profiles based on survey data are included. Extended country reports on Austria, Estonia, France, Germany, Italy, Poland, and Slovenia (forthcoming) will accompany this document.

1. Aims and acknowledgements

This report analyses the quality assurance policies for long-term care (LTC) in the following countries: Austria, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Poland, Slovakia, Slovenia, Spain, Sweden, the Netherlands, and the United Kingdom.

Data were collected in two ways: first, LUISS, together with the partners, coordinated the development of a survey on quality policies and submitted it to all the partners involved in WP5. Then, selected partners compiled separate country reports for the following countries: Italy (LUISS), Austria (IHS), Estonia and Latvia (PRAXIS), France (LEGOS), Germany (DIW), Poland (CASE), and Slovenia (IER). These reports are not included in this document. LUISS compiled the country profiles for Finland, Hungary, Slovakia, Slovenia, Spain, Sweden, and the UK using the survey data and the text descriptions by partners. These reports are included in the annex of the present document.

Survey data were analysed by LUISS in order to cluster countries according to their similarity in quality policies and systems.

* Roberto Dandi is a researcher at the Public Administration and Health Care Unit at LUISS Business School- LUISS Guido Carli University in Rome; Georgia Casanova collaborates with LUISS Business School in Rome; Roberto Lillini is a researcher at Registro Tumori Regione Liguria and instructor at Università Vita Salute San Raffaele in Milan; Massimo Volpe, is an epidemiologist at Gemelli University Hospital in Rome; Antonio Giulio De Belvis is a senior researcher at Università Cattolica del Sacro Cuore in Rome; Maria Avolio and Ferruccio Pelone are junior researchers at Università Cattolica del Sacro Cuore in Rome.

Even if this report is a collective effort, the authors of the specific sections are as follows:

- Sections 2.1, 2.2, 2.3 by Roberto Dandi
- Section 2.4 by Antonio Giulio De Belvis
- Section 2.5 jointly by Massimo Volpe
- Section 3.1 jointly by Massimo Volpe, Roberto Dandi, Maria Avolio, Ferruccio Pelone
- Section 3.2 jointly by Georgia Casanova, Roberto Lillini, and Roberto Dandi
- Section 3.3 jointly by Roberto Lillini and Georgia Casanova
- Chapter 4 by Roberto Dandi
- Country reports in the annex are based on texts authored and data provided by Edvard Johansson and Tarmo Valkonen, ETLA (Finland), Róbert Iván Gál, TARKI (Hungary), Marek Radvanský, B-IER (Slovakia), Sergi Jimenez and Raquel Vegas, FEDEA (Spain), Thomas Emilsson, Stockholm County Council, (Sweden), Esther Mot, Victoria Shestalova and Ali Aouragh, CPB (the Netherlands), and Juliette Malley, LSE-PSSRU (the UK).

Acknowledgements: we wish to thank all the partners for their collaboration in writing this deliverable. In particular, we wish to thank the scientific coordinators of the ANCIEN project, Esther Mot (Netherlands Bureau for Economic Policy Analysis, CPB, in The Hague) and Peter Willemé (Social Security Research Group at the Federal Planning Bureau, FPB, in Brussels) for the scientific supervision of the deliverable. Also, our profound thanks go to all the experts we contacted: Dr. Roberto Lillini (Università Vita Salute) for helping with the analyses in sections 3.2 and 3.3, Prof. Alberto Perucci (AGENAS) for his suggestions, Prof. Massimo Fini (Istituto San Raffaele, Roma) for his support, Dr. Giovanni Lamura (INRCA) for helping in finding assistance, Prof. Franco Fontana (LUISS) for his guidance.

2. Quality in LTC

2.1 Definition of LTC quality

Quality of care has been defined in different ways in the literature but the most influential definition (Legido-Quigley et al, 2008) is the one developed by the Institute of Medicine (IOM) in 1990. The IOM, after reviewing over 100 definitions and parameters of quality of care according to the presence or absence of 18 dimensions, defines quality of care as:

“The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (IOM, 1990).

This definition identifies both individuals and populations, not just patients, as targets of quality assurance efforts; furthermore it is goal-oriented since health care goals depend on the perspectives of whoever is setting them (government, administrators, patients, practitioners); ultimately, it implies that the state of professional performance depends on the latest advances in professional knowledge.

Is this definition applicable to the quality of LTC?

According to the World Health Organisation (2002) the goal of LTC is

“to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity”.

Unlike acute care, LTC does not eliminate diseases but aims to alleviate suffering, reduce discomfort, compensate for the effect of limitations caused by disease and disability, and maintain the best possible levels of people’s physical and mental functioning. Moreover, LTC needs to address issues such as the quality of life of the patient and the satisfaction with care experienced by the patient and his/her family.

These aims encompass a broad mix of services such as personal care, health care, life management (e.g. shopping, medication management, and transportation), and resources (for example assistive devices such as canes and walkers), more advanced technologies (e.g. emergency alert systems and computerised medication reminders), and home modifications (e.g. ramps and hand rails). Furthermore, as regards settings, LTC may be either institutional or home-based, and formal or informal (WHO, 2002).

Also, unlike the acute sector, much LTC work is unspecialised, labour-intensive, and relatively unskilled. Most LTC activities are performed by paraprofessionals with a variety of skills (home assistants, housekeepers, nurse assistants, activities staff, or informal caregivers). Skilled workers (nurses, physicians, etc.) are involved to a lesser degree than in acute care. Medical devices are also significantly less complex and costly than those used for acute care. Many of the core LTC activities are concerned with helping by means of basic functioning or improving patient autonomy in performing daily living activities.

The IOM definition of quality of care can therefore be applied to LTC as well but, as the IOM (2000) itself points out, the specific features of LTC need to be taken into account:

- 1) Long-term care is *both a health and a social programme*. For the health services components of long-term care, judgments about quality of care emphasise medical and technical aspects of care. For other aspects of long-term care, judgments about quality of care reflect the opinions and satisfaction of consumers.

- 2) The potential and actual role of consumers is an essential element of long-term care. The desired health outcomes thus depend on the patient's perspective and activeness.
- 3) For nursing homes and residential care settings, the physical environment of the facility can contribute to the physical safety and functional mobility of residents and, more broadly, to their quality of life.
- 4) The very characteristic of LTC, that is the persistent nature of the disabilities and of the chronic conditions, has an impact on: i) the development of interpersonal relationships among providers, families, and patients; ii) the physical adaptation of the home or the infrastructure of facilities to accommodate or attend patients on a long-standing basis; iii) the greater need for coordination among different segments of carers.

2.2 Dimensions of LTC quality

Legido-Quigley et al, 2008 reviewed the definitions of quality of care and identified the most common dimensions of quality:

- 1) Effectiveness of care: the extent to which the intervention produces the intended effects, or the degree to which attainable health improvements are realised; it may be associated with health outcomes.
- 2) Safety: the degree to which health care processes avoid, prevent, and ameliorate adverse outcomes or injuries that stem from the processes of health care itself (National Patient Safety Foundation, 2000). Safety is a dimension that is closely related to effectiveness, although distinct from it in its emphasis on the prevention of unintentional adverse events for patients.
- 3) Responsiveness: refers to how a system responds to people to meet their legitimate non-health expectations (WHO, 2000) and their preferences and values. The concept of responsiveness is close to patient-centeredness, which is the degree to which a system places the patient/user at the centre of its delivery of health care and is often assessed in terms of patients' experience of their health care. The emphasis here is on the patient's report of her or his experience with specific aspects of care, and goes beyond his/her general satisfaction or opinion regarding the adequacy of care.
- 4) Accessibility: is the ease with which health services are reached. Access can be operationalised as the proportion of a given population in need of health services that can obtain them. In other words, the health service is available to the persons needing it, at the time it is needed.
- 5) Equity: this dimension is closely related to access, although it is also used as a metric to assess health-system financing and outcomes/health status. Equity deals with the distribution of health care and its benefits among people.
- 6) Efficiency is the system's optimal use of available resources to yield maximum benefits or results (WHO, 2000). As Donabedian (1980) argues, quality assessment depends on the availability of resources.
- 7) Acceptability: how humanely and considerately the treatment is delivered. This concept is also associated to responsiveness.
- 8) Appropriateness, as a performance dimension, this is the degree to which provided health care corresponds to the clinical needs, given the current best evidence. This dimension is most often presented as part of effectiveness.

- 9) Competence of health system personnel: this dimension 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.
- 10) Continuity addresses the extent to which health care for specified users, over time, is coordinated across providers and institutions.
- 11) 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 moving people across providers and through the stages of care).
- 12) Satisfaction: how the treatment and the improvement in the patient's health meets his/her expectations.

Figure 2.1 OECD conceptual framework for Health Care Quality Indicator (HCQI) Project

HEALTHCARE SYSTEM PERFORMANCE					
How does the healthcare system perform? What is the level of care across the range of patient care needs? What does this performance cost?					
Dimensions of Healthcare Performance					
Healthcare Needs	Quality			Access	Cost / Expenditure
	Effectiveness	Safety	Responsiveness / Patient-centeredness	Accessibility	
Staying healthy					
Getting better					
Living with illness or disability					
Coping with end-of-life					

Source: Arah et al., 2006.

The OECD's project on quality indicators aggregated those quality dimensions in only three (see fig. 1): Effectiveness, Safety, and Responsiveness / Patient Centeredness. These concepts comprise most of the dimensions outlined above. However, as we will discuss later, we think that a dimension that should be addressed relates to the organisational side of LTC quality: coordination of providers may summarise other concepts not included in the three OECD dimensions, such as continuity of care and timeliness.

2.3 The assessment of quality in LTC

Following the classic approach by Donabedian (1985), quality in LTC is a multidimensional concept which includes:

- i) the quality of the *inputs*, or structure (equipment, drugs, facilities, personnel, etc.);
- ii) the quality of the *processes* or the use of resources (intervention rates, referral rates, management of waiting lists, etc.);
- iii) and the quality of *outcomes*, that is the effects of health care on the health status of patients and populations (mortality, disability or quality of life, functional ability, etc.), depending on the types of patients.

Table 2.1 Examples of input-process-outcome indicators

Quality of structure: examples	
	Quality and safety of buildings (fire hazards, sanitation)
	Amenity of housing environment
	Size of rooms
	Staff ratios; mix of staff qualification
Quality of process: examples	
	Mechanisms to protect resident rights
	Well-functioning transfer and discharge management
	Procedures of resident assessments used for care planning
	Availability of services needed to attain and maintain residents highest practicable level of functioning
	Availability of sufficiently qualified staff around the clock seven days a week
	Well-balanced diet
	Availability of and/or access to ancillary services (e.g., rehabilitation, pharmacy, infection control)
	Requirements for clinical records and process of care documentation
	Maintaining a quality assurance committee
Quality of outcomes: examples	
	Prevalence of pressure sores
	Prevalence of malnutrition (including dehydration); adequacy of tube feeding
	Preventable decline of ADL and IADL functioning
	Residents with poorly managed pain
	Restraints uses (physical and pharmacological)
	Residents with infections
	Prevalence of anti-psychotic drug use
	Prevalence of tube feeding
	Number of falls; falls prevention
	Prevalence of faecal incontinence
	Social engagement and privacy protection

Source: European Commission (2008), Long-Term Care in the European Union.

Historically (National Commission for Quality Long-term Care, 2005), the main focus of quality assurance agencies has been put on inputs and processes, because the assessments of quality indicators about them are easier to collect. As reported by WHO (2003) many mechanisms based on structural and process indicators have been developed to ensure an acceptable level of LTC services. The most basic interventions are the following:

- minimum staffing ratios and qualifications;
- skill-mix;
- minimum infrastructure and safety conditions;
- minimum content of long-term care services; and
- data collection requirements.

Input indicators measure the presence or absence of specific resources. Public bodies usually adopt these types of indicators in order to authorise and give accreditation to LTC facilities. The assumption is that the quality of inputs has an impact on patients. However, this cause-effect relation between inputs and outcome may be very weak.

Process indicators are the base for the detection of errors as they occur in workflow and for the development of a continuous improvement system. They are more tightly connected to outcomes.

Outcome-Based Quality Indicators (OBQI) measure health and functional status of patients, or their satisfaction with the experience of care. They are the most useful for measuring the quality of care but have several shortcomings in terms of reliability and validity (Clark, 2007).

When outcomes occur with a lag-time after health care interventions, or when other determinants may influence their occurrence, the attribution of specific achievements to specific care processes remains difficult. For example, outcome-based indicators such as percentage of incontinent or depressed residents may be interpreted as a proxy of quality of care or just of a

case-mix indicator. Some health outcomes may not be causally related to internal organisational processes. Assessing quality on these outcomes may provoke *cream skimming* practices for the selection of residents. Also, since LTC patients tend to present a combination of problems, isolated outcomes concerning specific conditions may not provide a complete picture of the impact of care.

WHO (2003) reported that the most diffused OBQI are the ‘activities of daily living’ (ADLs) and ‘instrumental activities of daily living’ (IADLs), which measure the functional level and variations in functional capacity. Other outcomes of interest in LTC are the level of pain and discomfort, the level of cognition, as well as social activity, and social relationships.

Another way to assess outcomes is to compare the observed and predicted outcomes, adjusted prior to the intervention. Such adjustments are made according to the patient’s features (case-mix) that may affect the occurrence of those outcomes. Otherwise, comparisons are not meaningful. Patients may be classified as high risk or low risk according to different criteria. The Resource Utilisation Groups (RUG) is one of the most diffused case-mix measurements for LTC.

Given the difficulty in gathering and interpreting outcome-based data, many advocate the use of self-reported data, in addition to other data, gathered from the patients themselves about the quality of their experience with the caregivers and about the quality of their life during the care process.

The quality of LTC however, needs to be judged not only in terms of the structure, processes, and outcomes of clinical care, but also in terms of access to care, the non-medical personal assistance services that are an important part of LTC, and the LTC user's quality of life. Because perspectives can differ among recipients of LTC services and between care recipients and care providers, one of the challenges is establish priorities reflecting different perspectives (IOM, 2000).

Shaw and Kalo (2002) matched these categories with the dimensions of quality of care: i) input measures deal with the dimensions of access and equity; ii) process measures are related to efficiency, safety, appropriateness, and continuity; iii) outcome measures are mainly concerned with effectiveness. As they argue, “it is not realistic to expect to concentrate on all of these values at the same time. Each country should define the strategic totality of values in quality (preferably in terms that could survive a change of government), and then define the operational priorities”.

2.4 Quality of life in LTC

To be useful in decision-making, quality indicators must be defined, tested, developed and monitored with scientific rigour, and all aspects of care must be measured to describe and appraise health-care quality in a sound way.

The variance in monitored quality of LTC services is associated to variables such as inadequate housing, poor social relationships and lack of privacy in nursing homes, as well as inadequate treatment of chronic pain, depression, bedsores or inappropriate use of chemical or physical restraints (EC, 2005)

Schalock (2001) proposes a framework for the assessment of quality of life of the elderly/disabled people in which, for the first time, the quality of perspective is primarily referred to patients, and strictly linked to values and performance, both at the individual and at the organisation level.

Recent developments in outcomes-based evaluation and results-based measurements indicate the need to measure both individual and organisation performances and value outcomes. The

outcome-focused evaluation model shown in Table 1 (derived from Schalock, 2004) indicates that there are two dimensions to take into account: type of outcome (performance or value) and type of actors (provider organisation or individual patient). Performance outcomes refer to the health status of the individual or to the organisational performance. Value outcomes refer to the perception or the point of view of the patient.

Table 2.2 Schalock (2001, 2004) Framework for Quality of Life

	Performance outcomes	Value outcomes
Organisation level	Effectiveness Efficiency Health and safety Stability (financial, staff)	Access to services Customer satisfaction
Individual level	Physical well-being Material well-being (employment, living status, educational status) Clinical status (symptom reduction) ADL, IADLs Activity patterns (in-home, out-of-home)	Emotional well-being Personal development Self-determination Interpersonal relations Social inclusion Rights

In this framework, different quality dimensions (structure, process or outcome, according to Donabedian, see before) and aspects of care provision (safety, effectiveness, efficiency, timeliness, patient-centeredness and equity) are no longer considered to be mutually exclusive but integrated.

2.5 Quality Policies in LTC

Nies et al. (2010) identified four different levels at which quality of care may be addressed:

- System level (regulation);
- Organisational level (quality management);
- Professional level (quality improvement by development of new skills);
- User level (empowerment).

We could add an international level, where international organisations (European Union or World Health Organisation) provide recommendations/guidelines and or funds for the development of quality systems and the spread of best practices at the national and local levels.

At each level several quality interventions are possible (Table 2.3).

Table 2.3 Levels of quality assurance

Level	Issues
International	<ul style="list-style-type: none"> • Recommendations / Guidelines / Best practices • Funds
System	<ul style="list-style-type: none"> • Legislation • Inspectorate • Accreditation • Certification

Organisation	<ul style="list-style-type: none"> • Quality management systems • Self-regulation and audits • Monitoring, performance evaluation and benchmarking • Integrated pathways of care
Professional	<ul style="list-style-type: none"> • New job profiles (e.g. discharge managers)/New roles (e.g. care managers) • Improvement structures (mandatory training, incentives/disincentives), formalised degrees or diplomas with emphasis on LTC • Accreditation of the professionals • New communication and information sharing tools (e.g. web based systems)
User	<ul style="list-style-type: none"> • Informed consent and shared decision making • Choice • Client satisfaction • Information about quality of services and providers • Quality of informal care

Source: Adapted from Nies et al., 2010.

At the international level, there are several agencies producing recommendations and guidelines for national LTC system quality management. These models have some common elements that national governments may take into account.

In the next section we will analyse the following levels of quality management in LTC:

- International recommendations/funds
- National priorities and organisation for LTC quality;
- System-level quality policies;
- Organisational level quality systems;
- User-level quality.

2.5.1 Quality of LTC at the international level

The *Charter of Fundamental Rights of the European Union* states that “the European Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”. Older people are also entitled to social security benefits and social services, in accordance with the rules laid down by Community law and national laws and practices. Everyone is entitled to preventative health care and medical treatment as provided for by national law.

In order to do so, a quality LTC should be promoted across EU member states. The EU vision for quality in LTC can be encapsulated by the following statements:

“Member states are committed to accessible, high-quality and sustainable health care and long-term care by ensuring: quality in health and long-term care and by adapting care, including developing preventive care, to the changing needs and preferences of society and individuals, notably by developing quality standards reflecting best international practice and by strengthening the responsibility of health professionals and of patients and care recipients” (EC, 2008b).

Priorities of the EU policies are (EC, 2008b):

- improvement of quality standards;

- improving of monitoring systems concerning quality measurement;
- improvement of interventions assessment;
- improvement of care coordination;
- improvement of patients' involvement and patients' choice.

Comparisons among quality policies of EU member states are difficult because (EC, 2008b):

- “Member states use a variety of definitions of LTC that do not always concur. The variations occur in the identification of care recipients, in the taxonomies of services provided and in the demarcation between health care (medical component) and social care (non-medical component), in the evaluation of dependency and its coverage;
- there are different levels of organisation and different divisions of responsibility among the public and private sector and family;
- there are different interventions addressed to the elderly and their families that may be related to LTC systems: prevention measures, active ageing, autonomy promotion and empowerment, social assistance, family support, etc.”

In Europe, the key organisations devoted to policy on quality in health and social care are the Council of Europe, the European Commission, and the WHO Regional Office for Europe.

In 1997, the Council of Europe developed a set of recommendations (see: Recommendation R(97)17) for the establishments of a quality improvement system in each member state. The aims were: “to create policies and structures, where appropriate, that support the development and implementation of ‘quality improvement systems’, i.e. systems for continuously assuring and improving the quality of health care at all levels”, including LTC.

The recommendations for the development of a quality system include:

1. Procedures and processes of quality improvement systems
 - a. identification of quality problems and successes;
 - b. systematic collection of data on care provision;
 - c. standards and evidence-based guidelines for high-quality cost-effective care;
 - d. implementing changes when needed by means of effective mechanisms and strategies;
 - e. measuring the impact of changes;
 - f. exploiting best practices.
2. Organisation of quality improvement at all levels of care provision
3. Responsibilities: all the actors need to participate in setting up the quality improvement system.
4. Guidelines should be developed systematically, disseminated effectively to the professionals as well as the public, and their effects monitored.
5. Health Technology Assessment should be diffused.
6. Quality indicators and information systems: health care information systems should be set up for using relevant quality of care and process indicators and allow for timely production, feedback, and reliable comparisons of health care data. Individual patient data must be kept confidential.

7. Information on the patient's perspectives (needs, priorities, experiences) should be gathered through appropriate methods ensuring active participation of patients.
8. Quality improvement systems should include effective mechanisms and strategies:
 - a. to achieve necessary changes in a planned and managed approach;
 - b. to involve all the actors in care and decision making, in particular, patients.
9. The necessary conditions should be created, according to each member state's legal and political system, to implement quality improvement systems namely:
 - a. supporting structures, such as agencies, boards, committees, and networks;
 - b. making full use of available resources, and providing resources and specific financing mechanisms for quality assessment, assurance, improvement and development;
 - c. pre- and postgraduate education for health care providers to gain knowledge of and skills in quality assessment and improvement systems;
 - d. appropriate incentives for participation in quality improvement.
10. Evaluation of Quality Improvement Systems should be fostered through public accountability and appropriate communication of the results.
11. The results of external assessment should be used to support continuous internal evaluation and improvement.
12. All necessary measures should be taken to promote research and development of quality improvement.
13. Stimulating exchange and collaboration in quality improvement at the national as well as the European level should be encouraged.

The European Commission in 2000 adopted a new public health strategy with three priorities:

1. Improving information for the development of public health;
2. Reacting rapidly to threats to health;
3. Tackling health determinants through health promotion and disease prevention.

In the same strategy paper the concept of spreading best practices for patient safety, efficacy, effectiveness, and cost-effectiveness of health care was introduced.

In 2005, in the document “Review of Preliminary National Policy Statements on Health Care and Long-term Care” the European Commission integrated reports on the policies of different member States and identified several issues related to quality of LTC:

1. *Definition and improvement of quality standards:* the national reports pinpoint as a key challenge the necessity to define /improve quality standards for medical and social care services, namely in relation to infrastructure (e.g. buildings and equipment), staff and the way the services are to be carried out.
2. *Weak monitoring systems:* the report states that in many member states it is difficult: to ensure that quality levels are the desirable ones, to promote informed policy in relation to the services (e.g. prescription of medicines) or to provide feedbacks to the various actors in the field.
3. *Lack of assessment and evaluation of interventions:* national reports underline the need to promote best-practice, cost-effective and evidence-based care, which can have positive implications not only for care quality but also for the system's financial sustainability.

4. *Lack of care coordination*, between primary, secondary, and social care. Coordination among types of care is very important in the context of chronic and long-term conditions where a patient may need to conduct various diagnostic examinations in a systematic way and consult with various types of staff (family doctor/GP, nursing homes, social workers).
5. *Patients' involvement and patients' choice*: in the context of greater patient expectations and demands the role of patients is often quite limited. Thus, it is important to strengthen the role of patients (e.g. via increased patient choice or patient involvement in the organisation of care).

Furthermore, WHO (2003) developed a set of recommendations:

1. Each health system should define the scope and extent of its long-term care coverage. All primary care services need to address also the long-term care needs of people with chronic conditions and disabilities, along with adequately responding to their needs for preventive and curative care.
2. Long-term care coverage should be based on an assessment of needs of the person requiring LTC. However, as the bulk of LTC is provided by informal caregivers and depends on their health and well-being, caregivers' needs must also be assessed in order to plan resource allocation.
3. Regulatory systems should establish minimum standards for long-term care facilities, including aspects such as the level and qualifications of staff, minimum staffing levels and skill-mix, procedural standards, and infrastructure specifications. Some countries may wish to regulate the rights of patients to long-term care, both in terms of technical care and in terms of civil rights. Compliance with standards should be enforced.
4. Standards or Protocols should be established where sufficient evidence is available, and research encouraged to expand the knowledge base necessary for quality LTC.
5. Interventions to improve care, such as Quality Assurance and Continuous Education, need to respond to changing needs and realities.
6. Some measure of outcomes assessment may need to be implemented in order to gauge the extent of outcomes achievement and thus improve care accordingly. Agreement over outcomes definitions should be established. The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) and The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) may provide a method approved by WHO member states.
7. The responsiveness to the legitimate expectations of persons with chronic conditions and disabilities, and the responsiveness to the legitimate expectations of their 'informal caregivers', must be translated into the continued improvement of services.
8. Evaluation of the extent of effective coverage across disability groups, and across social determinants that may hinder access to long-term care (such as age or gender, social and economic status, race, ethnic or religious groups, geographical residence, or other criteria) should be performed.

2.5.2 National policies for LTC quality

As Sorenson (2007) suggested, national priorities for LTC quality are of two types:

1. to inform regulation, in terms of standards, capacity, and sanctions, and
2. to enhance consumer choice and competition, primarily through benchmarks.

A first issue to be investigated is the existence of policy documents and or debates about the priorities of LTC quality, defining which quality dimensions for LTC are the most important at a national level.

Nies et al. (2010) reported for example that in The Netherlands, after a long debate on the role of government in fostering quality of health care, specific regulations for quality of care have been promulgated starting from 1996 (*Quality Act* in 1996 and *Quality Framework for Responsible Care*, 2008). They reported also that in Finland there is a *National Framework for High-Quality Services for Older People* which seeks to promote health and welfare in old age and to improve the quality and effectiveness of services to the elderly.

Several governments have established quality units for the development of quality policies. In Table 2.4, for example, there is a list of the policy groups founded in European member states for quality issues in health care (Shaw and Kalo, 2002).

Therefore another issue is the existence of such groups for the development of national quality policies in LTC, and the division of responsibilities, at national and local levels, for policy implementation. Also, in tables 2.5 and 2.6, there is the list of bodies devoted to the implementation of policies and to the development of guidelines.

Table 2.4 National policy groups on health care quality

Country	Founded	Title
Belgium	1995	Care Quality Department, MoH
Bosnia-Herzegovina	2001	Working group on quality and accreditation
Finland	1994	Quality Council for health care
Israel	1995	National committee for research in QHC: allocates government budget under health insurance law
Netherlands	1994	Harmonization of Health Certification (HKZ) (39): council to harmonize certification, accreditation, ISO, EFQM
Netherlands	1990	National "quality conferences" each five years to define policy, Leidschendam (40)
Russian Federation	1999	Federal Methodological Center for Quality Management within Central Public Health Research Institute to develop and disseminate quality methodology in Russia; supported by QAP/URC; website in English and Russian (41)
Spain	1998	Health care accreditation working group: national programme of regional and central governments
United Kingdom	2000	Quality Taskforce established by minister of health, comprising front line NHS staff and consumer representatives

Source: Shaw and Kalo (2002).

Table 2.5 National agencies for the implementation of health care quality policies

Country	Title	Function
Bulgaria 2001	Centre for medical technology assessment	Evaluate new technologies and disseminate results to purchasers, providers and the public
Finland 1994	Quality Council for Health Care STAKES www.stakes.fi	Responsibility delegated by MoH for national care registers, quality indicators, patient satisfaction databases, technology assessment
France 1997	Agence Nationale d'Accreditation et d'Evaluation en Santé ANAES (statutory) www.anaes.fr	Accreditation of health facilities, evaluation of clinical practice and guidelines, and definition of interventions which are reimbursable under health insurance
Italy 1995	Agenzia per i Servizi Sanitari Regionali	Under authority of the Ministry of Health collaborates with the Regions to support and survey health activity including CQ1, accreditation, indicators, guidelines etc.
Lithuania 1998	State Health Care Accreditation Service	Under authority of Ministry of Health, the Service licenses institutions and specialists, and approves medical devices
Netherlands 1979	Dutch Institute for Healthcare Improvement CBO www.cbo.nl/	Guideline development, visitation systems, indicator development and a national registry of quality indicators, methods and training
Poland 1994	National Centre for Quality Assessment in Health Care (statutory) www.cmi.pl	Support for local QA programmes, training, performance indicators, practice guidelines, technology assessment, voluntary accreditation of hospitals (since 1998) (42)
Portugal 1998	Instituto de Qualidade em Saude (IQS) www.iqs.pt	Clinical practice guidelines; "MoniQuOr" assessment and monitoring of organizational quality in health centres; development of hospital accreditation programme
Romania 2000	National Commission for Hospital Accreditation	Board represents MoH, doctors, insurers and hospital association; replaced sanitary authorization by MoH
United Kingdom	National Patient Safety Agency www.npsa.org.uk	Special health authority to coordinate United Kingdom efforts to report, and to learn from,

Source: Shaw and Kalo (2002).

Table 2.6 Agencies for the development of guidelines

Country	Title	Website
Austria	ITA (HTA Unit of the Institute of Technology Assessment – Austrian Academy of Science)	www.oeaw.ac.at/einheiten/ita
Denmark	DIHTA (Danish Institute for Health Technology Assessment)	www.dsi.dk/
Finland	FINOHTA (Finnish Office for Health Care Technology Assessment)	www.stakes.fi/finohta
France	ANAES (Agence Nationale d'Accréditation et d'Evaluation en Santé, France)	www.anaes.fr
Germany	German Scientific Working Group of Technology Assessment in Health Care	www.epi.mh-hannover.de/
Germany	Ärztliche Zentralstelle Qualitätssicherung ÄZQ	www.azq.de www.leitlinien.de
Italy	Agenzia per i Servizi Sanitari Regionali	www.assr.it
Netherlands	TNO Prevention and Health	www.tno.nl/instit/pg/index.html
Norway	SMM (The Norwegian Centre for Health Technology Assessment)	www.sintef.no/smm
Portugal	National Institute for Quality in Health, Portugal	www.iqs.pt
Russian Federation	Public Health Research Institute	
Spain	National HTA centre established 1994 by MoH; also regional centres for Catalonia, Basque Country, Andalusia	
Sweden	SBU (Swedish Council on Technology Assessment in Health Care)	www.sbu.se/sbu-site/index
Switzerland	Swiss Science Council/Technology Assessment	www.ta-swiss.ch
United Kingdom	Cochrane Centre: on-line publication "Bandolier"	www.jr2.ox.ac.uk/bandolier
United Kingdom	National Coordinating Centre for Health Technology Assessment	www.hta.nhsweb.nhs.uk
United Kingdom	NICE (National Institute for Clinical Excellence) 1998 (49)	www.nice.org.uk
United Kingdom	SIGN (Scottish Intercollegiate Guidelines Network)	www.sign.ac.uk
United Kingdom	NHS Centre for Reviews and Dissemination	www.york.ac.uk/inst/crd

Source: Shaw and Kalo (2002).

Another important national policy for LTC quality concerns the authorization/accreditation of private providers of LTC.

In the accreditation process two phases are mandatory:

- to fix quality standards;
- to check the respect of the standards by each provider.

Standards are developed and updated periodically by national or regional bodies, depending on the LTC system. Policy examples concerning quality standards are showed in Table 2.7.

Table 2.7 Policy examples aimed at improving quality standards

<ul style="list-style-type: none"> • Definition of general safety and quality requirements for institutions in both the private and public sectors, including long-term care institutions (e.g. AT, DK, DE, EE, HU, UK, NL, CZ, SK, MT, FI, LV, LU, LT, SI, PT, IT, PL, EL, SE), often associated with a health quality agency • Promote safety (e.g. safety of places, decrease hospital infections, care institutions infections and medical error) (PT, IT, IE, DE, FI, SE, NL) • Development of clinical practice guidelines, best-practice recommendations and service frameworks for staff (based on evidence-based care, clinical evaluation), including home help for medical and social care (AT, DK, EE, HU, UK, FR, BE, FI, LU, NL, PT, IE, PL, DE, SE). Guidelines sometimes freely accessible via internet and/or cd-rom • Provision of grants to support the implementation of standards (CY, NL, CZ, DE) • Transition period envisaged to adjust to requirements and guidelines (EE) • Development/implementation of accreditation/certification of institutions and staff based on national set of pre-determined standards (FR, BE, DK, DE, AT, CZ, SK, LV, PT, IT, IE, PL, EL, SE, NL) to ensure official state guarantee of adequate care. In some cases (FR, LV, DE, SE) accreditation/certification is compulsory and takes place routinely. Institutions define an accreditation steering team and project manager (IE), sometimes associated with an agency. Provisions regarding staff qualifications (PL) • Continuous staff training (BE, FR, FI, LU, HU, SE), namely via the establishment of a points system related to accreditation/certification or associated to the compulsory accreditation and certification process i.e. accreditation is based on training (BE) and via conferences, seminars, etc. (LU). Better training of hospital managers (PT) and setting up standards for corporate governance (IE) • Network of Health Promoting Hospitals whose hospitals are to promote a climate of good organisation (EE) • Establishing ethics commissions and the Ethics Charter to improve the humanisation of services (PT, DE, SE). Create a public relations office in each medical structure to gather patients' views and inform them of the services (IT) • Health forum (EL) for scientific and professional organisation in the areas to help define specifications/guidelines/recommendations/best practices • Mobilise executives from the business community to promote quality improvements, e.g. in logistics, patient safety, hospitality and accountability (NL) <p><i>Source:</i> European Commission (2008b).</p>

A view of current regulation and specific tools on LTC quality assurance in Europe is shown in tables 2.8 and 2.9, as reported by a survey performed in Work Package 1.

Table 2.8 Regulation of quality assurance in European Countries

Country	Institutional care	Home care	Home nursing care	Responsible party for regulation
Austria	Yes	Yes	Yes	Data not available
Belgium	Yes	Yes	Yes	Central government, provincial government
Bulgaria	Data not available	Data not available	Data not available	Data not available
Czech Republic	Partly	Yes	Yes	MoLSA

Denmark	Yes	Yes	Yes	Municipal Council
England	Yes	No	Yes	Central government plus specific technical bodies (Commission for Social Care Inspection, Care Quality Commission)
Estonia	Data not available	Data not available	Data not available	Data not available
Finland	Data not available	Data not available	Data not available	Data not available
France	Yes	No	No	State/provincial government
Germany	Yes	Yes	Yes	LTC funds are responsible for quality control, the Medical Review Board set up guidelines, the care providers are responsible for the quality of care in their institution
Hungary	Yes	No	Yes	Local/Municipal Government
Italy	Data not available	Data not available	Data not available	Data not available
Latvia	Yes	Yes	Yes	Data not available
Lithuania	Yes	Yes	Yes	Central government
Netherlands	Yes	Yes	Yes	Central government
Poland	Data not available	Data not available	Data not available	Data not available
Romania	Yes	No	Yes	Local/municipal government
Slovakia	Yes	Yes	Yes	Central government
Slovenia	Yes	Yes	Yes	Central government
Spain	Yes	Yes	Yes	State/provincial government
Sweden	Yes	Yes	Yes	Local/municipal government

Source: Work Package 1 data, modified.

Table 2.9 Tools of quality assurance in European countries

Country	Institutional care	Home care	Home nursing care
Austria	Structural quality: strictly criteria regarding size, furnishing and equipment of the rooms as well as infrastructure requirements Outcome quality: ongoing monitoring by a team consisting of a lawyer, an expert of care, medicine and psychology and a graduate social worker	Informal care: home visits by registered nurses (check on quality of care and offer of information) Formal care: visits by registered nurses, guidelines for professional home care and home help services, respite care, counselling and information for care giving relatives	Data not available

Belgium	Quality norms for infrastructure + qualification standards for nursing staff Annual quality control by regional administrative services	Data not available	Not available data
Bulgaria	Quality assurance committees; medicine and financial control departments at the insurance institution; Municipal commissions.	Data not available	Data not available
Czech Republic	Ministry of Health and health Insurance companies monitor quality of care	MoISA and regional authorities control quality of social services provided and fulfilment of contracts. The procedure of quality control is set by the State Control Act. The inspection services should be performed by a committee consisting of at least 3 members, not related to a service provider. Services are checked according to social services quality standards. A report should then be presented to interest parties.	
Denmark	The local authorities will set up quality standards for LTC provision, which are binding for all providers	Data not available	Data not available
England	All providers are assessed annually for quality assurance purposes and are given a star rating (excellent, good, adequate or poor). All registered providers are required to complete an AQAA (Annual Quality Assurance Assessment) form which is a self-assessment of performance. It asks providers to comment on how well they think they're meeting service users' needs and requires them to provide data about the service. The annual services review combines information from the AQAA with responses to a survey of service users and other information about the provider (e.g. from complaints) and show the rating assigned to each provider.	As for institutional care	Data not available
Estonia	Ministry of Social Care regulates quality assurance	Nothing	Data not available
Finland	Data not available	Data not available	Data not available
France	Contract of the institution with local government and Social and Health Department of the State services. This contract implies the respect of a price regulation	Agreement delivered by local government (departmental level)	Agreement delivered by Social and Health Department of the State

			services
Germany	On behalf of the Regional Associations of the LTC funds, the Medical Review Board of the Social Health Insurance and other bodies assume the technical monitoring of inpatient and outpatient facilities. From 2011, the facilities are inspected annually without prior notice. The inspection report must be published in understandable language and a summary of the current report visibly posted in each facility.	Data not available	Data not available
Hungary	Quality assurance system has two parts, an internal quality assurance system and the supervisory authority.	Data not available	Data not available
Italy	Data not available	Data not available	Data not available
Latvia	Ministry of social care regulate quality assurance	Nothing	Not available data
Lithuania	Not available data	Not available data	Not available data
Netherlands	Organisations that deliver care have to deliberate a policy to ensure the right care (effective, efficient, patient-centered and attuned to the realistic needs of the patient), to have a quality system to guard the quality and to make an annual report that has to sent to the Inspection for Health Care office	See institutional care	See institutional care
Poland	Data not available	Not available data	Data not available
Romania	Legislation sets minimum quality standard	Legislation sets minimum quality standard (only for formal care)	Legislation sets minimum quality standard
Slovakia	Provider must have at least 60/100 points in 24 criteria	Data not available	Provider must have at least 60/100 points in 24 criteria
Slovenia	No legal demands	No legal demands	Data not available
Spain	Quality standards established for the services included in a specific catalogue regulated by a national law. Residential centres for dependent persons will be subject to internal regulations governing organisation and functioning including a quality management system and establishing the participation of users.	See institutional care	See institutional care

Sweden	Comparative study and quality index	Comparative study and quality index	Comparative study and quality index
--------	-------------------------------------	-------------------------------------	-------------------------------------

Source: Work Package 1 data, modified.

The data shown in the previous tables can be summarised as follows:

- Legislation about quality in LTC has been reported in 16 out of 21 countries. The laws concern residential care in 16 out of 16 countries, home care in 12 out of 16 and home nursing care in 15 out of 16 cases. Level of regulation is the central government in 7 countries out of 16, local government in 3 out of 16 cases and central plus local authorities in 4 of 16 cases (in two countries the level has not been specified);
- Availability of quality assurance tools has been reported in 15 out of 21 countries. The more frequent and best described tools are: quality standard (fixed at central/local level), monitoring systems, inspections, internal quality management systems and public reporting of performance.

Another important national priority is the development of a quality monitoring system: a national body responsible for the periodical inspection of LTC organisations. The next table shows the frequency of data collection by Country according to a recent study (Du Moulin et al., 2010).

Table 2.10 Institutional LTC Quality monitoring

General characteristics of the quality frameworks.

Country	Name of the framework	Start date	Frequency of data collection
Austria [16-19]	Nationale Qualitätszertifikat für Alten-und Pflegeheime (National Quality Certificate for residential homes and nursing homes)	Pilot finished March 2009; implementation will follow	Once every 3 years
Germany [15,20,21]	MDK Qualitätsprüfungen der Pflegeheime (Medical Advisory Services of Social Health Insurance quality inspections in nursing homes)	July 2009	Once a year
Ireland [14,22,23]	National Quality Standards for residential care settings for older people in Ireland	July 2009	Once a year
The Netherlands [13,24,25]	Quality framework responsible care	May 2007	Once a year; patients' satisfaction once every 2 years
Sweden [26]	Elderly guide	2007	Once a year
UK			
England [27,28]	National Minimum Standards	June 2003	Varies from at least once every 3 years to twice a year
Northern Ireland [29,30]	Nursing Homes Minimum Standards	Planned for halfway 2010	Twice a year
Scotland [31,32]	National Care Standards	April 2008	Twice a year
Wales [33,34]	National Minimum Standards	June 2003	Varies (from at least twice a year to once every 3 years)
USA [35-37]	Minimum Data Set (MDS)/Nursing Home Compare	November 2002	At admission and quarterly thereafter

Source: Du Moulin et al. (2010).

Monitoring systems are needed to support quality evaluation, to promote informed policy and to provide feedback to the various actors in the field (EC, 2008). The EU Commission (2008) identified several policy examples regarding monitoring, as shown in Table 2.8.

Table 2.11 Policy examples regarding monitoring

- Inspection of facilities (UK, FR, NL, CZ, LV, IT, IE, DE, EL) and auditing providers' activities (EE, SK, MT, LU, PT). Inspection reports published (IE, EL, NL).
- Development, implementation and publication of activity indicators including quality dimensions and health outcomes (DK, HU, FR, BE, NL, CZ, MT, FI, LT, PT, IT, IE, PL).
- Use of questionnaires directed at institutions and their self-assessment (DK, FR, NL, IT), then reviewed by an independent institution.
- Establishment of councils to monitor / analyse staff and hospital conditions and activities (BE). Establishing a national health system and social solidarity observatory (EL) associated with the national health information system (EL).
- Peer review methods used to analyse activity (BE, NL), benchmarking (MT, IT, FI particularly of hospital performance data).
- Feedback or ratings (UK, BE, IT) and sometimes sanctions if activity is found to be well below the average (BE).
- Publish reports on the performance of medical departments (DK, NL, DE).
- Publish reports on certification and accreditation (FR).
- Regional mechanisms for continuous monitoring of quality of care (PL).
- Computerisation of system to improve data collection (EL) as well as improving the quality of the services.

Source: European Commission (2008), "Review of Preliminary National Policy Statements on Health Care and Long-Term Care".

2.5.3 Organisational level quality management

Quality assurance is the object of the quality management that can be defined as a "method to improve structures, process and results of any kind of service or product" (Nies et al., 2010).

Public authorities influence the organisation and behaviour of LTC providers by imposing specific quality assurance mechanisms: minimum standards of care, quality policies and recommendations, periodic reports and data flows.

LTC providers, due to market competition, are also induced to adopt quality control mechanisms beyond what is requested by the public authorities (third party certification).

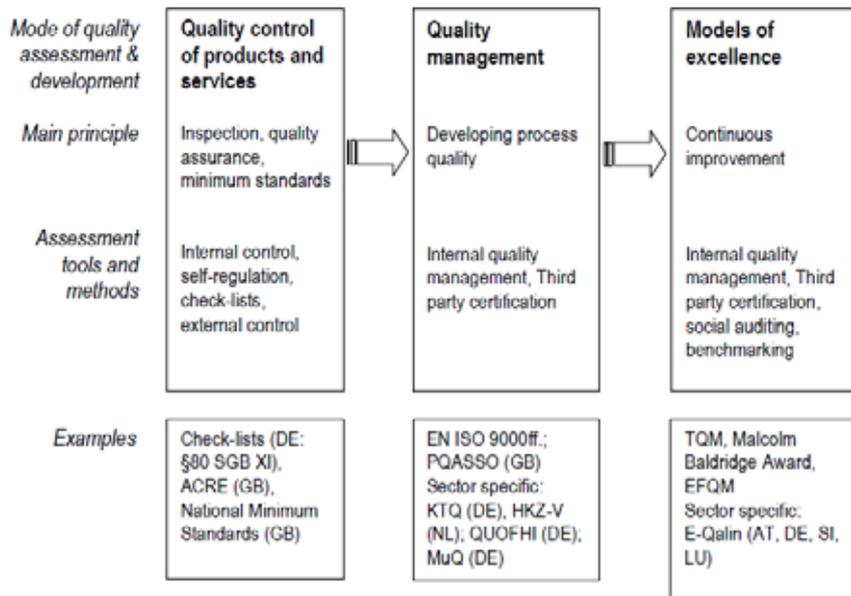
Huber et al (2006) produced a scheme (below) that synthesises different models of quality assurance. Quality control is a way to check if a system meets a given standard, e.g. if a LTC provider has no more beds than the number it is allowed to have. If not, specific interventions should be put in place to steer the system towards reaching the standard.

Quality management systems are based on the analysis of processes, that is, sets of activities transforming inputs into outputs. Mapping processes and their results is the way these systems assess that the necessary steps for providing the service take place.

Models of excellence are focused more on continuous improvements. Improvements derive from the monitoring of processes and from the analysis of errors. Errors should be analyzed immediately after their occurrence, in order to avoid the occurrence of further similar errors. In this way the sources of errors are traced down and eliminated once and for all. As an example,

if, in a facility, patients often fall while reaching the room bathroom, an analysis of the path to the bathroom or an assessment of the bathroom layout should be done in order to individuate and eliminate the cause of the falls.

Figure 2.2 Models of quality of care



Source: Huber et al. 2006.

Third party certifications, or voluntary certifications, for LTC and health care are:

- JCI: Joint Commission International has developed quality standards specifically for LTC organisations. “The Care Continuum standards, first published in 2003, are designed to assess a variety of community-based care settings such as: home care, assisted living, long-term care and hospice care. The standards have been equally applicable to social service models and medical care models of community based care. The standards address community care as a continuum of services between acute and non-acute community settings” (From: <http://www.jointcommissioninternational.org/Care-Continuum/>);
- ISO: the International Organisation for Standardisation provides standards against which organisations or functions may be certificated by accredited auditors. Although originally designed for the manufacturing industry (e.g. medicines, medical devices), these have been applied to health care, specifically to radiology and laboratory systems, and more generally to quality systems in clinical departments;
- European Foundation for Quality Management model: the Baldrige criteria for management systems have evolved from the United States into assessment programmes in Europe. Peer review collegial, usually single-discipline programmes assess and give formal accreditation to training programmes but are also extended to clinical services;
- Accreditation: independent, voluntary programmes developed from a focus on training into multidisciplinary assessments of health care functions, organisations and networks. Mandatory programmes have recently been adopted in France, Italy and Scotland;
- Registration and licensing: statutory programmes ensure that professional staff or provider organisations achieve minimum standards of competence (e.g. training,

registration, certification and revalidation); there are also function-specific inspectorates for public health and safety (e.g. fire, radiation and infection) in many countries;

- Peer review (Dutch *visitatie*): collegial, usually single-discipline programmes assess and give formal accreditation to training programmes but are also extended to clinical services.

2.5.4 User-level quality

In recent years, the role of the patient and the family in the success and quality of care is recognized of increasing importance (European Commission, April 2008; MISSOC, 2009). Patient value responsiveness and patient-centred approaches that take into account the satisfaction of patients and families with the experience of care are starting to diffuse across countries as indicators of quality of care. In this sense Sweden, where the monitoring of patient satisfaction in LTC is widespread across regions, is a benchmark in Europe.

Improving transparency and making better information available to users permits patients to make informed choices on the selection of LTC providers, thus increasing the involvement of the users in the LTC system.

Policy examples concerning patients' involvement and choice are summarised by a report of the European Commission (2008) in table 2.13.

Table 2.12 Policy examples associated with patient choice and involvement in LTC

- | |
|--|
| <ul style="list-style-type: none"> • Developing user friendly contact points (incl. web) with information on access, patient rights and complaining mechanisms (SE, UK, PT, DE). • Enlarging patient choice of provider: FI and IT are giving services vouchers to patients to buy home help or home nursing services that they can choose from the private sector. Personal budgets help choose long-term care providers (NL) • Choice of housing and choice of personal and practical help after an assessment of patients' needs (AT, DK, SK, DE). • Insured persons represented in the Health Insurance Institute Assembly and other public health institutes (SI, DE). Consumers represented in regional advisory and planning committees (IE). • Conducting patient satisfaction surveys (DK, EE, HU, MT, FI, IT, PL, DE) • Patient rights (to health and social services) and providers responsibilities are being established and better enforced through legislation and the development/improvement of more easily accessible mechanisms for complaint, sometimes involving patient councils or mediation service or the ombudsman (DE, DK, EE, AT, FR, HU, BE, NL, SK, FI, LU, PT, IT, IE, EL). A report with recommendations is to be submitted annually (BE, NL). • Patients are entitled to injury compensation associated with treatment (FI, PT, DE) • Community representatives are part of various committees and agencies (e.g. Local Health and Social Care Groups in the UK, MT) providing input to the planning and design of services in their areas. More involvement of consumer organisations (NL) • Patients' advocates (DE). Patients' discussion forum (MT). |
|--|

Source: European Commission (2008). Review of Preliminary National Policy Statements on Health Care and Long-Term Care.

2.5.5 Coordination of LTC providers

LTC, being inherently multidimensional, requires the integration of different providers, decisions, technologies, competencies. Coordination of LTC providers is therefore an essential requisite for a high quality LTC (MISSOC, 2009).

Coordination, in terms of the quality dimensions identified by Legido-Quigley et al. (2008) can be defined as composed of these issues:

- 1) *Timeliness*, which is the degree to which patients are able to obtain care promptly. Coordination of care is key for timeliness when a patient needs to go through different stages of care and across providers.
- 2) *Continuity*, or the extent to which health care for specified users, over time, is coordinated across providers and institutions.
- 3) *Integration* between primary and secondary care, and between health care and social care. Without this coordination quality may be undermined.

Coordination may be vertical or horizontal, or both. Vertical coordination integrates providers in primary, secondary, and tertiary care, or providers at the local, regional, and national levels. Horizontal coordination integrates providers at the same level of service, like health care and social services. In different countries there is a growing awareness that quality of LTC is based on an effective integration of health and social services. We think that coordination of care is therefore an important dimension for assessing the quality of LTC.

Examples of policies concerning care coordination in the specific field of chronic and long-term condition are listed in table 2.14.

Table 2.13 Policy examples related to care coordination in LTC

- | |
|---|
| <ul style="list-style-type: none"> • Evaluating each patient's needs and defining each patient care plan (with the various needs and care specified) (BE, DK, DE, EE, ES, SE, SK, FI, LV, PT, IT) • Provision of interdisciplinary care via interdisciplinary teams (e.g. BE, ES, EE, HU, FI, IT) • Case manager at the district level helping GP and patient to find the most appropriate care to the patient (IT). GP plays important role in ensuring integrated care (PL, DE) • Coordination between public institutions and different levels of public institutions (national, regional, local) for the provision of services (AT, SE, FI, LT, PL, IE namely with the redefinition of responsibilities). Cooperation also between municipalities, third sector organisations, voluntary workers and enterprises (FI, SI, PL, DE) |
|---|

Source: European Commission (2008). Review of Preliminary National Policy Statements on Health Care and Long-Term Care.

3. An Analysis of European Quality Policies in LTC

3.1 Data gathering: the survey

Based on the above review by LUISS, a survey was developed in order to obtain data about quality policies in different countries. LUISS developed the first version of the survey. Subsequent versions were fine-tuned by coordinators and the partners involved in WP5.

Each partner was responsible for collecting the answers in his/hers own country (with the exception of Praxis, which covered Estonia and Latvia, and ETLA, which covered Finland and Sweden). Data were collected from July 2010 to February 2011.

The survey questions are:

1. **QUALITY DOCUMENTS.** Please list below the references to all the public and official documents defining a national or regional vision, framework, or plans about LTC quality in your country (if you answer referring to a regional level, please specify what regions)
2. **QUALITY DIMENSIONS.** For each LTC type (Formal Institutional Care, Formal Home Care, Formal Home Nursing Care, Informal Home Care), please mark (with an X) whether or not the LTC quality policies in your country address the following quality dimensions at a national or a regional level (please specify what regions)
 - a. Effectiveness
 - b. Safety
 - c. Patient value responsiveness
 - d. Coordination
3. **NATIONAL QUALITY INDICATORS.** For each LTC type (IC, HC, HNC, informal care), please state which indicators are monitored by the public authorities in your country for each of the following LTC quality dimensions at a national level or a regional level.
 - a. Effectiveness
 - b. Safety
 - c. Patient value responsiveness
 - d. Coordination
4. **QUALITY ACCOUNTABILITY IN FORMAL CARE:**
 - a. Are public data about quality results of LTC providers available to the public?
 - i. Data are publicly available but aggregated at a national level
 - ii. Data are publicly available but aggregated at a regional level
 - iii. Data about each provider are publicly available
 - b. How frequently are data about quality results publicised? (mark with an X)
 - i. Once every 3 years
 - ii. Once every 2 years
 - iii. Once a year
 - iv. Twice a year
 - v. Other (please specify)
5. **QUALITY MEASURES.** For each quality indicator reported in question 3, please provide, if available, the measures of the last 4 years (include the source of data. Sources of data may be official statistics or research projects – like the SHARE project for those accessing SHARE data).
6. **MINIMUM QUALITY STANDARDS:** Based on the previous indicators (please copy and paste them on the second column) what are the minimum standards of quality (the thresholds) for the accreditation/authorisation of formal providers at a national level or a regional level (specify the region)?
7. **MONITORING SYSTEM FREQUENCY:** What is the frequency of inspections/data collection to monitor the quality standards of accreditation/authorisation? (Mark with an X)

- i. Once every 3 years
 - ii. Once every 2 years
 - iii. Once a year
 - iv. Twice a year
 - v. Other (please specify)
8. EXTERNAL PEER REVIEW FOR QUALITY CERTIFICATION: How many LTC institutions got a voluntary quality certification in your country? As a reference, please consider the following quality certifications for LTC institutions:
 - i. ISO
 - ii. European Foundation for Quality Management Model
 - iii. Joint Commission International
 - iv. Dutch visitatie
 - v. Australian Council on Health care Standards
 - vi. Canadian Council on Health Services Accreditation
 - vii. HKZ keurmerk , HKZ opstapcertificaten 1 en 2
 - viii. OTHER (Please specify)
 - ix. TOTAL
 - x. total number of LTC institutions in your country
9. QUALITY GUIDELINES: Have evidence-based guidelines on the following issues been developed and diffused to support high-quality LTC? Please mark with an X all those that apply
 - i. Risk management and malpractice
 - ii. Alzheimer's disease and dementia
 - iii. Fall prevention
 - iv. Pressure ulcers
 - v. Physical restraints
 - vi. Other (please specify)
10. LTC SPECIFIC EDUCATION: is it mandatory for the following LTC professions to attend educational programmes on the following issues? (please mark with an X)
 - i. General practitioner\ Family Physician\ Primary Care Physician
 - ii. Hospital physicians
 - iii. Social worker
 - iv. District nurses
 - v. Care managers and nurses
 - vi. Health educators
 - vii. Nurse practitioners
 - viii. Nursing staff
 - ix. Care workers or care assistants
11. QUALITY IN INFORMAL LTC: what strategies have been implemented in your Country to support informal care quality? (for each please provide examples)
 - i. Assessment of LTC needs and personalised self-care plans

- ii. Courses for informal care-givers (family members, friends, etc.)
 - iii. Statutory visits in the home environment by health and social care personnel
 - iv. Awareness raising campaigns about quality in LTC and home devices or technologies supporting self-care
 - v. Financial support for buying technologies for self-care and home devices
 - vi. Other (please specify)
12. TECHNOLOGY AND QUALITY: Please provide examples of any initiatives supporting the development and diffusion of technologies to improve the following LTC quality dimensions
- i. Effectiveness
 - ii. Safety
 - iii. Patient value responsiveness
 - iv. Coordination

3.2 Analyses

Input data: data is taken from the questionnaires filled by the partners from the 15 Countries participating to the study: Austria, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Poland, Slovakia, Slovenia, Spain, Sweden, the Netherlands, the United Kingdom.

In the following tables answers to survey questions are showed.

Table 3.1 Policies (P) about Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C), in Formal Institutional Care (FIC), Formal Home Nursing Care (FHNC), Formal Home Based Care (FHBC), Informal Home Care (IHC) (question 2)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK	TOTAL
P_E_FIC	1	1	1	1	1	1	1	1	0	1	0	1	1	1	1	13
P_E_FHBC	1	1	1	1	1	1	1	1	0	1	0	1	1	1	1	13
P_E_FHNC	1	1	1	1	1	1	1	1	0	0	0	1	1	1	1	12
P_E_IHC	0	0	0	0	1	0	0	0	0	1	0	1	1	0	0	4
P_S_FIC	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	15
P_S_FHBC	1	1	1	1	1	1	1	1	0	1	0	1	1	1	1	13
P_S_FHNC	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	12
P_S_IHC	1	0	0	0	0	0	0	0	0	0	0	1	1	0	0	3
P_R_FIC	1	1	1	1	1	1	0	1	1	1	0	1	1	1	1	13
P_R_FHBC	1	0	1	1	1	1	0	1	0	1	0	1	1	1	1	11
P_R_FHNC	1	1	1	1	0	1	0	1	0	0	0	1	1	1	1	10
P_R_IHC	1	0	1	0	0	0	0	0	0	0	0	1	0	0	0	3
P_C_FIC	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	14
P_C_FHBC	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	14
P_C_FHNC	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	12
P_C_IHC	0	0	1	0	0	0	0	0	0	0	0	0	1	0	1	3
tot	14	11	14	12	10	12	9	12	2	9	5	15	15	12	13	

Table 3.2 Indicators (I) about Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C), in Formal Institutional Care (FIC), Formal Home Nursing Care (FHNC), Formal Home Based Care (FHBC), Informal Home Care (IHC) (questions 3 and 5)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK	TOTAL
I_E_FIC	0	1	1	1	1	1	1	1	0	1	0	1	1	1	1	12
I_E_FHBC	0	0	1	1	1	1	1	1	0	1	0	0	1	1	1	10
I_E_FHNC	0	1	1	1	0	1	1	1	0	0	0	0	1	1	1	8
I_E_IHC	0	0	1	0	0	0	0	0	0	1	0	0	1	0	0	3
I_S_FIC	0	1	0	1	1	1	0	1	1	1	0	1	1	1	1	11
I_S_FHBC	0	1	0	1	1	0	0	0	0	1	0	1	1	1	1	8
I_S_FHNC	0	1	0	1	0	0	0	1	0	0	0	1	1	1	1	6
I_S_IHC	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	2
I_R_FIC	0	1	0	1	1	0	0	1	1	1	0	1	1	1	1	10
I_R_FHBC	0	0	0	1	1	0	0	1	0	1	0	0	1	1	1	7
I_R_FHNC	0	1	0	1	0	0	0	0	0	0	0	0	1	1	1	4
I_R_IHC	0	0	0	0	0	0	0	0	0	1	0	0	1	0	0	2
I_C_FIC	0	0	0	1	1	0	1	1	0	1	0	0	1	1	0	7
I_C_FHBC	0	0	0	1	1	0	1	1	0	0	0	0	1	1	0	6
I_C_FHNC	0	0	0	1	0	0	1	1	0	0	0	0	1	1	0	4
I_C_IHC	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	2
Tot	0	7	4	12	8	4	6	10	2	9	0	6	16	12	10	

Table 3.3 National visibility of providers' quality indicators (question 4) and monitoring frequency (in years) for authorisation/accreditation (question 7)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK
National visibility	0	0	0	0	1	1	0	1	0	0	0	0	1	1	1
Monitoring freq. (years)	5	1	na	7	3	2	5	5	na	1	3	na	na	1	5

Table 3.4 Development (dev) and dissemination of guidelines (GL) about Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C), and the presence of a national agency for disseminating (diss) guidelines and monitoring guideline implementation (question 9)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK	TOTAL
GL_E_dev	1	1	0	1	1	1	1	1	0	1	0	1	1	1	1	12
GL_S_dev	1	1	0	1	1	1	1	1	0	0	0	1	1	1	1	10
GL_R_dev	1	1	0	1	1	1	1	0	0	0	0	0	0	1	1	8
GL_C_dev	1	1	0	1	1	1	0	0	0	0	0	1	0	1	1	9
GL_E_diss	1	1	0	0	1	1	0	1	0	1	0	1	1	1	1	10
GL_S_diss	1	1	0	0	1	1	0	1	0	0	0	1	0	1	1	8
GL_R_diss	1	1	0	0	1	1	0	0	0	0	0	0	0	1	1	6
GL_C_diss	1	1	0	0	1	1	0	0	0	0	0	1	0	1	1	7
GL_agency_diss	1	1	0	1	1	0	0	1	0	1	0	1	1	1	1	10
GL_agency_monitor	0	1	0	1	1	0	0	0	0	1	0	1	1	0	0	6

Table 3.5 Is it mandatory for the following LTC professions to attend educational programmes on LTC issues? (question 10)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK	TOTAL
Edu_GP	1	1	1	0	0	0	1	1	0	1	1	1	1	1	0	10
Edu_Hospital _physician	1	1	1	0	0	0	1	1	0	1	1	1	1	1	0	9
Edu_Social _worker	0	1	1	1	0	0	0	1	0	0	1	1	1	0	0	7
Edu_district _nurse	0	1	1	1	0	0	0	1	0	1	1	1	1	0	0	8
Edu_care _manager	1	1	0	1	1	0	0	0	0	0	1	0	1	0	0	6
Edu_health _educator	1	0	0	1	1	0	0	0	0	1	0	1	1	0	0	6
Edu_nurse _practitioner	1	1	0	1	1	0	0	1	0	1	1	1	1	0	0	9
Edu_nursing _staff	1	1	0	1	1	0	1	1	0	1	1	1	1	0	0	10
Edu_care _worker	1	1	0	1	1	0	1	1	0	0	0	1	1	1	0	8

Table 3.6 Policies supporting quality of informal care

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK	TOTAL
Assessment of LTC needs and personalised self-care plans	1	1	1	1	0	0	0	0	0	1	0	0	1	1	1	8
Courses for informal care-givers	1	1	1	0	1	0	1	1	0	1	0	0	1	1	1	10
Statutory visits in the home environment by health and social care personnel	1	0	1	0	1	0	0	0	0	1	0	0	1	0	0	5
Awareness raising campaigns about quality	0	1	1	1	1	0	1	1	0	1	0	0	1	1	1	10
Financial support for buying technologies for self-care and home devices	1	1	1	1	1	0	1	1	0	1	0	0	1	1	1	11
Other	0	0	0	0	0	0	0	1	0	1	0	0	1	1	0	4

Table 3.7 Initiatives supporting the use and diffusion of technology for the improvement of Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C) (question 12)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK
Tech_E	0	1	0	0	1	1	1	1	0	0	0	0	1	1	1
Tech_S	1	1	0	0	1	0	1	0	0	0	0	0	1	1	1
Tech_R	1	0	0	0	1	1	1	0	0	0	0	0	1	1	1
Tech_C	0	1	0	0	1	1	1	0	0	1	0	0	1	1	1

Some of the variables used in the survey have been synthesised to include them in the analyses. In particular:

- Policies about quality dimensions such as Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C) vary from 0 to 4, depending on to how many organisation types they are applied to.
- Policies for Formal Institutional Care (FIC), Formal Home Nursing Care (FHNC), Formal Home Based Care (FHBC), Informal Home Care (IHC) also vary from 0 to 4 depending on to how many quality dimensions they refer.
- Indicators about quality dimensions such as Effectiveness (E), Safety (S), Responsiveness (R), Coordination (C) vary from 0 to 4, depending on to how many organisation types they are applied to.
- Indicators for Formal Institutional Care (FIC), Formal Home Nursing Care (FHNC), Formal Home Based Care (FHBC), Informal Home Care (IHC) also vary from 0 to 4 depending on to how many quality dimensions they refer to.

In the analysis three variables gathered in WP1 have been included:

- O4: Choice of providers (Can recipients choose the provider freely in FIC/HBC):
 - Value 1: Free provider choice in both, FIC and HBC
 - Value 2: No provider choice in FIC, free provider choice in HBC
 - Value 3: No provider choice in both, FIC and HBC
- O5: Quality assurance (Quality assurance in FIC/HC/HNC is mandatory OR not mandatory)
 - Value 1: Mandatory quality assurance in both, FIC and HBC
 - Value 2: Mandatory quality assurance in FIC or HBC
 - Value 3: No mandatory quality assurance in both, FIC and HBC
- O6: Integration (Quality of coordination BETWEEN LTC and other services is ...)
 - Value 1: rather good – there might be some organisational challenges for the individual but they are usually not too severe
 - Value 2: rather poor – provision of care is fragmented and often can pose a challenge for (prospective) care recipients
 - Value 3: very poor – provision of care is very fragmented and poses regular or severe challenges for (prospective) care recipients

Moreover, three variables from the data included in Deliverable 5.2 have been included:

- Percentage of input quality indicators
- Percentage of process quality indicators
- Percentage of outcome quality indicators

The variables included in the analyses are shown in the following table:

Table 3.8 Variables included in the analyses

National visibility of quality performance	Quality Indicators Patient Value
Frequency of monitoring for confirming accreditation/ authorisation to FIC (in years)	Quality Indicators Coordination
Quality guidelines effectiveness	Quality Policies Formal Institutional Care
Quality guidelines safety	Quality Policies Formal Home Based Care
Quality guidelines responsiveness	Quality Policies Formal Home Nursing Care
Quality guidelines coordination	Quality Policies Informal Home Care
WP1 Choose FIC/HBC	Quality Indicators Formal Institutional Care
WP1 assurance mandatory	Quality Indicators Formal Home Based Care
WP1 coordination between LTC and other services	Quality Indicators Formal Home Nursing Care
Quality Policies Effectiveness	Quality Indicators Informal Home Care
Quality Policies Safety	Proportion of quality indicators on inputs (scale 0-4), based on data in del. 5.2
Quality Policies Patient value	Proportion of quality indicators on processes (scale 0-4) based on data in del. 5.2
Quality Policies Coordination	Proportion of quality indicators on outcomes (scale 0-4) based on data in del. 5.2
Quality Indicators Effectiveness	LTC specific education mandatory for how many LTC roles
Quality Indicators Safety	

The variables pertaining the quality policies, quality indicators, the characteristics of the technology, the main dimensions from the WP1 (Tab. 1) have been synthesised by a multiple correspondence analysis (final dimensions selected by Cronbach's Alphas). Overall, we found three factors explaining 50.4% of the variance.

Countries were then classified on the basis of the highest similitude respect to the synthetic dimensions extracted by the correspondence analysis, using the hierarchical cluster analysis.

3.3 Results

The correspondence analysis extracted three synthetic dimensions, which express 50.4% of the total variance; the factors composition and their individual contribution to variance are shown in the following table.

Table 3.9 Factors

Factor 1		Factor 2		Factor 3	
Quality Policy FIC	1.524	Education mandatory for how many LTC roles	.892	Quality Indicators Effectiveness	.777
Quality guidelines effectiveness	1.454	Quality Policy FHNC	.871	Quality Indicators FHNC	.745
WP1 assurance mandatory	1.194	Frequency of monitoring FIC (in years)	.793	Quality Indicators Coordination	.658
Quality guidelines safety	1.076	Quality Indicators FIC	.566	Quality Indicators Formal Home Based Care	.600
Quality Policy Responsiveness	1.006	WP1 Choose FIC/HBC	.531	Quality Indicators Informal Home Care	.479
Quality Policy Safety	.956	Quality Policy IHC	.517	Proportion of indicators on inputs	.453
Proportion of indicators on outcomes	.743	Quality Policy Coordination	.473	Quality Policy Effectiveness	.312
Quality Policy FHBC	.734	Proportion indicators on processes	.291	WP1 coordination LTC-other services	.309
Quality Indicators Responsiveness	.586				
Quality guidelines Responsiveness	.539				
Quality Indicators Safety	.509				
Quality guidelines coordination	.501				
National visibility of quality performance	.448				

Factor 1 includes variables related mostly to formal services (FIC, FHBC), to outcomes (effectiveness, responsiveness) and guidelines.

Factor 2 includes variables about input indicators (education of personnel) and process indicators (proportion of process indicators) across all organisation types (including informal care).

Factor 3 includes mostly quality indicators across all organisation types.

By crossing the 3 factors we obtain the following pictures.

Figure 3.1 Factor 1 (x) Factor 2 (y)

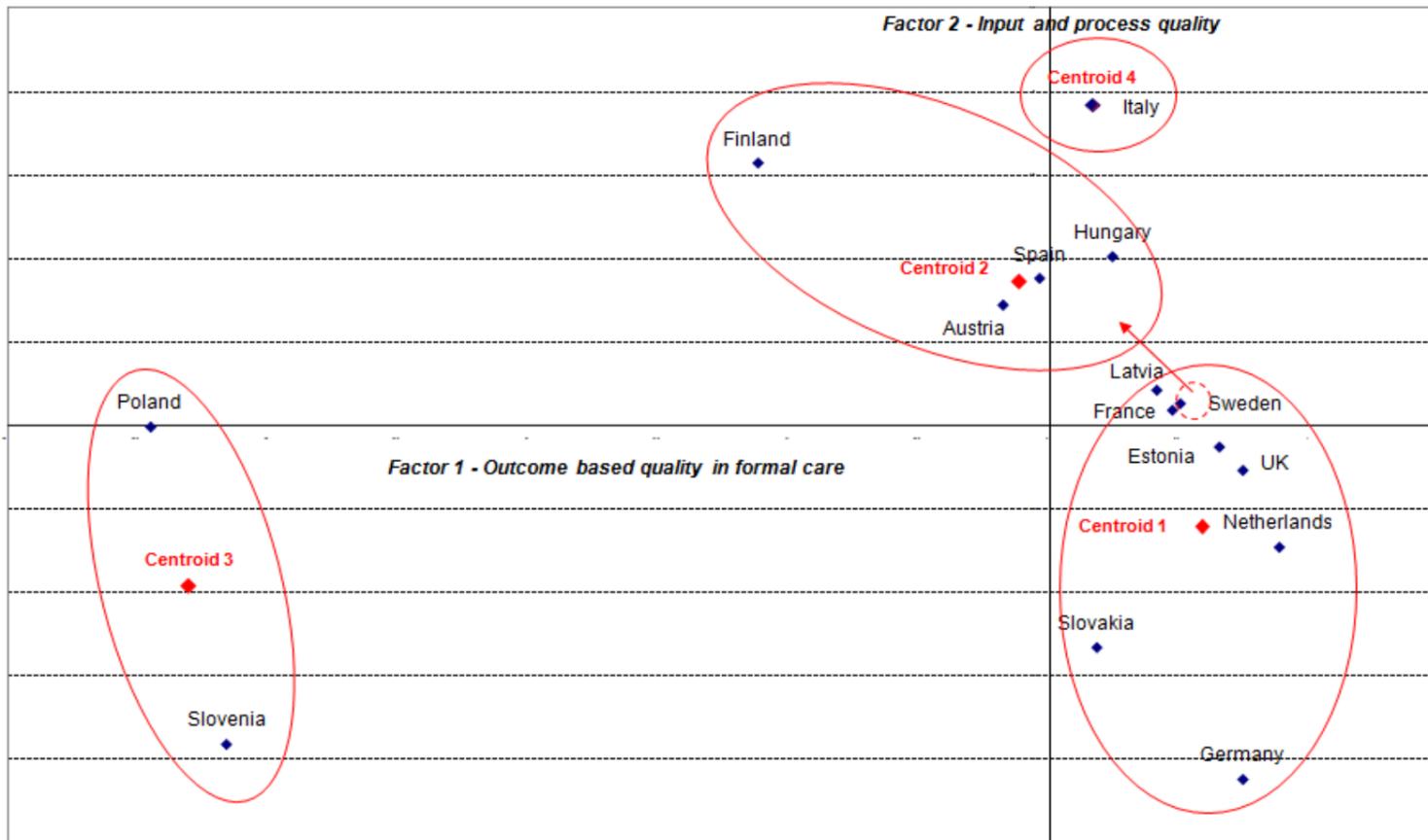


Figure 3.2 Factor 1 (x) Factor 3 (y)

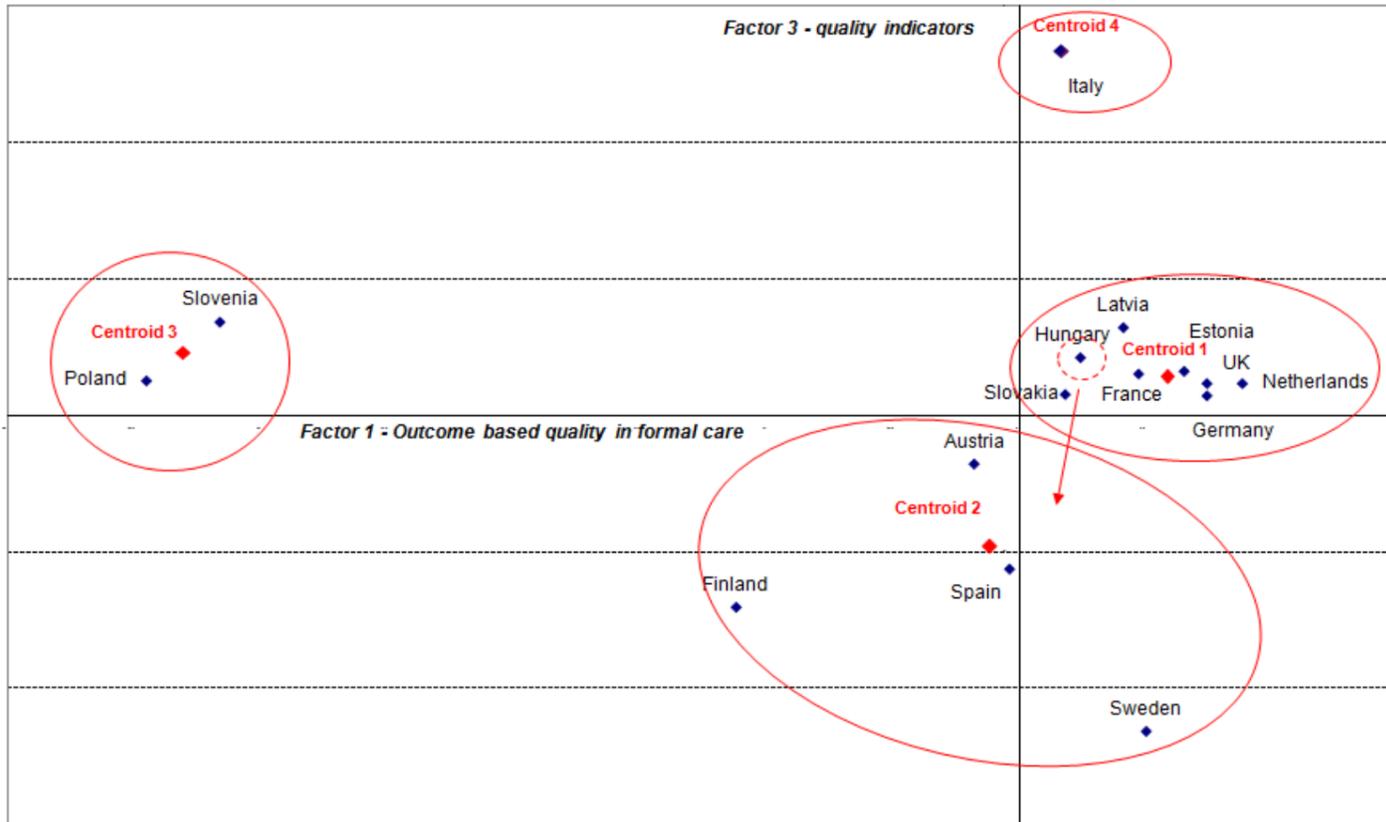
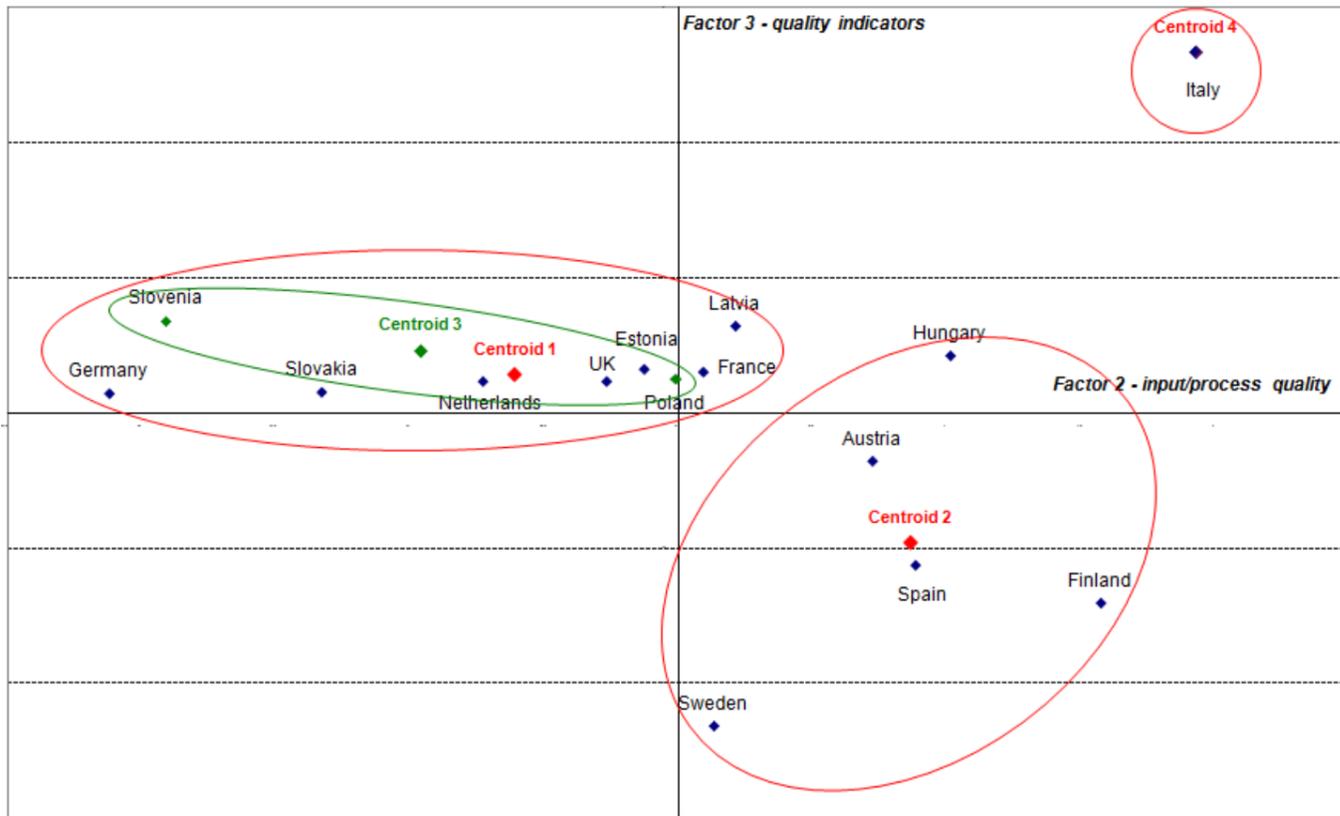


Figure 3.3 Factor 2 (x) Factor 3 (y)



In fig. 3.1, on the right side we find those countries with a high propensity for quality policies regarding formal care (institutional and home-based) and for outcome indicators (Factor 1), while on the upper side there are those countries that based their quality policies more on quality policies about input and processes than on other variables.

On the lower right we find a large group of countries (around a centroid point) including central/north European Countries, such as Germany, the Netherlands, Slovakia, and Estonia. Sweden is also part of this group but it has an arrow pointing towards another group, which is more explained by Factor 2 (input and process indicators). This means that Sweden, alone in its group, has a behaviour that is also explained by Factor 2.

This second group is composed of countries such as Spain, Hungary, Austria, and Finland. They rely on input-process indicators and policies across all types of organisation. On the upper right side, Italy makes up a group on its own.

On the opposite side, Slovenia and Poland are together in a group that is at some distance from the others. This means that the characteristics of the other groups do not explain their behaviour. As a matter of fact, Slovenia and Poland have the fewest quality policies and indicators among all countries. They are characterised by the lack of quality policies and indicators.

By crossing factors 1 and 3, we find that the first larger group (the one including the Netherlands, Germany, and the UK, among others) is characterised by both factors (outcome indicators for formal care and quality indicators in general). With the exception of Sweden, which is more focused on outcome indicators. Also, in this chart Hungary belongs to the first group but has an arrow pointing to another group (Finland, Spain, Austria), which is explained by the lack of the features of factors 1 and 3. In fact, we already know these countries are more related to factor 2.

In the figure about factors 2 and 3 we find the same group (Finland, Spain, Austria, Sweden) being characterised by factor 2 only (except Hungary which is just over the line, thus being very slightly characterised by factor 3).

By looking at these pictures it is evident that there are 4 clusters of countries, and that each group is characterised by a main factor and, to a lesser extent, by the others.

In fact, if every cluster is mainly defined by one main characterising factor, in some cases other factors can contribute to improving the description of the cluster, when the main factor presents a low value. In this case, the secondary factors don't change the main classification but must be considered an add-on in interpreting the position of the single cases (i.e. the nations) inside the classification.

Hereafter, this situation is manifested for Latvia (classified by the factor 1 but whose description is improved by the factor 3) and Sweden (classified by the factor 2, but whose description is improved by factor 1).

In Table 3.10 all the clusters are related to each factor. Through the cluster analysis other discriminatory (significant) variables related to each cluster are identified. This means that each cluster is characterised by the dominant factor(s) and the discriminatory variables. These variables have been selected by testing the odds ratio coming from the logistic regression, in which belonging to the cluster is the dependent variable and the single variables the dependent ones. The variables, whose odds ratio was statistically significant higher than 1, are the discriminatory ones.

Table 3.10 Cluster analysis

Clusters	Countries	Related Factors	Factor value by Country	Discriminant variables ($p \leq 0.05$)
Cluster 1	Estonia	Factor 1 (Latvia also Factor 3)	0.65	Quality guidelines effectiveness: Yes
	France		0.47	Quality Policy Effectiveness: Policies about effectiveness for 3 types of organisations
	Germany		0.74	Quality Policy Safety: Policies about safety for 3 types of organisations
	Latvia		0.41 (0.64)	Quality Policy Responsiveness: Policies about patient value for 2/3 types of organisations
	Netherlands		0.88	Quality Policy FIC: Policies about FIC for 4 types of dimensions
	Slovakia		0.18	Quality Policy FHBC: Policies about FHBC for 4 types of organisations
	UK		0.74	Quality Policy FHNC: Policies about FHNC for 4 types of organisations Quality Policy FHBC: Indicators about FHBC for 3/4 types of organisations Quality Policy FHNC: Indicators about FHNC for 0 or 3 types of organisations
Cluster 2	Austria	Factor 2 (Sweden also Factor 1)	0.72	Quality guidelines effectiveness: Yes
	Finland		1.57	Quality Dimension Effectiveness: Policies about effectiveness for 3/4 types of organisations
	Hungary		1.01	Quality Dimension Safety: Policies about safety for 4 types of organisations
	Spain		0.88	Quality Dimension Responsiveness: Policies about responsiveness for 4 types of organisations
	Sweden		0.13 (0.50)	Quality Dimension FIC: Policies about FIC for 4 types of organisations Quality Dimension FHBC: Policies about FHBC for 4 types of organisations Quality Dimension FHNC: Policies about FHNC for 4 types of organisations Quality Indicators FHBC: Indicators about FHBC for 1 types of organisations Quality Indicators FHNC: Indicators about FHNC for 1 types of organisations
Cluster 3	Poland	Factor 3	0.25	Quality guidelines effectiveness: No
	Slovenia		0.68	Quality Dimension Effectiveness: Policies about effectiveness for 0 types of organisations Quality Dimension Safety: Policies about safety for 1/2 types of organisations Quality Dimension Responsiveness: Policies about responsiveness for 0/1 types of organisations Quality Dimension FIC: Policies about FIC for 2 types of organisations Quality Dimension FHBC: Policies about FHBC for 0/1 types of organisations Quality Dimension FHNC: Policies about FHNC for 0 or 2 types of organisations Quality Indicators FHBC: Indicators about FHBC for 0 types of organisations Quality Indicators FHNC: Indicators about FHNC for 0 types of organisations

Cluster 4	Italy	Factor 3	2.67	Quality guidelines effectiveness: Yes Quality Dimension Effectiveness: Policies about effectiveness for 3 types of organisations Quality Dimension Safety: Policies about safety for 3 types of organisations Quality Dimension Responsiveness: Policies about patient value for 0 types of organisations Quality Dimension FIC: Policies about FIC for 3 types of organisations Quality Dimension FHBC: Policies about FHBC for 3 types of organisations Quality Dimension FHNC: Policies about FHNC for 3 types of organisations Quality Indicators FHBC: Indicators about FHBC for 2 types of organisations Quality Indicators FHNC: Indicators about FHNC for 2 types of organisations
-----------	-------	----------	------	--

- Cluster 1 is characterised by formal types of LTC, both residential and at home, outcome-related policies and indicators, and guidelines. It is composed of countries in the north and centre of Europe. Latvia is also characterised by factor 3.
- The second cluster has also a focus on formal care, but relies more on monitoring processes and quality of inputs differently from cluster one.
- Poland and Slovenia (cluster 3) are together mainly because they lack of many variables present in other clusters. They are characterised by the lack of many national policies for quality in LTC.
- Italy (group 4) may be interpreted as a country with some indicators about formal LTC across different dimensions but responsiveness.

Below we compare these results with the clusters found in WP1. In WP1 (Kraus et al, 2010), clusters based on use and financing of care were:

Table 3.11 WP1 clusters based on LTC use and financing

Cluster 1: Belgium, Czech Republic, Germany, Slovakia	Oriented towards informal care, low private financing (low spending, low private funding, high IC use, high IC support, cash benefits modest)
Cluster 2: Denmark, the Netherlands, Sweden	Generous, accessible, and formalised (high spending, low private funding, low IC use, high IC support, cash benefits modest)
Cluster 3: Austria, Finland, France, Spain, United Kingdom	Oriented towards informal care, high private financing (medium spending, high private funding, high IC use, high IC support, cash benefits high)
Cluster 4: Hungary, Italy	High private financing, informal care seems a necessity (low spending, high private funding, high IC use, low IC support, cash benefits medium)

Source: Krause et al. (2010: 44).

The following figure shows the comparison between the WP1 and WP5 clusters. Clusters of the same colour in both WP1 and WP5 belong to the same clusters.

Some countries belonging to WP1 cluster 1 (Germany, Slovakia, Estonia) and others to WP1 cluster 3 (France and the UK) correspond in WP5 to cluster 1, which is characterised by formal care, outcomes, guidelines. These countries, as by description of WP1 clusters 1 and 3, present a high use and high support to informal care. However, in WP5 they do not support a similar strategy as for quality policies and indicators. Apparently, there is a gap to be filled in these countries: since informal care is that important, quality strategy ought to be developed in this field.

The Netherlands, by contrast, is perfectly consistent with its strategy. In WP1 it belongs to cluster 2, which is generous in public spending and invests a lot in formal LTC (both residential and home care). This is consistent with its belonging to WP5 cluster 1, where the quality of formal care is a key factor.

As for their use of informal care, also Austria, Spain, and Finland (WP1 cluster 3) would be expected to invest in the quality of informal care. This is to a slight degree the case since they belong to WP5 cluster 2, which is mainly characterised by input-process indicators but also by quality policies for informal care.

Poland and Slovenia, since they focus on private spending, consistently do not have many national quality policies and indicators. Italy also well relies on private spending and informal care but has not developed policies on informal care.

Figure 3.4 Comparison between WP1 clusters based on use and financing and WP5 clusters (same colour countries are those belonging to same clusters in WP1 and WP5)

In WP1, the other types of clusters were based on LTC organisational depth and financial generosity. *Organisational depth* includes variables such as: means-tested access to publicly financed FIC/HBC; presence of an entitlement that applies to FIC/HBC/HBNC; availability of cash benefits; free choice of providers; quality assurance in FIC/HBC/HBNC is mandatory; quality of coordination between LTC and other services (rather good, rather poor, and very poor). *Financial generosity* includes cost-sharing in FIC/HBC/HBNC and public expenditure (Kraus et al. 2010: 17).

Below are the features of WP1 clusters based on organisational depth and financial generosity:

Table 3.12 WP1 clusters based on LTC organisational depth and financial generosity

Cluster 1: Belgium, Denmark, France, Germany, the Netherlands, Sweden (corresponds to WP1 cluster 2 based on LTC use)	High organisational depth, high financial generosity.
Cluster 2: Austria, Finland, Italy, Latvia, Slovenia, Spain, UK (corresponds to WP1 cluster 3 based on LTC use)	Medium organisational depth, medium financial generosity.
Cluster 3: Bulgaria, Estonia, Czech Republic, Slovakia (corresponds partly to WP1 cluster 1 based on LTC use)	High organisational depth, low financial generosity
Cluster 4: Hungary, Lithuania, Poland, Romania (corresponds in part to WP1 cluster 4 based on LTC use)	Low organisational depth, low financial generosity

Source: Kraus et al. (2010: 19 and 37).

Below, the comparison between WP1 clusters based on organisational depth and financial generosity and WP5 clusters.

Figure 3.5 Comparison between WP1 clusters based on organisational depth and financial generosity and WP5 clusters (same colour Countries are those belonging to same clusters in WP1 and WP5)

	Country	Cluster WP1	Cluster WP5		
C3: High organizational depth, low financial generosity	Estonia	3	1	} C1 Formal LTC / outcome	
	Slovakia	3	1		
	Germany	1	1		
C1: High organizational depth, high financial generosity	Netherlands	1	1		
	France	1	1		
	UK	2	1		
C2: Medium organizational depth, medium financial generosity	Latvia	2	1		} C2 Formal LTC /input process
	Sweden	1	2		
	Austria	2	2		
	Finland	2	2		
	Spain	2	2		
C4: low organizational depth, low generosity	Hungary	4	2	} C3: No policies C4: indicators / no responsiveness	
	Slovenia	2	3		
	Poland	4	3		
	Italy	2	4		

Estonia and Slovakia (WP1 cluster 3), Germany, the Netherlands, and France (WP1 cluster 1) all belong to WP5 cluster 1 (outcome-based quality of formal care). This is consistent with their high organisational depth.

Austria, Finland, and Spain are again together in WP1 cluster 2 (medium organisational depth and generosity) and in WP5 are in cluster 2 (input-process indicators and informal care policies).

Poland has low organisational depth and low generosity and consistently makes little effort in terms of national policies for quality in LTC. Slovenia, even if with a medium organisational depth and generosity, lacks quality policies for LTC.

Finally, Italy is medium in organisational depth and generosity, and developed some policies and indicators, even if it is not so modern as to include responsiveness issues. Responsiveness may be a luxury when the LTC system is not highly generous.

4. Conclusions

According to the World Health Organisation (2002) the goal of Long-Term Care (LTC) is

“to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity”.

Unlike acute care, LTC does not eliminate disease but aims to alleviating suffering, reduce discomfort, improve the limitations caused by disease and disability, and maintain the best possible levels of people’s physical and mental functioning.

These aims encompass a broad mix of services such as personal care, health care, life management (e.g. shopping, medication management, and transportation), and resources such as assistive devices (e.g. canes and walkers), more advanced technologies (e.g. emergency alert systems and computerised medication reminders), and home modifications (e.g. ramps and hand rails). Also, as for the settings, LTC may be institutional or home-based, and formal and/or informal.

Also, unlike the acute sector, many LTC professionals are unspecialised, and relatively unskilled. The sector is labour-intensive. Most LTC activities are performed by paraprofessionals with a variety of skills (home assistants, housekeepers, nurse assistants, activities staff, or informal caregivers). Skilled workers (nurses, physicians, etc.) are involved to a lesser degree than in acute care. Medical devices are also significantly less complex and costly than those used for acute care. Many of the core LTC activities are concerned with helping with basic functioning or with improving patient autonomy in performing the basic or instrumental activities of daily living.

Any approach for assessing quality of LTC needs to recognise all these differences from acute care. In particular (IOM, 2000):

- Long-term care is both a health and a social issue. For the health services components of long-term care, judgments about quality of care may emphasise medical and technical aspects of care. For other aspects of long-term care, judgments about quality of care reflect the opinions and satisfaction of consumers.
- The potential and actual role of consumers is an essential element in long-term care. Thus, the desired health outcomes depend on patients’ perspectives and level of engagement.

- For nursing homes and residential care settings including assisted living, the physical environment of the facility can contribute to the physical safety and functional mobility of residents and, more broadly, to their quality of life.
- The very characteristic of LTC, that is the persistent nature of the disabilities and chronic conditions in question, has an impact on: i) the development of interpersonal relationships among providers, families, and patients; ii) the physical adaptation of the home or the infrastructure of facilities to accommodate or attend to patients on a long-term basis; iii) the greater need for coordination between different segments of carers.

In WP 5 of the ANCIEN project we took into account all these variables in understanding the different national approaches to promoting the quality of LTC. A caveat is that having a sound quality policy does not automatically guarantee that a country will actually have high quality LTC in place.

We defined quality as a multi-dimensional concept encompassing: effectiveness of care, patient safety, responsiveness (or patient-centeredness), and coordination of providers. The first three dimensions have been identified by the OECD (Arah et al. 2006) as the main issues of any quality approach in health care. We included coordination as a fourth dimension because we believe that quality in LTC, given the complexity of LTC, has to include the coordination of different providers. Continuity of care (across social and health care and across levels of care) is a key issue in ensuring the quality of LTC.

As was to be expected, there is a great variety of policy measures across European countries (and within countries in some cases). Comparisons among quality policies of EU member states are difficult because (EC, 2008b):

- Member states use a variety of definitions of LTC that do not always concur.
- There are different levels of organisation and different divisions of responsibility among public and private sector and family;
- There are different interventions addressed to the elderly and their families that may be related to LTC systems: prevention measures, active ageing, autonomy promotion and empowerment, social assistance, family support, etc.

The analysis of the context for quality policies is therefore key to understanding quality policies across countries. The context has been analysed in WP1 of the ANCIEN project (Kraus et al. 2010). WP1 identified four clusters of countries according to the type of use of LTC and financing systems (Table 1) and four clusters according to LTC organisation and public spending on LTC (Table 2).

Table 4.1 Country clusters based on LTC use and financing

Cluster 1: Belgium, Czech Republic, Germany, Slovakia	Oriented towards informal care, low private financing (low spending, low private funding, high IC use, high IC support, cash benefits modest)
Cluster 2: Denmark, the Netherlands, Sweden	Generous, accessible, and formalised (high spending, low private funding, low IC use, high IC support, cash benefits modest)
Cluster 3: Austria, Finland, France, Spain, UK	Oriented towards informal care, high private financing (medium spending, high private funding, high IC use, high IC support, cash benefits high)
Cluster 4: Hungary, Italy	High private financing, informal care seems a necessity (low spending, high private funding, high IC use, low IC support, cash benefits medium)

Source: Markus Kraus, Monika Riedel, Esther Mot, Peter Willemé, Gerald Röhring and Thomas Czipionka, *A Typology of Long-Term Care Systems in Europe*, ENEPRI Working Paper No. 91, Centre for European Policy Studies, Brussels, August 2010.

Table 4.2 Country clusters based on LTC organisational depth and financial generosity

Cluster 1: Belgium, Denmark, France, Germany, the Netherlands, Sweden (corresponds to WP1 cluster 2 based on LTC use)	High organisational depth, high financial generosity.
Cluster 2: Austria, Finland, Italy, Latvia, Slovenia, Spain, United Kingdom (corresponds to WP1 cluster 3 based on LTC use)	Medium organisational depth, medium financial generosity.
Cluster 3: Bulgaria, Estonia, Czech Republic, Slovakia (corresponds partly to WP1 cluster 1 based on LTC use)	High organisational depth, low financial generosity
Cluster 4: Hungary, Lithuania, Poland, Romania (corresponds in part to WP1 cluster 4 based on LTC use)	Low organisational depth, low financial generosity

Source: Markus Kraus, Monika Riedel, Esther Mot, Peter Willemé, Gerald Röhring and Thomas Czipionka, *A Typology of Long-Term Care Systems in Europe*, ENEPRI Working Paper No. 91, CEPS, August 2010.

In WP5 we also identified four clusters based on quality policies across countries.

Table 4.3 Country clusters based on LTC quality policies and indicators

Cluster 1: Estonia, France, Germany, Latvia, the Netherlands, Slovakia, United Kingdom	Quality policies on formal LTC, both residential and at home; outcome related policies and indicators; and guidelines on quality of LTC. Latvia actually belongs to cluster 1 but presents features of cluster 2 as well.
Cluster 2: Austria, Finland, Hungary, Spain, Sweden	Quality policies on formal LTC, as in cluster 1, but with a focus on monitoring quality of processes and inputs rather than outcomes. Some policy about quality of informal care is present.
Cluster 3: Poland, Slovenia	Lack of quality policies and indicators
Cluster 4: Italy	Quality policies and indicators about formal LTC; presence of guidelines on quality of LTC; lack of policies and indicators on responsiveness to patient needs.

What is the relationship between the type of LTC system and quality policies and indicators? The results are mixed.

Some countries showed in Table 3.4.1 and belonging to WP1 cluster 1 (Germany, Slovakia, Estonia) and others belonging to WP1 cluster 3 (France and the UK) correspond in WP5 to cluster 1, which is characterised by quality policies aimed at formal care, quality policies aimed at outcomes, and quality guidelines. These countries, according to the description of WP1 clusters 1 and 3, present a high use and high support of informal care. However, in WP5 most of them do not support a similar strategy as regards quality policies and indicators. Apparently, there is a gap to be filled in these countries: since informal care is extremely important, a quality strategy ought to be developed in this field.

The Netherlands, by contrast, is perfectly consistent with its strategy. In WP1 it belongs to cluster 2, which is composed of countries that are generous in public spending and invest a lot

on formal LTC (both residential and home care). This is consistent with the Netherlands' position in WP5 cluster 1, where quality of formal care is a key factor.

As for their use of informal care, Austria, Spain, and Finland (WP1 cluster 3) would also be expected to invest in quality of informal care. This is the case to only a limited degree, since they belong to WP5 cluster 2, which is mainly characterised by input-process indicators but also by quality policies for informal care.

Based on our data, Poland and Slovenia focus on private spending and have not developed national quality policies and indicators. Italy also relies on private spending and informal care but has not developed policies on informal care.

Also, if we look at Table 3.4.2 we see that Germany, the Netherlands, and France (WP1 cluster 1) all belong to WP5 cluster 1 (outcome-based quality of formal care). This is consistent with their high public spending and good organisational structure of LTC.

In general, we can conclude that countries with a high organisational depth (Kraus et al. 2010) consistently score high on quality policies.

By analysing 15 EU countries, we identified the following main results for quality policies:

Integration: since LTC is intrinsically a multidimensional activity that needs multiple competencies to be effectively carried out, coordination of LTC providers is key to guaranteeing a high level of quality (MISSOC, 2009). Coordination is in fact related to the following key issues for quality in LTC:

- 1) **Timeliness:** the degree to which patients are able to obtain care promptly. Coordination of care is key to timeliness when a patient needs to go through different stages of care and across providers.
- 2) **Continuity:** the extent to which health care for specified users, over time, is coordinated across providers and institutions.
- 3) **Integration between primary and secondary care, and between health care and social care.** Without this coordination, quality may be undermined.

In different countries there is a growing awareness that quality of LTC is based on an effective integration of health and social services. On average (see WP 1 data of the ANCIEN project) there is a medium integration of the components of LTC. However, quality indicators on coordination are fewer than for other dimensions (such as effectiveness and responsiveness). According to country reports, the transition from/to hospitals is an issue to be addressed.

Consistency between LTC policies and LTC quality policies: consistency is a key issue in some countries because of the lack of integration of responsibilities. LTC policies and LTC quality policies may be developed by different actors. Also, quality policies may not reflect the actual use of LTC.

As discussed in the above section, countries with high scores in the use of formal care and high public spending on LTC have consequently invested in quality policies on formal care. Countries with high co-payments are less prepared as for quality systems. The latter should invest more in quality policies on home-based care and informal care. The latter aspect may also be relevant for countries with high public spending that are trying to increase the role of informal care.

Transparency: Today, in LTC the role of the user/patient is often very limited. Therefore, it is very important not only to take into account the patients' needs but also their expectations including the desire for choice. In order to do so patients need to be informed about the quality of the providers. This can be done by improving transparency and making better information

available to users (European Commission, April 2008; MISSOC, 2009). However, our results show that most countries do not report to the public data about quality of care of LTC institutions.

Table 4.4 National visibility of providers' quality indicators (question 4)

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK
National visibility	X	X	X	X	V	V	X	V	X	X	X	X	V	V	V

V=Yes, X=No

Quality of informal care: in many countries informal caregivers sacrifice part of their lives to take care of their elderly family members. A quality LTC system should therefore not only be based on an assessment of patient needs. As the bulk of LTC is provided by informal caregivers and also depends on their health and well-being, caregiver needs must also be assessed and satisfied.

Our results show that most interventions deal with financial support for buying devices; training/counselling of the informal caregivers; assessment of the health conditions and personal needs of patients (see table, below).

Table 4.5 Policy options for supporting quality of informal care

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	Netherlands	UK	TOTAL
Assessment of LTC needs and personalised self-care plans	V	V	V	V	X	X	X	X	X	V	X	X	V	V	V	8
Courses for informal caregivers	V	V	V	X	V	X	V	V	X	V	X	X	V	V	V	10
Statutory home visits by health and social care personnel	V	X	V	X	V	X	X	X	X	V	X	X	V	X	X	5
Awareness raising	X	V	V	V	V	X	V	V	X	V	X	X	V	V	V	10

campaigns about quality																
Financial support for buying technologies for self-care and home devices	V	V	V	V	V	X	V	V	X	V	X	X	V	V	V	11
Other	X	X	X	X	X	X	X	V	X	V	X	X	V	V	X	4

V=Yes, X=No

Monitoring. Monitoring systems are needed to support quality evaluation, to promote informed policy and to provide feedback to the various actors in the field (EC, 2008). On average monitoring for authorisation/accreditation occurs every 3 years (range 1-5).

Table 4.6 Monitoring frequency (in years) for authorisation/accreditation

	Austria	Estonia	Finland	France	Germany	Hungary	Italy	Latvia	Poland	Slovakia	Slovenia	Spain	Sweden	The Netherlands	UK
Monitoring frequency (years)	5	1	na	7	3	2	5	5	na	1	3	na	na	1	5

Education: competent staff is a key factor in the quality of LTC provision. LTC needs staff specialised in the care of the elderly people, however. Among the many professional roles that are involved in LTC, the most prepared professionals seem to be the general practitioners (GPs). Ten countries report that GPs receive specific education for LTC. Fewer countries report the same for other roles. Nurses also play a key role in LTC facilities and home nursing care. Their shortage jeopardises the quality of LTC.

References

- Arah OA, Westert GP, Hurst J, et al. (2006). Conceptual framework for the OECD Health Care Quality Indicators project. *International Journal for Quality in Health Care* 18:5-13
- Anonymous. Strategic report on social protection and social inclusion, 2008-2010. Spain. Accessed online on 17/03/2010: http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/spain_en.pdf.
- Clark, L.A. (2007). Measuring Quality in Long-Term Care: A 360-Degree Approach. *Journal of Health care Quality* 29(6): 25-32
- 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 1997). Strasbourg, Council of Europe.
- Donabedian, A. (1980). *The Definition of Quality and Approaches to Its Assessment*. Ann Arbor, MI: Health Administration Press
- Donabedian A. (1985). *The Methods and Findings of Quality Assessment and Monitoring: An Illustrated Analysis*. Ann Arbor, MI: Health Administration Press, 1985.
- Du Moulin, M.F.M.T., van Haastregt, J.C.M., & Hamers, J.P.H. (2010). Monitoring quality of care in nursing homes and making information available for the general public: State of the art. *Patient Education and Counseling*, forthcoming
- EUCOMM Strategic report on social protection and social inclusion, 2008-2010. Cyprus, Accessed online on 17/03/2010: http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/cyprus_en.pdf
- European Commission (2005). Policies Review on preliminary national policy statements on health care and long-term care. Memorandum of the Social Protection Committee, Brussels, European Commission. Accessed online on 17/03/2010: http://ec.europa.eu/employment_social/spsi/docs/social_protection/spc_ltc_2005_en.pdf. Last
- European Commission (2008a). Review of Preliminary National Policy Statements on Health Care and Long-Term Care. Accessed online on 17/03/2010. http://ec.europa.eu/employment_social/spsi/docs/social_protection/spc_ltc_2005_en.pdf
- European Commission (2008b). Long Term Care in the European Union. Accessed online on 17/03/2010: <http://ec.europa.eu/social/BlobServlet?docId=768&langId=en>
- European Commission (2009). Long-term Care in the European Union. Accessed online on 17/03/2010: http://ec.europa.eu/employment_social/news/2008/apr/long_term_care_en.pdf.
- Huber, M, Maucher, M., and Sak, B. (2008). Study on Social and Health Services of General Interest in the European Union. Vienna/Brussels, European Centre for Social Welfare Policy and Research, ISS, CIRIEC, 2008. Accessed online on 17/03/2010: www.euro.centre.or/data/1216816977_32580.pdf
- Kraus, M., Riedl M., Mot, E., Willemé, P., Röhring, Czypionka, T. (2010). A typology of Long-Term Care Systems in Europe. Report of the ANCIEN Project, Assessing Needs of Care in European Nations. *ENEPRI Research Report n. 91*. <http://www.ancien-longtermcare.eu/>

- Institute of Medicine (1990). *Medicare: A Strategy for Quality Assurance*. Vol.1. Washington, DC: National Academy Press.
- Institute of Medicine (2000). *Improving the Quality of Long-Term Care*.
- Legido-Quigley, H., McKee, M., Nolte, E., & Glinos, I. (2008). *Assuring the quality of health care in the European Union*. World Health Organisation on behalf of the European Observatory on Health Systems and Policies, Copenhagen, No 12.
- Leichsenring K. Developing integrated health and social care services for older persons in Europe. *International Journal of Integrated Care* 2004; 4: 1-15.
- Ministry of Labour and Social Affairs of the Czech Republic. Strategic report on social protection and social inclusion, 2008-2010. Accessed online on 17/03/2010: http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2008/nap/czech_en.pdf
- Mutual Information System on Social Protection in the EU Member States (MISSOC). MISSOC analysis (2009). *Long Term Care*. August 2009. Accessed online on 17/03/2010: <http://ec.europa.eu/social/BlobServlet?docId=4320&langId=en>.
- National Patient Safety Foundation (2000). *Agenda for Research and Development in Patient Safety*. Chicago, IL: National Patient Safety Foundation;
- Nies, H. et al. (2010). *Quality in Long Term Care*. European Overview Paper. INTERLINKS Project report
- Schalock, R.L. (2001). *Outcome-Based Evaluation*. New York: Kluwer Academic/Plenum Publications
- Schalock, RL. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research* 48: 203-216
- Shaw, C.D. & Kalo, I. (2002). A background for national quality policies in health systems. *World Health Organisation*. <http://test.cp.euro.who.int/document/e77983.pdf>
- Sorenson, C. & Mossialos, E. (2007). Research Note on Measuring quality and standards of long-term care for older people. *Manuscript*.
- Sorenson, C. (2007). Quality measurement and assurance of long-term care for older people. *Euro Observer* 9(2): 1-8
- WHO (2002.) *Lessons for LTC Policies*. Accessed on May 14 2010 from: http://whqlibdoc.who.int/hq/2002/WHO_NMH7CCL_02.1.pdf

Annex. Country reports on LTC Quality Policies

In the following sections we include the country reports on Finland, Hungary, Poland, Slovakia, Spain, Sweden, the Netherlands, and the United Kingdom. These reports have been compiled by LUISS and derive from the data partners added to the survey responses.

Eight extended country reports by WP5 partners are published separately. In particular:

Extended country reports are (in parenthesis the authoring partner):

1. Austria (IHS)
2. Italy (LUISS)
3. Estonia (Praxis)
4. Latvia (Praxis)
5. France (Legos)
6. Germany (DIW)
7. Poland (CASE)
8. Slovenia (IER)

Derived country reports (based on data provided by partners in the survey) are included for:

9. Finland (ETLA)
10. Hungary (TARKI)
11. Slovakia (B-IER)
12. Spain (FEDEA)
13. Sweden (ETLA)
14. The Netherlands (CPB)
15. The United Kingdom (LSE-PSSRU)

1. Finland (by ETLA)

1.1 LTC quality documents

- National Framework for High-Quality Services for Older People. Helsinki, Finland 2008. 55 pp.
- Ministry of Social Affairs and Health publications:
http://www.stm.fi/c/document_library/get_file?folderId=39503&name=DLFE-6710.pdf

1.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	4
Safety	Policies	1	1	1	0	3
	Indicators	0	0	0	0	0
Responsiveness	Policies	1	1	1	1	4
	Indicators	0	0	0	0	0
Coordination	Policies	1	1	1	1	4
	Indicators	0	0	0	0	0
Tot		5	5	5	3	18

The Finnish public administration system consists of three levels: state, province and municipality. There are two main laws that govern LTC services provision in Finland. They are the Primary Health Care Act and the Social Welfare Act. They prescribe that it is the municipalities that are responsible for public sector provision of health care and social services, including LTC. However, Finland's municipalities enjoy a very broad autonomy, and state level regulations and management in health care in general are not very detailed. Thus, legislation is not very specific about how municipalities' duties are to be performed in practice. Indeed, it has been argued that public responsibility for health care and social services are decentralised in Finland, to a greater extent than in any other country.

The regional evaluation of basic services is one of the essential statutory tasks of the State Provincial Office. In total, there are six of these provinces in Finland. The aim is to establish the accessibility and quality of basic services within the province. The evaluation conducted by the State Provincial Offices supports national development goals and complements municipal evaluations. It also serves the municipalities in the development of basic services. There is also a nationwide authority, the National Supervisory Authority for Welfare and Health (Valvira), which, as from 2010, is responsible for quality control at the national level. In practice, this authority will deal only with particularly severe problems or cases with implications for future practice in the field.

Thus, there is not really any quality control yet in Finland of the type being investigated in this survey. There are in principle guidelines for how municipalities are to organise LTC, but if a client or relative is not satisfied with the service provided, the only way to change things is to seek legal redress.

However, since 2000, roughly one third of LTC facilities adopted a voluntary quality certification called RAI (*Benchmarking project for long-term institutional care*). RAI is a

multidimensional assessment tool composed of 26 quality indicators. Every six months LTC institutions send the data to the National Supervisory Authority for Welfare and Health that provides feedback and recommends actions. From 2000 to 2009, RAI data reveal that LTC facilities have improved across many performance indicators. Only one indicator has a negative trend: multiple medication has increased over time (Harriet Finne-Soveri, Teija Hammar and Anja Noro, 2010, Measuring The Quality of Long-Term Institutional Care in Finland, *Heurohealth* Volume 16 Number 2, 2010)

Human resources. It is mandatory for the following LTC professions to attend educational programmes on the following issues:

	Risk management and malpractice	Alzheimer's disease and dementia	Fall prevention	Pressure Ulcers
General practitioner/ Family Physician/ Primary Care Physician	yes	yes	yes	yes
Hospital physicians	yes	yes	yes	yes
Social worker	yes	yes	yes	yes
District nurses	yes	yes	yes	yes

1.3 Strategies for quality in informal LTC

- Assessment of LTC needs and personalised self-care plans are essential to quality in informal care support
- Courses for informal carers (family members, friends, etc.) are provided. See: <http://www.omaishoitajat.fi/english.php>
- Statutory visits in the home environment by health and social care personnel are necessary for quality in informal care support
- Awareness-raising campaigns about quality in LTC and home devices or technologies supporting self-care: <http://www.omaishoitajat.fi/kehittamishankkeet.php>
- Financial support to buy technologies for self-care and home devices is provided, depending on the status of the elderly, but is sometimes granted by the municipal social services.

2. Hungary (by TARKI)

2.1 LTC quality documents

- Act 3/1993 on social care
- Act 154/1997 on health care
- “Quality of care in hospitals” by Health Insurance Supervisory Agency www.ebf.hu/letoltes/fmi_v1_02.pdf
Guideline for health care services on quality of care (Ministry for Health Care, 2009)

2.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Safety	Policies	1	1	1	0	3
	Indicators	1	0	0	0	1
Responsiveness	Policies	1	1	1	0	3
	Indicators	0	0	0	0	0
Coordination	Policies	1	1	1	0	3
	Indicators	0	0	0	0	0
Tot		6	5	5	0	16

Quality is covered in legislation in general terms but in the regulatory details it is less specified; authorities control some minimum standard requirements. Minimum standards in social care (2010-2011) are under construction by the Institute of Social Policy. The indicator set has been developed and published and it is currently tested in a pilot project.

Publicity of data. Some aggregated data are publicly available but there are a lot of indicators which are not collected; these indicators can be found only in internal quality monitoring systems. Data on certain minimum requirements (such as space per capita, ratio of clients to staff, etc) are collected by the authorities on an annual basis but not published. More detailed quality assurance requirements are idiosyncratic; authorities do not collect information on them and quality results are not published.

Monitoring frequency. In social care the law requires monitoring bi-annually. In health care, legislation requires "regular" supervision. The practice is annual supervision.

Voluntary certification. In health care every service must have a quality assurance system but no information is collected or published on what certificates are applied. In social care there is no such requirement. According to private information given by experts, the most frequently applied quality certificate is the ISO 9004 standard both in health care and social care.

No guidelines. No EBM guidelines for LTC have been developed in the last three years. No EBM guidelines have been disseminated to professionals and the public. There is no agency for the integration and dissemination of EBM guidelines. There is no agency for the systematic monitoring of the effects of EBM guideline implementation.

Human resources. There is a general unspecified obligation for professionals to attend training programmes. They have to collect a certain number of credits over time but no fields are specified.

Informal LTC. Among those strategies mentioned in the survey, none has been implemented to support quality in informal LTC.

Technology: technology is being implemented to support effectiveness through a monitoring system for human resources in health care. The initiative ISZER (Hungarian acronym for integrated social and health care) aims to promote coordination between health and social care.

3. Slovakia (by B-IER)

3.1 LTC quality responsibilities and documents

The issue of LTC in the Slovak Republic falls within the competence of both the Ministry of Health and the Ministry of Social Affairs. There are specific regulations for both branches.

Social care: the legal framework of LTC quality in Slovakia is defined in Act No 448/2008 Coll on Social Services, which came into force on 1st January 2009. The Act on Social Services charges social services providers with the duty to draw up and fulfil procedural, personnel and operating conditions for the provision of social services (also known as quality standards). The structure of these services is precisely set out in the act (appendix No.2), which enables not only the inspection body (Ministry of Labour, Social Affairs and Family, department of supervision/control of social services), but also independent institutions and the public to monitor and check the quality of social services.

The evaluation system uses criteria to score the actual quality of the provision of social services. It sets a maximum number of points (100) that social services providers can achieve and a minimum number of points (60) that the social services provider can achieve to meet quality standards. At the same time, in the interests of quality assurance, other obligations have been placed on providers (e.g. duty to plan the course of social provision (an individual development plan, to fulfil general technical and internal environmental requirements for the construction of buildings, qualification requirements for individual professions in social services (e.g. social worker, social adviser, carer, social rehabilitation instructor and coordinator). The procedural, personnel and operating conditions for the provision of social services will be checked from 1st January 2011. The period from 1st January 2009 to 1st January 2011 is the period in which the providers need to fulfil the conditions required by law. The frequency of monitoring the standards of quality by inspection body is not fixed by law. One reason is the inadequate personnel capacities of the inspection body.

HEALTH CARE: The legal framework is defined by the Act No 581/2004 Coll. on health insurance companies (HICs) and health care supervision, the Act involves the question of quality indicators for assessment of health care provision, some aspects (and methodology) are still in preparation.

"The Ministry of Health has already identified the need to improve some of the problematic areas on chronic care and long-term care. In general, since the HICs do not as yet cover the whole period of long-term care, they have consequently very limited data."

The Ministry of Health addresses three main partially overlapping targets:

- Institutional and home care
- Care for the frail elderly
- Care for disabled children and adults

Home nursing services: the general situation with home nursing services is that there are currently 161 agencies for this kind of services in Slovakia. Most are located in cities and are different in size. The agencies provide skilled nursing care, physiotherapy and social care at the home of the patient. Usually the home nursing agencies deliver skilled nursing care services, which are provided by registered nurses. Physiotherapists with special training and home help or home aid workers provide further services.

Services are reimbursed by the health insurance companies. Coverage is only on performance issues clearly related to a health problem; social care is excluded from HIC coverage.

Access to the nursing service is upon indication by a physician. Only then can the nursing agency get involved. Due to financial restrictions nurses have no access to a car and need to visit patients on foot or by public transport. Considerable time is thus spent in travelling to see the patient.

Nurses are paid by fee for performance. Patients taken care of by the nursing agency are mostly terminally ill, immobile, very sick patients who are usually covered by the HIC, often by readmitting them to hospital.

3.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	0	1	3
	Indicators	1	1	0	1	3
Safety	Policies	1	1	0	0	2
	Indicators	1	1	0	0	2
Responsiveness	Policies	1	1	0	0	2
	Indicators	1	1	0	1	3
Coordination	Policies	1	1	0	0	2
	Indicators	1	0	0	0	1
Tot		8	7	0	3	18

The health insurance companies are responsible for executing an assessment of quality of care with a selected set of quality indicators by health care providers once a year.

There are three levels for assessment of quality of care for each indicator: level of provider above average, level of provider on average (statistically largest group), level of provider under average.

A new list of quality indicators for the assessment of health care provision is in progress. It will offer a more differentiated option of assessment than the list applied up to now. There is the intention of including economic indicators to obtain relevant data on the efficiency of use of common diagnostic and treatment units and transport service, data on hospital discharges and outpatients, and data on costs spent on drugs and medical aids.

Health insurance companies publish criteria when concluding contracts with health care providers based on personnel and technological equipment available to the health care provider and on the new list of approved quality indicators.

The health insurance companies are using the results of measuring the quality of delivered health care (set of quality and economy indicators) for contracting of health care services by providers of health care.

Health insurance companies use the results of quality indicators to select health care providers according to their quality. There are some benefits by volume and payments for good providers.

As for social care, data about quality results will be publicly available as the new legislation comes into effect, from 2013 on.

Health care monitoring will take place every three years.

The Ministry of Health is responsible for the dissemination of EBM guidelines about LTC issues. The Health Care Surveillance Authority is responsible for monitoring of the effects of guidelines.

Human resources: The professions listed below need to attend educational programmes on the following LTC issues.

	Risk management and malpractice	Alzheimer's disease and dementia	Fall prevention	Pressure Ulcers	Physical restraints
General practitioner/ Family Physician/ Primary Care Physician	x	x	x	x	
Hospital physicians	x	x	x	x	x
District nurses				x	
Health educators				x	
Nurse practitioners	x		x	x	x
Nursing staff	x	x	x	x	x

3.3 Strategies for the improvement of quality in informal LTC

1. Assessment of LTC needs and personalised self-care plans.

Health care: the Ministry of Health, in cooperation with the Health Care Surveillance Authority, health insurance companies and LTC providers specify and assess the needs on the local, regional and national level. The assessment of LTC needs is financed generally by the budgets of the Ministry of Health, health insurance companies and the Health Care Surveillance Authority.

Social care: individual needs are assessed, taking into account personal, family and the general circumstances of the client's life, including daily activities (ADL), housekeeping and contact with the social environment. Slovak legislation recognises six degrees of dependency according to the activities that the person is not able to carry out and the number of hours needed to provide them (Act 447/2009 on financial allowances to compensate severe disability).

2. Courses for informal care-givers (family members, friends, etc.) are provided for health care (not social care).
3. Statutory visits in the home environment by health and social care personnel.

HEALTH CARE: GPs and Agencies of nurses for delivering care at home

SOCIALCARE: Obligation for state departments (Office of Labour, Social Affairs and Family) to visit a dependent person and by social worker to control quality and extent of his/her assistance/care, if for care of this person is paid care allowance (Act 447/2009 on financial allowances to compensate severe disability).

4. Awareness raising campaigns about quality in LTC and home devices or technologies supporting self-care.

HEALTH CARE: Health care providers, companies and distributors of home devices promote public campaigns about quality in LTC.

SOCIALCARE: social counselling provided by the state administration, municipalities or civic organisations.

5. Financial support for buying technologies for self-care and home devices.

HEALTH CARE: Ministry of Health can give financial support for buying new technologies for selected Hospitals of LTC. Health insurance companies support buying technologies for self care and home devices with co-payments or prefer lending such devices for extended time to the patients.

SOCIALCARE: Dependent person can receive financial allowance for different purpose, e.g. home support devices - for purchasing, training of using, adapting and repairing aids, purchasing lifting appliance, home adaptation- house, apartment and garage (Act 447/2009 on financial allowances to compensate severe disability).

6. Possibility to have a rest (max. 30 days/year) and during this time the informal carer can receive care allowance (Act 447/2009 on financial allowances to compensate severe disability; Act 448/2008 on Social Services).
7. Health and social insurance of carers. This insurance for carers receiving care allowance is paid by the state.

4. Spain (by FEDEA)

4.1 LTC quality documents

- Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. Título II: La calidad y eficacia del Sistema para la Autonomía y Atención a la Dependencia
- RESOLUCIÓN DE 2 de diciembre de 2008, de la Secretaria de Estado de Política Social, Familias y Atención a la Dependencia y a la Discapacidad, por la que se articula el Acuerdo del Consejo Territorial del Sistema para la Autonomía y Atención a la Dependencia, sobre criterios comunes de acreditación para garantizar la calidad de los centros y servicios del Sistema para la Autonomía y Atención a la Dependencia
- Ley 63/2003 de Cohesión y Calidad del Sistema Nacional de Salud.
- Informe del Defensor del Pueblo sobre la Atención Socio-sanitaria en España: Perspectiva Gerontológica y otros aspectos conexos" Recomendación del Defensor del Pueblo a las AAPP e informes de la SEGG y de la AMG.
- Sistema de acreditación en servicios sociales de atención a las personas mayores en situación de dependencia (SEGG).
- Planes gerontológicos o de atención a las personas con discapacidad (Iniciativas Autonómicas), enumerados en el libro Blanco de la Dependencia en España, cap. VII; pág. 513.
- Resolución de 4 de febrero de 2010, de la Secretaría General de Política Social y Consumo, por la que se publica el Acuerdo del Consejo Territorial del Sistema para la Autonomía y Atención a la Dependencia, en materia de órganos y procedimientos de valoración de la situación de Dependencia
- Resolución de 4 de febrero de 2010, de la Secretaría General de Política Social y Consumo, por la que se publica el Acuerdo del Consejo Territorial del Sistema para la Autonomía y Atención a la Dependencia, para la mejora de la calidad de la prestación económica para cuidados en el entorno familiar del Sistema de Autonomía y Atención a la Dependencia
- Orden ESD/1984/2008, de 4 de julio, por la que se crea la Comisión Especial para la mejora de la calidad del Sistema para la Autonomía y Atención a la Dependencia.
- Resolución de 4 de noviembre de 2009, de la Secretaría General de Política Social y Consumo, por la que se publica el Acuerdo del Consejo Territorial del Sistema para la Autonomía y Atención a la Dependencia, sobre criterios comunes de acreditación en materia de formación e información de cuidadores no profesionales.
- Each Autonomous Community develops its own legislation and rules on the provision of LTC services; Libro Blanco de la Dependencia. Ministerio de Trabajo y Asuntos Sociales
- Normas de gestión de servicios en residencias para personas mayores: UNE-158000; Servicios Integrales: UNE 158001; Espacios e Instalaciones: UNE 158002; Dotación y Equipos: UNE 158003; Cualificación y Formación: UNE 158004
- Competencies of personnel: UNE 18005. Norma UNE 158:101:2008 "Servicios para la promoción de la autonomía personal. Gestión de los centros residenciales y centros residenciales con centro de día o centro de noche integrado". It specifies the requirements and level of services that must be achieved by residential home centres and day care

centres, regarding the facilities, services provided and quality standards. This rule applies both to public and private centres.

- Norma ISO 9001:2000. Sistemas de gestión de la calidad. Requisitos.
- LEY 16/2003, de 28 de mayo, de cohesión y calidad del Sistema Nacional de Salud .

4.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	1	1	4
	Indicators	0	0	0	0	0
Safety	Policies	1	1	1	1	4
	Indicators	1	1	1	0	3
Responsiveness	Policies	1	1	1	1	4
	Indicators	1	0	0	0	1
Coordination	Policies	1	1	1	0	3
	Indicators	0	0	0	0	0
Tot		6	5	5	3	19

Publication of quality results is not mandatory. There are quality standards, but there is not any record where the public can view performance results. Private and public providers sometimes show the public their observance of the current regulation about quality.

The monitoring frequency depends on the type of service and the region.

Home care services in ANDALUCIA: Accreditation every four years subject to submission of Annual Reports that should include the Annual Budget and information about quantitative and qualitative features related with the service.

Home care services in ASTURIAS: no information about frequency of inspection: once the institution acquires the authorisation it needs subsequent authorisations for any changes done on a) site and building conditions; b) Conditions required?; materials and equipment; c) Number of effective assistance staff; d) Changes about requirement for professional certification of workers.

Voluntary certifications. There are around 20 institutions (March 2010) that obtained a voluntary quality certification in Spain according UNE 158000, that aims to guarantee quality of the services included in Law 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. Additionally, AENOR, (Asociación Española de Normalización y Certificación), has provided more than 250 quality management certificates. Autonomous Community of Madrid is an example of the EFQM implementation through Alba II Project Self-Assessment that has been established in residences and home care centres in Madrid.

Among the professionals who provide LTC services, the following need to comply with a formal specific educational curriculum & continuing education for LTC:

- General practitioner/Family Physician/Primary Care Physician
- Hospital physicians
- Social workers

- District nurses
- Health Educators
- Nurse Practitioners
- Nursing Staff

4.3 LTC quality guidelines

	Effectiveness	Safety	Responsiveness	Coordination
1. EBM guidelines for LTC have been developed in the last 3 years	X	x		x
2. EBM guidelines have been disseminated to professionals and the public	X	x		x
3. There is an agency for the integration and dissemination of EBM guidelines (please specify)			x	
4. There is an agency for the systematic monitoring of the effects of EBM guideline implementation (please specify)			x	

Evidence-based practice on internet resources:

- Joanna Briggs Institute for Evidence-based Nursing, <http://www.joannabriggs.edu.au>

The Joanna Briggs Institute, established in 1995, is an initiative of Royal Adelaide Hospital and the University of Adelaide to provide a collaborative approach to the evaluation of evidence derived from a diverse range of sources. With the support of leading hospitals and universities, the JBI Collaboration has grown steadily to include state collaborating centres within Australia, as well as Hong Kong, New Zealand, The United States, Scotland, China, South Africa, Spain, Canada, Thailand and England.

- Information in Spain is accessible on JBI CO^NNET España, Red clínica online de cuidados y procedimientos, <http://es.jbiconnect.org/>. JBI CO^NNECT (Clinical Network of Evidence for Care On-line) is a platform that provides users resources and tools to assist health professionals to take informed clinical decisions about care and treatment of their patients / residents / clients using the "best evidence available." CO^NNECT JBI is composed of a series of "nodes". Each node acts as a portal for different areas health (eg LTC care, mental health care, physiotherapy, burns care). Each node contains the same resources, however, only includes information specific its area. Users can access a node to locate specific evidence relevant to that area of health or access the website and locate CO^NNECT JBI evidence from all available nodes. The JBI proposes to monitor and to provide health care based on evidence:

Step 1 - Find the best available international evidence;

Step 2 - Evaluate the evidence;

Step 3 - Summarise and disseminate the evidence;

Step 4 - Implementing evidence in practice and systems;

Step 5 - Using evidence and;

Step 6 - Assess the impact of the evidence. Each stage contains a number of tools that can be accessed from JBI CO^NNECT

5. Sweden (by ETLA)

5.1 LTC quality documents

This is a list of important documents, both of policy and legislative Content. The English titles are roughly translated and are not the formal English translations. The documents are from the Government (similar to White papers), National Guidelines developed by The National Board of Health and Welfare.

- The Swedish Health and Medical Services Act
- The Social Services Act
- National action plan for development on elderly care (Nationell utvecklingsplan för vård och omsorg om äldre Prop. 2005/06:115, Proposition 22 mars 2006)
- National action plan for development on health care (Nationell handlingsplan för utveckling av hälso- och sjukvården Prop.1999/2000:149)
- Dignity in elderly care (Värdigt liv i äldreomsorgen Socialdepartementet, Världighetsutredningen, Statens offentliga utredningar (SOU) SOU 2008:51)
- Action Plan for development of Regional Comparisons on elderly care (Handlingsplan för utveckling av Öppna jämförelser inom äldreomsorg och hemsjukvård 2009-12-16 Dnr 7270/2009)
- General Quality Indicators in health Care (Hälso och sjukvårdsövergripande indikatorer 2009)
- National Guidelines on dementia (Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010)
- Patient Safety: What has been done? And what needs to be done? (Patientsäkerhet. Vad har gjorts? Vad behöver göras? Socialdepartementet, Patientsäkerhetsutredningen, Statens offentliga utredningar (SOU) SOU 2008:117)
- Better co- operation. Questions regarding the co-operation between health care and social insurance (Bättre samverkan. Några frågor kring samspelet mellan sjukvård och socialförsäkring Socialdepartementet, Utredningen om patientens rätt, Statens offentliga utredningar (SOU) SOU 2009:49)
- Needs and resources in health care (Behov och resuser i vården - en analys SOU 1996:163, Statens offentliga utredningar (SOU) november 1996)
- Sweden's strategy report for social protection and social inclusion 2008-2010 S2008.028, Rapporter, 30 September 2008
- National guidelines on musculoskeletal disorders support for management (Nationella riktlinjer för rörelseorganens sjukdomar 2010 – stöd för styrning och ledning – Preliminär version)
- National guidelines on Depression and anxiety disorders (Nationella riktlinjer för vård vid depression och ångestsyndrom 2010)
- National guidelines on National guidelines on musculoskeletal disorders care preliminary version (Preliminär version: Nationella riktlinjer för vård av rörelseorganens sjukdomar)

- National guidelines on psychosocial interventions in schizophrenia (Nationella riktlinjer för psykosociala insatser vid schizofreni eller schizofreniliknande tillstånd 2011 – stöd för styrning och ledning)
- National guidelines on diabetes care (Nationella riktlinjer för diabetesvården 2010 – Stöd för styrning och ledning)
- National guidelines on Dental care preliminary version (Nationella riktlinjer för vuxentandvård 2010 – Preliminär version)

5.2 Organisational Overview

The Ministry of Health and Social Affairs is responsible for health care. The areas of responsibility of the Ministry of Health and Social Affairs relate to social welfare: financial security, social services, medical and health care, health promotion and the rights of children and disabled people.

To the Ministry of Health and Social Affairs several agencies are subordinated, these agencies are responsible for the “day to day” business within the sphere of Swedish government.

The National Board of Health and Welfare is a government agency under the Ministry of Health and Social Affairs, with a very wide range of activities and many different duties within the fields of social services, health and medical services, environmental health, communicable disease prevention and control and epidemiology. The Government determines the policy guidelines for The National Board of Health and Welfare work.

The majority of The National Board of Health and Welfare activities focus on staff, managers and decision makers in the above mentioned areas. The National Board of Health and Welfare gives support, exerts influence and supervises in many different ways.

Regions, County Councils and Municipalities

Sweden is divided into 290 municipalities, 18 county councils and two regions (Västra Götaland and Skåne). There is no hierarchical relation between municipalities, county councils and regions, since all have their own self-governing local authorities with responsibility for different activities. The only exception is Gotland, an island in the Baltic Sea, where the municipality also has the responsibilities and tasks normally associated with a county council (Swedish Government Offices Elderly care, 2011).

Health and medical care in the Swedish health care system is the shared responsibility of the state, county councils and municipalities. The State is responsible for overall health and medical care policy.

The national Health and Medical Services Act (hälso- och sjukvårdslagen) regulates the responsibilities of county councils and municipalities in health and medical care. The Act is designed to give county councils and municipalities considerable freedom with regard to how their health services are organised.

Municipalities

Municipalities are responsible for care of the elderly and support and service to those whose medical treatment has been completed and who have been discharged from hospital care. Municipalities are also responsible for housing, employment and support of people with psychiatric disabilities (Swedish Government Offices Elderly care, 2011).

A freedom of choice system will be introduced to help develop elderly care that more clearly responds to the needs and desires of the individual. In order to make an educated choice, the elderly and their family need information on how elderly care works. The Government is working for the development and follow-up of quality with national open comparisons, improved statistics and a more efficient supervisory body (Swedish Government Offices Elderly care, 2011).

Municipalities' tasks are child care, schools, care of the elderly, social welfare, water and sewerage, waste treatment and spatial planning. Swedish municipalities and regions have independent power of taxation. They employ almost one third of the Swedish labour force, and their services make up more than 20% of Swedish GDP (Lacoutre, 2011).

Local authorities are responsible for

- Care in special housing (Nursing Homes)
- Primary home care in ordinary housing (in 50 percent of the counties)
- Support from personnel in social care

County councils are responsible for:

- Hospitals (acute care)
- Primary care in medical centres (GPs)
- Primary home care in ordinary housing (in 50 percent of the counties)
- All doctors except for health care in school (Lacoutre, 2011)

5.3 Laws for LTC

The Swedish Health and Medical Services Act

The Swedish Health and Medical Services Act states as follows: Health and medical services are aimed at assuring the entire population of good health and of care on equal terms. Care shall be provided with due respect for the equal worth of all people and the dignity of the individual. Priority shall be given to those who are in the greatest need of health and medical care (Health and Medical Services Act, 1982: 763).

The Social Services Act

The Social Services Act states that the municipal authorities are ultimately responsible for ensuring that the residents of a municipality receive the support and assistance they need. Despite that there is in some areas a framework that regulates the responsibilities within the family, for instance the marriage Act states that within families there is a mutual responsibility for married people to individually contribute, according to their own capability, to the supply of means that are needed to meet their individual and family needs. Although this does not mean that a spouse is responsible for giving informal care within the family. This is a major difference compared to several countries in Europe. The obligation by law to provide informal care was excluded from the Social Services Act in 1956.

5.4 Monitoring, Quality Indicators a Overview

The following parts are an attempt to describe the main sources to monitor quality in Sweden.

Quality Registries

Health and social services are developing and changing rapidly in Sweden, as in other nations. The organisation and management of these services has been similar and stable for many years. At the general political and administrative level the focus has been on financial and staffing issues, i.e., the framework for providing services. The content of health services has been determined mainly by the various groups of health care professionals, while the dynamics of change have been heavily influenced by new treatment options generated through research. The traditions of health and social services explain why we have the types of management systems that we do. In health care, we have well-developed and functioning systems to monitor economic and human resource activities.

Corresponding systems have not been developed for working with patients, although this is the actual core and the ultimate aim of provider organisations. The traditional patient record systems have not facilitated the compilation and analysis of data needed for quality improvement. Although increasingly more records are electronic, they essentially continue to be note pads that individual caregivers use for memory support in treating individual patients.

The National Quality Registries have been developed to fill the gap left by the lack of primary monitoring systems. The quality registries collect information on individual patient's problems, interventions, and outcomes of interventions in a way that allows the data to be compiled for all patients and analysed at the organisational level.

Since the registries are national, the entire country is in agreement on what indicates good care. This also makes it possible to compare different organisations.

In the areas where National Quality Registries have been established, the tools are available for any organisation that wants to participate to continuously monitor their effectiveness and the benefits that they create for patients.

The successful development of the Swedish National Quality Registries is explained largely by their decentralised nature. Caregivers that have the greatest use for the data also have the main responsibility for developing the system and its contents, and the databases are spread out among different clinical departments throughout Sweden.

Registry content is continually validated in different ways by registry managers and organisational units that use the registers. This is complemented by annual quality control, represented by the annual reports and grant applications submitted for central funding. Data quality in the National Quality Registries is sufficient for use in clinical research. A system of national quality registries has been established in the Swedish health and medical services in the last decades. There are about 70 registries and four competence centres that receive central funding in Sweden.

The national quality registries contain individualised data concerning patient problems, medical interventions, and outcomes after treatment; within all health care production. It is annually monitored and approved for financial support by an Executive Committee.

The vision for the quality registries and the competence centres is to constitute an over-all knowledge system that is actively used on all levels for continuous learning, quality improvement and management of all health care services.

Quality and efficiency comparisons in Swedish elderly care

Since 2007 there are comparisons available to the public on Quality and efficiency comparisons in Swedish elderly care. The comparisons have been slightly changed during the years (Sveriges

Kommuner och Landsting och Socialstyrelsen Öppna jämförelser 2010 Vård och omsorg om äldre, 2010). Indicators are based on seven areas:

1. The users own perceptions (satisfaction)
2. Accessibility
3. Care for special needs
4. Risk prevention
5. Unsafe use of medicines
6. Staff and education
7. Costs.

Quality and Efficiency in Swedish Health Care – Regional comparisons

In Sweden 21 county councils and regions are responsible for supplying their citizens with health care services. This includes hospital care, primary care, psychiatric care and dental care.

The county councils and regions are of different size. Stockholm, Västra Götaland and Skåne are considerably larger than the rest, with a population between one and two million each. Gotland is smallest, with about 60 000 inhabitants. Most of the other county councils have populations in the range of 200–300 000 inhabitants.

Within the framework of national legislation and varying health care policy initiatives from the national government, the county councils and regions have substantial decision-making powers and obligations towards their citizens. The Swedish health care system is, in short, a decentralised system. This makes it natural to put focus on the comparative performance of the county councils and regions.

The report *Quality and Efficiency in Swedish Health care – Regional Comparisons* has been published since 2006, in yearly reports. A shorter, figures-only English version of the fourth report was published in November 2009. A full, English version of the 2008 report is available for downloading.

Outcomes are presented for most of the 124 performance indicators which are used to compare the county councils and regions. Figures and indicators for hospitals are excluded. Each indicator is described in Deliverable 5.2 on quality indicators.

The county councils and regions are ranked, from better outcomes to less good ones, corresponding to the top and the bottom of the figures, respectively. The reader should observe that a good/bad relative outcome, in comparison to other county councils, not without qualifications is a good/bad absolute outcome. All county councils could have top results, for example in an international comparison – or vice versa. Variation of outcomes should be interpreted in the light of this observation.

For most indicators 95% – confidence intervals are used to illustrate statistical uncertainty. There are other sources of uncertainty, some of which are commented on in the description of an indicator. The set of indicators is chosen to mirror the health care system as a whole as good as possible, given the obvious and grave restriction of varying data availability and quality. Still, the main evaluative effort is the comparison per each indicator.

The Elderly Guide

In recent years the discussion about client empowerment has aroused. There is an emerging movement towards more openness. The national Board of Health and Welfare provides for instance a guide on elderly care (Äldreguiden) where people online can compare different

quality indicators for nursing homes and short stay homes. Some of the indicators are about support to family and educational level for staff (The National Board of Health and Welfare, 2011).

5.5 LTC quality system

There are approximately 3000 Nursing Homes in Sweden (Alaby, 2011) and 3000+ Home Care units. There is a mix of public and private providers. There is no quality system on a national level. It is basically the responsibility of each single provider to have a Quality system. Several municipalities are organised in purchaser/provider systems so when a provider is about to get contracted, municipalities use their own guides of requirements addressed to the providers. The structure, content and quality on the Purchaser process (requirements) varies between the 290 Municipalities

Monitoring quality and safety has recently become the responsibility of The National Board of Health and Welfare (NBHW). The NBHW works in a systematic way on a regional level with both structural and random inspections of Nursing Homes and Home Care. Apart from the regular monitoring, NBHW also get special assignments from the Government on different areas within Health and Social care.

NBHW can initiate inspections by itself. This is due to the particular interest and/or complaints from the public (staff, informal cares and users).

The Swedish Government has recently assigned NBHW the development of a certification system based on a set of values within elderly care. This work has just started and is subject of development (Bergh, 2011).

5.6 LTC clinical guidelines

The guidelines developed by the National Board of Health and Welfare can be divided in three types of guidelines.

- Firstly, there are national guidelines that provide decision makers and professionals with recommendations within a certain area, for example within the area of a disease.
- Secondly, there is support for decision making within the field of Health Insurances
- Thirdly the National Board of Health and Welfare also gives recommendations regarding HIV prevention and Disease Control (The Swedish Board of health and Welfare, Nationella riktlinjer, 2011).

These guidelines are not specifically addressed to LTC but some of them are relevant. A special attention should be recognised to the National Guidelines in Dementia. The guidelines contain indicators regarding informal carers.

5.7 Human resources

In Sweden there are 21 regulated health care professions that require a license to practice issued by Socialstyrelsen (The National Board of Health and Welfare).

Professions that require a license to practice		
Audiologist	Midwife	Prescriptionist
Biomedical scientist	Naprapath	Psychologist
Chiropractor	Nurse responsible for general care	Psychotherapist

Dental hygienist	Occupational therapist	Radiographer
Dental practitioner	Optician	Speech Therapist
Dietician	Orthopaedic engineer	
Doctor of medicine	Pharmacist	
Medical physicist	Physiotherapist	

Source: (The National Board of Health and Welfare Application for Swedish licence to practise for applicants from countries outside of the EU/EEA, 2011)

Only doctors (General Practitioner\ Family Physician\ Primary Care Physicians \Hospital physicians) and Nurses (Nurse Practitioners District nurses and Specialised Nurses) require a specific LTC education.

Within their curriculum there are areas addressed to LTC, such as risk management and malpractice, Alzheimer's disease and dementia, fall prevention, pressure ulcers, physical restraints.

As regards the other professions (e.g., Social workers, Care managers, Health Educators, Nursing Staff, Care workers or care assistants), the LTC knowledge areas addressed are a part of the educational programme. The length of education programmes varies between the different professions. In some cases, such as Care workers or care assistants, sometimes no formal education is needed, but is of course an ambition by providers, that all staff have professional training. Efforts have been made by the government to set a minimum standard of education, but so far this standard is not implemented (Emriksdotter, 2011).

After formal education for the different professions listed it is not mandatory to attend educational programmes. It is a matter of the provider and the individual (Emriksdotter, 2011).

5.8 Strategies for the improvement of LTC informal care

Several programmes to develop informal care and especially support for family carers have taken place during the last decade in Sweden. These different programmes have addressed issues about informal carers in particular, and issues about elderly care in general. These issues have been given a more prominent role in the agenda. The main purposes of several of these programmes have been to highlight the role of being an informal carer and develop direct and/or indirect support to reduce the burden for caregivers and also to develop the quality in elderly care. The following list gives an overview of the programmes.

- 1999 -2001. Anhörig 300, programme to develop support to family carers
- 2002 -2004. Nationell handlingsplan för utveckling av hälso- och sjukvård. The National action plan to develop health care
- 2005 Additional programme for development of support to family carers
- 2006 -2007. A continuation of the previous programme to develop support to family
- 2008. A programme to make the support permanent

The National Board of Health and Welfare concludes that incentive payments have been a desirable distribution, since almost all municipalities have applied for funds. The emphasis of the programmes has been on sustainability, duration, infrastructure and quality.

Overall these programmes have led to that virtually all municipalities having a variety of different forms of respite care and other support forms for informal carers. There is also a fairly wide range of different forms of personal support; support calls and so-called family groups.

The incentive funds have also enabled a wide variety of so-called feel-good activities, provided by municipalities. Despite these developments, however, almost all the municipalities express that there is continuing need of further development.

Nowadays, there are many different types of support to family carers. As described in the table below, the support in form of respite care, support groups and coaching is very frequent in the municipalities. About 90-99% of Swedish municipalities offer these support forms.

Amount (%) of municipalities with different forms of support to informal carers, years 2005 and 2008 and the difference between the years

Form of support	2005	2008	Difference
Respite care on short stay home	100	99	-1
Respite care on day centre	92	93	1
Respite care in home	94	98	4
Coaching	81	90	9
Groups for informal carers	76	90	14
Training of informal carers	33	78	45
Informal career centre	40	65	25
Voluntary centre	-	37	-
"Feel good" activities	18	57	39
Health checkups for informal carers	2	4	2
Other support forms	34	46	12

Source: National Board of Health and Welfare.

Several of these support forms are free of charge, although some of them are not, especially those requiring a needs' assessment done by the municipalities. In several municipalities there are teams specialised in dementia and they often have a support plan addressed to the informal carers.

How much support a family carer receives is to a high degree decided by the different municipalities.

5.9 Use of technology for LTC quality

Some examples of some major projects and additional references about technology and quality of LTC:

The Technology and Dementia Project

Managed by the Swedish Institute of Assistive Technology – SIAT has stimulated increased use of new technologies and tools that can provide support in daily life that help to be active, safe and secure. The three-year project engineering and dementia was completed in autumn 2008.

Assisting Carers using Telematics Interventions to Meet Older People's Needs (Action)

The ACTION service was initially primarily developed to provide support to family caregivers, but with time this technology evolved to also a self-care support system used directly by the patients. The Service is connected via an ordinary TV Screen.

ACTION service is currently active in 25 municipalities in Sweden and has approximately 300 users.

The ACTION service is composed of:

- Information provision and educational programmes on health care in daily lives; programmes on how family members and older people more easily can cope with daily life; information about help and support available in the community; technical aids.
- Gymnastic and relaxation programmes.
- Programme for stimulation of the cognitive functions
- Programmes where users can enter their life story and illustrate with photos.
- Recorded lectures on care, help and support.

IPPI

IPPI is a tool developed to facilitate, and include, older people in the modern information society. The goal of the project IPPI, is that everyone can use a TV to be able to communicate in the digital world.

IPPI enables people to receive movies and pictures from children's or grandchildren's camera phones and IPPI enables the service users to get picture and name of the carers who will visit them from the home care provider. Relatives can provide text, voice, and video messages

AMIGO

The Amigo Service is a merge of 3 different services where IPPI is one part. The other two parts are a digital "manual" for informal carers and the access to a call centre. The AMIGO service is approximately used in 20 municipalities.

Technology in apartments (Malmö)

The project aims at developing 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.

The project includes obtaining guidelines for the resource centre's organisation, creating a display environment and mobile showrooms, implementation of workshops and training and developing sales activities in the Resource Centre.

Artemis II

The Multicultural Association of Pensioners has received funds to further develop methods to prevent accidents and raise awareness about older people's security and various facilities for older people and their dependents from other countries.

Technologies for the elderly in Kramfors

The purpose of this project is that technology in everyday life for people over 80 should be included as part of the municipality's Prevention Centre, where the interaction takes place with support to relatives and other actors involved in prevention. The aim is to gain greater knowledge of and interest in the technology of everyday life by getting the opportunity to test technical solutions.

5.10 References on LTC quality in Sweden

- Alaby, G. (2011, 08 03). National Board of Health and Welfare . (T. Emilsson, Interviewer)
- Bergh, A. (2011, 03 08). National Board of Health and Welfare Project Manager. (T. Emilsson, Interviewer)
- Emriksdotter, B. (2011, 03 09). Staff and Education officer Swedish Association of Local Authorities and Regions (SALAR). (T. Emilsson, Interviewer)
- Lacouture, T. (2011, 03 08). Quality and efficiency comparisons in Swedish elderly care. Sockholm, Sweden.
- Livergren, N. B. (2011, 03 07). Project Manager . (T. Emilsson, Interviewer)
- Quality and Efficiency in Swedish Health Care – Regional comparisons 2009. (2010). *Quality and Efficiency in Swedish Health Care*. Retrieved 03 08, 2011, from <http://www.socialstyrelsen.se/publikationer2010/2010-4-37>
- Swedish Government Offices Elderly care (2011, 03 02). *Elderly care*. Retrieved 03 02, 2011, from Elderly care: <http://www.sweden.gov.se/sb/d/12073>
- Swedish Association of Local Authorities and Regions (SALAR). (2009). *Quality and Efficiency in Swedish Health Care Regional comparisons 2009 County Council Comparisons – Figures Description of Indicators*. Retrieved 03 08, 2011, from Swedish Association of Local Authorities and Regions: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18023/2010-4-37.pdf>
- Swedish Government Health and medical care. (2011, 02 25). *Swedish Government* . Retrieved 02 25, 2011, from <http://www.sweden.gov.se: http://www.sweden.gov.se/content/1/c6/08/60/40/982480dd.pdf>
- Sveriges Kommuner och Landsting och Socialstyrelsen Öppna jämförelser 2010 Vård och omsorg om äldre. (2010, 12). *Öppna jämförelser 2010 Vård och omsorg om äldre*. Retrieved 03 08, 2011, from Öppna jämförelser 2010 Vård och omsorg om äldre: http://brs.skil.se/brsbibl/kata_documents/doc39863_1.pdf
- The National Board of Health and Welfare Application for Swedish licence to practise for applicants from countries outside of the EU/EEA. (2011, 03). *Application for Swedish licence to practise for applicants from countries outside of the EU/EEA*. Retrieved 03 2011, from <http://www.socialstyrelsen.se/applicationforswedishlicencetopractiseothercountries>
- The National Board of Health and Welfare. (2011, 02 25). *The National Board of Health and Welfare*. Retrieved 02 25, 2011, from [www.socialstyrelsen.se: http://www.socialstyrelsen.se/en/](http://www.socialstyrelsen.se/en/)
- The Swedish Board of health and Welfare, Nationella riktlinjer. (2011, 03 02). *The Swedish Board of health and Welfare, Nationella riktlinjer*. Retrieved 03 02, 2011, from The Swedish Board of health and Welfare, Nationella riktlinjer: <http://www.socialstyrelsen.se/riktlinjer/nationellariktlinjer>

5.11 References on technology and LTC quality

- Magnusson L, Hanson E & Borg M. (2004). A literature review study of Information and Communication Technology as a support for frail older people living at home and their family carers. *Technology and Disability*. 16, 223-35.

- Magnusson L. (2005). *Designing a responsive support service for family carers of frail older people using information and communication technology*. Göteborg: Göteborgs Universitet.
- Magnusson L, Hanson E & Nolan M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Ageing and Society*. 25, 693-713.
- Magnusson L & Hanson E. (2005). Supporting frail older people and their family carers at home using information and communication technology: cost analysis. *Journal of Advanced Nursing*. 51(6), 645-57.
- Umefjord G, Hamberg K, Malker H & Petersson G. (2006) The use of an Internet-based Ask the Doctor Service involving family physicians: evaluation by a web survey. *Family Practice*. 23(2), 159-66. Epub 2006 Feb 7.
- Umefjord G, Sandström H, Malker H & Petersson G. (2007). Medical text-based consultations on the Internet: A 4-year study. *International Journal of Medical Informatics*. 19, 19.

6. The Netherlands (by CPB)

6.1 LTC quality documents

Policy goals

The Minister of Health has ministerial responsibility for a functioning system for long-term care by:

1. Creating conditions for the accessibility, quality, safety and affordability of care for those with a chronic or prolonged restriction of a physical, mental or psychological character;
2. Strengthening the position of citizens and in particular clients and/or their representatives with a long-term or chronic illness or disability;
3. Promoting and enhancing the innovative capability.

There are 4 objectives in the operational area of long-term care:

1. The position of the citizen in the care system is strengthened;
2. For each client the necessary care is available;
3. The care is effective and a safe and positive experience for the customer (quality of care);
4. The costs of care are socially acceptable.

General information on quality policy

In the annual publication on the budget, policy for the upcoming year is described, including the policy regarding quality of LTC (Budget Ministry of Health, Welfare and Sport for the year 2010, article 43, Long-term care)

Other resources:

http://www.rijksbegroting.nl/2010/voorbereiding/begroting,kst132834b_6.html

http://www.igz.nl/english/_phased_supervision/quality-indicators/

The Health care Inspectorate (IGZ) is responsible for the supervision of the quality of care. Their website describes the process of supervision.

The Quality Act states that providers have to deliver 'responsible' care. In VWS (2005) the State secretary decided to make the use of quality systems compulsory. VWS (2006) contains the directions of the new policy of the Ministry of Health on quality. The main principles: measurability and observability of quality, binding norms on safety, supervision by the IGZ (Inspectorate of Health care) on top of the supervision that has to take place within provider-organisations.

The letter VWS (2007), entitled 'Direction on quality', can be seen as the next policy statement of the Ministry concerning quality. The Ministry stresses the importance of systematic quality improvements. The focus is on observability of quality, client responsiveness and safety. This forms the basis for the collection of two types of information: health safety indicators and indicators that focus on client experiences.

Relevant publications of the Ministry of Health on quality policy:

- VWS (2005). Voortgangsrapportage over Zorg voor Beter. Tweede Kamer, vergaderjaar 2004–2005, 28 439, nr. 9. Den Haag: Sdu.

- VWS (2006). Beleidsbrief Kwaliteit van zorg hoog op de agenda. Tweede Kamer, vergaderjaar 2005–2006, 28 439, nr. 12. Den Haag: Sdu.
- VWS (2007). Brief Koers op kwaliteit. Tweede Kamer, vergaderjaar 2007–2008, 28 439, bijlage 2 bij nr. 18 (herdruk). Den Haag: Sdu.
- VWS (2007a). Vaststelling van de Begroting VWS 2007. Tweede Kamer, vergaderjaar 2007–2008, 31 016, 28 439, 31 200 XVI, nr. 19. Den Haag: Sdu.
- VWS (2008a). Reactie van de staatssecretaris van VWS op het IGZ rapport
- De toon gezet. Tweede Kamer, vergaderjaar 2007–2008, 31 200 XVI, nr. 186.
- Tweede Kamer, vergaderjaar 2008–2009, 31 961, nrs. 1–2 87
- VWS (2008b). Begroting VWS 2009. Tweede Kamer, vergaderjaar 2008–2009, 31 700, nr. 2. Den Haag: Sdu.
- VWS (2008c). Brief Regie op richtlijnen. Tweede Kamer, vergaderjaar 2008–2009, 31 765, nr. 1. Den Haag: Sdu.

The development of quality indicators

The Quality Act states that providers have to deliver 'responsible' care. This concept has been made measurable, in a system of quality indicators. Before 2005, there was no standard to determine what good quality long-term care was. The development of the quality programme that focuses on long-term care and the aged population (called 'Zorg voor beter') began in 2004. By 2005, the first set of norms for the nursing sector ('VVT' in Dutch) had been developed (in collaboration with the sector). In 2007 a semi-final set of quality indicators for long-term care became available.

Quality indicators' are intended to render the quality of health care services measurable and transparent. The indicators are developed by the field itself. In each care sector, the Inspectorate works jointly with health care providers, insurers, and representative groups of patients as well as the disabled and elderly to produce appropriate indicator sets.

The Minister of Health has appointed the Inspectorate to supervise the production of quality indicator sets, resulting in the 'Visible Care' programme. The website at www.zichtbarezorg.nl provides information about the care sectors in which quality indicators are already in place, and the progress of implementation in other sectors.

From September 2008, the quality indicators are published in the Annual Social Responsibility Reports (Maatschappelijke verantwoording) and on the website kiesbeter.nl

The Framework for responsible care shows the quality of institutional care, for the industry as a whole and for individual care providers.

Publications on quality indicators:

Overzicht indicatoren voor Verantwoorde zorg VVT: (An overview of the quality indicators for the long-term care sector (in Dutch))

Publieksversie bij het rapport van de Stuurgroep Kwaliteitskader Verantwoorde Zorg Verpleging, Verzorging en Zorg Thuis (VV&T) (Popular version of the report of the steering committee responsible for the Quality Framework in formal institutional care and home care (in Dutch))

6.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Safety	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Responsiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Coordination	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Tot		8	8	8	0	24

Quality publicity: data about quality results in LTC are publicly available but aggregated at a national level. Data about each provider are publicly available on a voluntary basis.

One of the government targets in the health care sector (government target 45b) is to increase transparency in health care by publishing quality indicators on <http://www.kiesbeter.nl>. In 2007 only 15% of the providers in the LTC sector published the quality indicators. In 2008 this number increased to 49%, the target for 2010 is set to 75%. The long-term target is set to 100%. Source: http://www.rijksbegroting.nl/2010/voorbereiding/begroting_kst132834b_6.html

Raw data (not adjusted for case mix differences) about individual providers are not publicly available. For the publication, the quality indicators of individual providers are adjusted and ranked according to a five star system.

Minimum standards: in the Netherlands, there are no minimum standards that are directly based on quality indicators. However, the indicators allow the Health Inspectorate to identify providers, which are likely to put patients at risk and to intervene. If an LTC-provider shows an extremely bad performance and does not improve after receiving the Inspectorate's warnings, the Inspectorate can in the end close it down.

Voluntary certifications are diffused. 605 organisations with 1415 branches (out of 1991 provider institutions) are certified according to the standards of the HKZ keurmerk, HKZ opstapcertificaten 1 and 2. There are other institutions certified by ISO and other standards but we do not know the number of these institutions.

Human resources: To improve the level of medical care in nursing homes, the Ministry of Health, Welfare and Sports decided to acknowledge nursing home medicine as a new medical specialist field in 1990. The Netherlands became the first country in the world where nursing homes started to employ specially trained physicians on a permanent basis (1 fulltime physician for every 100 patients). The number of trainees who started the mandatory training course has increased annually, rising from 15 to 100 between 1989 and 2009. In 2007 the Minister of Health, Welfare and Sports decided to extend the duration of the training course from two years to three.

Nursing home physicians tend to work outside nursing homes more and more, as a treating physician at geronto-psychiatric hospitals, at outpatient wards and transfer wards of hospitals, or at hospices. Many nursing home physicians also began to work for patients suffering from dementia who were living at home. From 2009 onwards, a nursing home physician is renamed elderly care physician. Source: <http://www.soon.nl/content.asp?kid=10002778>

A working group of general practitioners and specialists in geriatric medicine/social geriatricians initiated a national collaboration (the so-called Landelijke Eerstelijns SamenwerkingsAfspraak LESA) to provide better care for patients with dementia and their families. Source: <http://verenso.artsenet.nl/Artikel/LESA-Dementie-1.htm>

The training institute for professionals working with elderly (Gerion) developed training in cooperation with the Alzheimer foundation for case managers who deal with people with dementia. Source: <http://www.gerion.nl/index.php/Nascholing/Opleiding-Casemanager-dementie/menu-id-647.html>

Clinical Geriatric Nursing Education is a voluntary training initiated by the Association of Nurses and Carers <http://geriatrie.venvn.nl/Home.aspx>

In 2008, the average partitioning into the five qualification levels in a nursing home of the persons taking care of the patients, was as follows: level 1:0%; level 2:8 %; level 3:79 %; level 4:6 % and level 5:3%. Hence, the most of the staff in nursing homes are care workers that have a third (middle) qualification level. Level 0 consists of unskilled workers and volunteers. Highly qualified nurses are typically present in the nursing home during the day hours. They have generally a management position and therefore often do not work in the evening hours, nights and weekends. Source: www.btsg.nl

6.3 LTC quality guidelines

	Risk management and malpractice	Alzheimer's disease and dementia	Fall prevention	Pressure Ulcers	Physical restraints	Other (please specify)
1. EBM guidelines for LTC have been developed in the last 3 years		since 2005	since 2004	since 2002	since 2001	Guidelines on Parkinson disease (2010).
2. EBM guidelines have been disseminated to professionals and the public		yes (see footnote 9a)	yes (see footnote 9a)	yes (see footnote 9a)	yes (see footnotes 9a abd 9b)	
3. There is an agency for the integration and dissemination of EBM guidelines (please specify)	The Dutch Institute for Health care Improvement CBO (Kwaliteitsinstituut voor de Gezondheidszorg CBO, CBO=Centraal BegeleidingsOrgaan) develops and disseminates the guidelines in collaboration with medical professional organisations.					
4. There is an agency for the systematic monitoring of the effects of EBM guideline implementation (please specify)	The Dutch Institute for Health care Improvement CBO is also a centre for implementation of innovative technologies. As far as we know, no systematic monitoring of the effects takes place.					

Footnotes:

9a) The Dutch Institute for Health care Improvement CBO (Kwaliteitsinstituut voor de Gezondheidszorg CBO, CBO=Centraal BegeleidingsOrgaan) develops and disseminates the guidelines in collaboration with medical professional associations. The CBO disseminates their guidelines by making them accessible using the online tool DiliGuide (www.diliguide.nl). DiliGuide stands for Digital Living Guide, which works similarly to wikipedia. A difference with Wikipedia is that updating is performed by professionals who know their field well. Information is updated under the supervision of the scientific associations. E-learning modules are available to support the professionals in using these new generations of guidelines and indicators.

9b) The aspect of freedom restrictions is under special attention of the Health Care Inspectorate. The intention is to reduce the usage of these restrictions: <http://www.igz.nl/onderwerpen/verpleging-en-chronische-zorg/vrijheidsbeperking/>

There is also an agreement made at the national level that the freedom restrictions should be reduced. See e.g. Verbeterd kwaliteitskader VV&T 2010.

6.4 Strategies for quality in informal LTC

- Assessment of LTC needs and personalised self-care plans are performed, depending on circumstances. The assessment of the needs of patients is performed by a special assessment institution (called 'Centrum Indicatiestelling Zorg, CIZ'). However, this assessment only takes place when the client puts in a request for publicly funded care (in kind or as cash benefits). Thus informal care giving can be carried out without an assessment. Patients in formal care facilities have their personalised 'living plan'. See the list of indicators in DEL. 5.2.
- Courses for informal care-givers (family members, friends, etc.) are provided. E.g., the association of informal care Mezzo organises courses on providing care at home (washing patients, prevention of pressure ulcers, etc.) and courses on taking care of patients with dementia. http://www.mezzo.nl/praktijkvoorbeelden/cursussen_voor_mantelzorgers/831
- Awareness raising campaigns about quality in LTC and home devices or technologies supporting self-care: e.g., the association for informal care Mezzo organises workshops on different topics which increase the awareness of informal care providers. Financial support for buying technologies for self-care and home devices. Some home supporting devices (house adjustments needed for living, special lifts, etc., and transportation devices, e.g. a wheelchair or adjustments of a personal car) are partly reimbursed by local authorities. In particular, wheelchairs are reimbursed fully. There can be however a restriction on income to be eligible for this compensation. <http://www.mezzo.nl/hulpmiddelen>
- At the national level, there is an association of informal care, called Mezzo, which provides advice and information to informal care givers. In 2008, 244 organisations were members of Mezzo. www.mezzo.nl

6.5 Use of technology for LTC quality

Effectiveness: Telecare services involve the use of ICT to deliver care to clients located elsewhere. For example, one such project has started as cooperation between an insurer, a patient organisation and a telecommunication provider (the Koala project in province Groningen, covering telecare en telecure). The clients could contact any time (24x7) a nurse or a Medical Service Centre (MSC) via their own TV. This project has initially focused on patients

with chronic conditions, but it is seen as the basis for the future teleservices for long-term care in general. Website of the organisation Koala: <http://www.koalaweb.nl/index.php>;

Groningen University (2008) 'Onderzoek naar de effectiviteit en efficiency van Koala telecare en telecare' <http://www.zorginnovatieforum.nl/projecten/ZoA/Koala%20eindrapport.pdf>

Safety. Different 'domotica' applications are used by most formal care institutions, such as bellmats, sensors, doorblockers and cameras (on average, 3 applications per nursing home). Many nursing homes also use cameras and listening devices. Some use Radio Frequency Identification (RFID) as well. The Dutch Health Care Inspectorate especially promotes their use in order to reduce strong limitations on the movement freedom of patients. One of examples 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 and /or personal care at home. IGZ (2009) 'Toepassing van domotica in de zorg moet zorgvuldiger'; <http://www.nza.nl/publicaties/nieuws/NZa-zorg-op-afstand-krijgt-vervolg/>

Responsiveness. The domotics applications described above also increase the quality of life by increasing the client's independence. In addition, telecare has been used. This includes monitoring, consulting and treatment. For example, a nurse can monitor the client via a video network, or address the client's psychic problems. In care outside institutions, there are possibilities of financing such care, e.g. in special housing zones and complexes. "IGZ (2009) 'Toepassing van domotica in de zorg moet zorgvuldiger'

Sources: Algemene Rekenkamer (2009) 'Zorg op afstand, Een innovatie in de langdurige zorg' Beleidsregel 'Zorginfrastructuur'

Coordination. Telecare services support coordination. The TeleCare project of the firm 'Novay' (see www.novay.nl) aims at the improvement of care by means of communication and information exchange between the various care providers and institutions using integrated fixed and mobile ICT applications. Another example is the Koala project (see above), where the MCS's also perform external coordination of services for their clients, such as calling for the nursing team, making appointments or sending faxes to contact persons. www.novay.nl

7. United Kingdom (by LSE)

7.1 LTC quality documents

- DH (2010) Liberating the NHS: transparency in outcomes - a framework for the NHS. A consultation on proposals. TSO: London
- Care Quality Commission (CQC) (2010) Guidance about compliance. Summary of regulations, outcomes and judgement framework. CQC: London
- Information centre (2010) Social Care and Mental Health Indicators from the National Indicator Set - further analysis, final, England 2008-09, IC: Leeds downloaded from: <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/social-care-and-mental-health-indicators-from-the-national-indicator-set--further-analysis-final-england-2008-09>
- See <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/user-surveys> for details of past user surveys of home care and other social care services & for future survey programme
- Information Centre (2009) Personal Social Services Home Care Users in England aged 65 and over, 2008-09 Survey. Ic: Leeds. Downloaded at: <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/user-surveys>
- Information centre (2006) Personal Social Services Survey of Home Care Users in England aged 65 and over, 2005-06. IC: Leeds. Downloaded at: <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/user-surveys>
- CQC (2010) Guidance about compliance. Essential standards of quality and safety. CQC: London
- DH (2010) Equity & excellence: liberating the NHS. Cm7881. TSO: London

7.2 LTC quality system

		FIC	FHBC	FHNC	IHC	Tot
Effectiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Safety	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Responsiveness	Policies	1	1	1	0	3
	Indicators	1	1	1	0	3
Coordination	Policies	1	1	1	1	4
	Indicators	0	0	0	1	1
Tot		7	7	7	2	23

NB: the above framework did not really work for indicators in England as they have taken an outcomes-based & disease-specific approach, rather than a service-led approach. This approach will continue under new Coalition Govt.

Under Labour there was a data collection for performance called the performance assessment framework (PAF) which stopped being collected in 2008 and was replaced by the National Indicator Set (NIS). Many of the indicators were disbanded at this time. The NIS aimed to capture outcomes and indicators tend to capture elements of these aspects of quality but not really specifically by service. In fact very few indicators have ever focused on particular service apart from the patient value responsiveness indicators as surveys have in the past been service specific.

The elements of effectiveness, safety and patient value responsiveness (+ coordination) are all monitored by the regulator (CQC). CQC is currently developing a new framework to monitor compliance with quality and safety standards and they have not yet published how they will do so for any of the above services. Not clear if they will make this data available as indicators.

Publicity of data. Data about publicly-funded services are collected through performance framework, but it is not clear what data will be until Coalition announces plans & NICE develop quality standards. The system of providing quality ratings for providers, which has operated since 2003 for formal institutional care and 2005 for formal domiciliary care is no longer in operation from June 2010. It is not yet clear whether there will be a ratings system for providers to replace it.

The previous system for providing quality ratings for providers, used to undertake inspections (the basis for making quality ratings) on a risk-adjusted basis. Poor and adequate providers are inspected at least annually, good and excellent providers are inspected biennially or triennially respectively. Since quality ratings were only awarded following an inspection, good/excellent performers received less regular updates of their ratings. However, quality ratings are available on an ongoing basis throughout the year as consumers can search for providers by quality ratings. Quality ratings are still found on the website but these will be removed once the new system becomes fully operational

Minimum standards of quality. Quality indicators do not have any minimum standards attached. Minimum standards, known as quality and safety standards, are set out in legislation and implemented by regulator, CQC. The aim is also that NICE will publish quality standards for health and social care and that these will inform the development of indicators.

7.3 LTC quality guidelines

	Risk management and malpractice	Alzheimer's disease and dementia	Fall prevention	Pressure Ulcers	Physical restraints
1. EBM guidelines for LTC have been developed in the last 3 years	legislation, CQC state how to ensure compliance and monitor compliance. As part of professional development Royal College of Nursing provides courses and materials for nurses on risk management	x	in 2004 and 2005. NICE guidelines due for review in 2011	in 2005, NICE due for review in 2011	legislation, CQC state how to ensure compliance and monitor compliance

2. EBM guidelines have been disseminated to professionals and the public	legislation, CQC state how to ensure compliance and monitor compliance. Nurses study as part of professional development	x	x	x	legislation, CQC state how to ensure compliance and monitor compliance
3. There is an agency for the integration and dissemination of EBM guidelines (please specify)	National Institute for Health and Clinical Excellence (NICE) writes guidelines for cost-effective treatment for various conditions & NHS evidence brings together a library of sources of information on best practice; Social Care Institute of Excellence (SCIE) publishes guidance on topics and research reviews which summarise the available research evidence in particular areas. It also has a searchable library on best practice known as Social care online. NICE is also in charge of developing quality standards which are designed to set out the best practice for all the main pathways of care (including social care), drawing on evidence and providing information for clinicians and patients on relevant studies. NICE has worked with SCIE to develop guidelines where the pathways cut across health and social care e.g. dementia				
4. There is an agency for the systematic monitoring of the effects of EBM guideline implementation	There isn't a single agency, but guidelines will often state who should be monitoring optimal management of individuals e.g. GP, care manager and CQC will often be looking for adherence to standards in their inspections e.g. minimal use of restraints, good processes in place for risk management and so on.				

7.4 Strategies for quality in informal LTC

- Assessment of LTC needs and personalised self-care plans: carers have a legal right to an assessment of their own needs when they are providing "regular and substantial care" to someone. There is no legal definition of what "regular and substantial" means.
- Courses for informal care-givers (family members, friends, etc.). Plans for on-line self-study. There was a government-funded programme of courses for informal carers called 'Caring with Confidence' (initially announced as the 'Expert Carers Programme'). However, it was discontinued on 28th September 2010, although local carers' organisations (run by the voluntary sector) may continue to provide some training courses. There are plans for an on-line self-study learning programme on the NHS website to help people in their caring role, but this has not been established to date (October 2010).
- Awareness raising campaigns about quality in LTC and home devices or technologies supporting self-care. The NHS website includes information on home devices and technologies (telecare). Local carers' organisations may hold similar information.
- Financial support for buying technologies for self-care and home devices. Carers who wish to apply for telecare or other equipment are advised to contact their social services department and, if the person they are looking after is eligible, social services should pay for it. However, eligibility criteria may mean that many people with carers are ineligible for support. Carers can also contact their NHS trust, who may pay for a telecare system as part of a continuing health care or intermediate care package. Alternatively, carers are advised to pay for telecare themselves.

In general it is extremely difficult to monitor the quality of informal care since most carers are not in touch with social services departments.

7.5 Use of technology for LTC quality

Technology has been implemented in order to support all quality dimensions; see for example the Whole Systems Demonstrator's project (DH-funded research project). There are also a number smaller pilots which have taken place in different parts of the country (including Scotland) e.g. West Lothian pilot. See this link for examples of other projects: (<http://www.networks.nhs.uk/nhs-networks/whole-system-demonstrator-action-network-wsdan>).

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).