Health systems and long-term care for older people in Europe
Modelling the interfaces and links between
prevention, rehabilitation, quality of services and informal care

The INTERLINKS Framework for LTC

Themes, sub-themes, key issues and the template to describe and analyse long-term care

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Introduction

Following the first two project phases of INTERLINKS, a framework has been developed to describe and analyse long-term care systems and their links with the health system, focusing on prevention and rehabilitation, informal care and quality development. Indeed, in INTERLINKS national reports and European overview papers concentrating on these aspects, long-term care[1] has been identified in all European countries as a rather loosely coupled system between health and social care, as an area of fragmented services, with various kinds of residential facilities, and often inconsistent policy initiatives and governance mechanisms for (potential) users and informal carers (Kümpers et al, 2010; Nies et al, 2010; Triantafillou et al, 2010; Allen et al 2011).[2]

Integrated long-term care systems with an own identity, pathways and processes, management and organisational structures as well as proper means and resources are thus only just emerging – with some countries more advanced than others. In order to contribute to the analysis and improvement of this development in Europe, the INTERLINKS framework has been developed to illustrate which elements have to be in place to address the links and interfaces between social and health care systems and to construct an integrated long-term care system. This framework is structured by four levels, namely themes, sub-themes, key issues and practice examples. The latter are described and analysed by means of a mutually agreed template. All these elements are defined and exposed in the following.

The themes include:

- Identity of Long Term Care
- Policy and Governance
- Pathways and Processes

[1] Our initial starting-point was to follow the definition provided by the OECD and WHO. According to the OECD long-term care "is a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL), such as bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom. This is frequently provided in combination with basic medical services such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care. Long-term care services also include lower-level care related to help with instrumental activities of daily living (IADL), such as help with housework, meals, shopping and transportation. Long-term care can be received in institutions or at home. A long-term care institution is a place of collective living where care and accommodation is provided as a package. It refers to a specially designed institution or a hospital-like setting where the predominant service component is long-term care. Long-term care at home is provided to people with functional restrictions who mainly reside at their own home. It also includes institutions used on a temporary basis to support continued living at home -- such as community care and day care centres and respite care facilities. Home care also includes specially designed or adapted living arrangements for persons who require help on a regular basis while guaranteeing a high degree of autonomy and self-control and adapted/supportive living arrangements." (OECD Health Data, 2008). According to WHO long-term care entails "activities undertaken by informal caregivers (family, friends and/or neighbours) and/or professionals (health and social services) to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity" (WHO, 2000).

[2] see http://interlinks.euro.centre.org to download national reports and European overview papers.

- Management and Leadership
- Organisational Structures
- Means and Resources

Each theme contains an introductory explanation of its purpose in the modelling process, and is further defined by a number of sub-themes that, again, are further specified by relevant key issues. Each of the six themed sections contain a rationale of how the construction of sub-themes and key issues was informed by initial work undertaken within the first two project phases that resulted in European overview papers. Key issues also reflect the primary foci of INTERLINKS, namely prevention and rehabilitation, informal care, quality development and governance and finance. The selected practice examples will be described and analysed with a view to these key issues that, in general, serve to identify the links and interfaces or respective gaps addressed by the practice example.

At the heart of the INTERLINKS framework is the user and/or informal carer. Themes, sub-themes and key issues are embedded within a person-centred approach. The framework is based upon some underlying principles that are applicable to older frail and dependent people. These imply that self-direction is important for quality of life; that the needs of frail older people using long-term care are multiple and should be addressed in their social, physical and societal context; that care provision and support should empower clients, strengthen their self-direction, and support them to live a valuable and dignified life. Cohesion and continuity of service delivery and staff support are therefore key values for the construction of integrated long-term care systems. Practice examples to facilitate their implementation can be found, for instance, under the theme 'Identity of Long-Term Care'.

These and other practice examples will in some cases be situated at the systems or macro-level, including national and regional policy, legislation or funding processes. Many examples, however, will be illustrating the organisational or meso-level, e.g. local delivery processes, organisation's service charters or specific organisational structures. Finally, some examples will show processes and initiatives concerning the micro-level, e.g. specific approaches or methods to tackle users' or carers' needs. As the construction of long-term care systems is taking place at all levels – with different speed and outcomes – the framework adds 'bricks and mortar' to all of them in order to learn from other experiences, to find suggestions for improvement and to compare own practice against lessons from abroad.

Between December 2010 and February 2011, a validation and review exercise was carried out with National Expert Panels from all the participating countries. This working paper was subsequently revised according to comments and suggestions, for which we would like to thank all members of National Expert Panels.

The interactive web-site that will go public in Spring 2011 will further link the INTERLINKS framework with on-going practice. About 100 peer-reviewed practice examples prepared by the project team will improve understanding of the framework as their description and analysis will focus on individual themes, sub-themes and selected key issues. Web-site users will then be invited to add their own examples that will be peer-reviewed by the project team.

Themes, sub-themes and key issues

1 Identity of Long Term Care

INTERLINKS research findings have shown that long-term care (LTC) as a defined concept is only beginning to emerge and is placed at the junction between health and social care. In some countries LTC is taking shape as an incipient system, at times with a growing formal identity. Everyday care, however, which is provided on an informal basis to older people with long-term needs, is evident in all countries.

To improve LTC in Europe, it is important to find and highlight any systematic approaches that define LTC as a single entity or at least as a specific area of social risk. These approaches can be on either the systems level (eg national governments' key papers, legal guidelines and principles, the regulation of migrant caregivers) and on the organisational level (eg mission statements addressing links and interfaces, civil society initiatives, educational aims).

Furthermore, basic values and rationales in given societies are essential preconditions for understanding political and societal choices in LTC and how LTC is carried out in everyday practice.

The key issues within the sub-themes draw out particular concerns in relation to diversity, gender, dignity and empowerment that are embedded within the European reports and provide a rationale for their prominence. Kümpers et al (2010) for example point out the tension between the consequences of on-going demographic changes, social disadvantage and developing family and gender roles and ***values***. Specific needs relating to gender and disadvantage are seldom taken into account when conceptualising health and social care services and this affects the dignity and empowerment of these individuals. Changing roles, both for women and men alongside the dispersal of traditional, multi-generational family units is leading to a demand for LTC services that clearly define the position of the client within them, are flexible enough to meet individual needs and take account of both growing diversity and those who are marginalised by society.

In addition, Kümpers et al (2010) note that the concepts of self-determination and self-care associated with empowerment and choice represent values that recently seem to have gained importance in regulating social welfare and social policies within EU countries. This is visible in principles and policies of 'enabling' governments. Tendencies towards greater individualisation and self-determination have also become more pronounced.

Across Europe there is a growing number of older people from ethnic minorities whose specific cultural values and family ethics are often neglected by mainstream services especially at the interfaces (Triantafillou et al 2010) and must be reflected in organisational LTC values and ***mission statements***. Nies et al (2010) add that a common ***organisational definition*** and view of the LTC system, of its nature, its goals and of the conditions of access to services provided between the stakeholders involved is a fundamental prerequisite to quality management in LTC, and hence quality of life for the recipient.

1.1 Values

Values are important for shaping political, organisational and individual choices in LTC. By organisational values we mean beliefs and ideas about what kinds of goals for the organisation workers should pursue. Organisational values tell workers about what sort standard or norms of behaviour are acceptable to achieve these goals. In addition, values can be formed in terms of outcomes for users. Organisational norms, guidelines and expectations about workers are developed from these values.

Examples must describe at least one of the following key issues:

a) how key principles that characterise LTC are expressed; what values dominate for which stakeholder perspectives (eg economic and quality perspectives, citizenship)

b) whether there are sets of values that are shaping political, organisational and individual choices in LTC (eg through surveys of older peoples' specific needs for care and support)

c) how informal care and/or family ethics are addressed in legislative frameworks

d) how issues of dignity, quality of life and empowerment are described in policy papers

e) how values relating to prevention and rehabilitation are considered

f) how values embrace the diversity of users and carers (according to gender, culture and social inequalities) and support the specific needs of hard-to-reach groups

1.2 Mission statements

A mission statement is a formal, short description of an organisation's fundamental purpose. It should answer the question, "Why do we exist?" and spell out the overall goal for the organisation eg the approach to care and the position of the user within the organisation. Examples of mission and/or vision statements describe how LTC is represented and must include at least one of the following key issues:

a) organisations that explicitly address problems at the interfaces between, for example, formal/informal and health and social care, prevention and rehabilitation or the use of migrant care workers

b) a description of how the problems are addressed and what particular factors distinguish an organisation as a 'LTC organisation', rather than a health or social care organisation

1.3 Organisational definitions

This sub-theme includes examples from innovative, LTC-oriented organisations that provide specific definitions and concepts of LTC in practice. Examples must include at least one of the following key issues:

a) how LTC is defined within or between organisations

b) how health care providers define their purpose in relation to LTC (cure vs. care; needs vs. supply; expectations vs. preferences)

c) how clients are defined and positioned

2 Policy and Governance

The focus in this theme is on how policy and governance in LTC address links and interfaces both at the organisational and systems levels. 'Policy' here consists of implementation directives, while 'governance' is concerned with the linkages between government at different administrative levels and other stakeholders involved in decision-making, performance and control. This theme includes examples within policy papers, reform proposals, task force or working group reports for Ministries or governments, legal texts (preambles), statements by interest organisations or other political stakeholders. Programmes, guidelines and strategies are included as well as analyses and results of comparative research in this area.

With reference to the European overview papers, all signified the importance of ***policy*** and political commitment to overcoming barriers to LTC integration and equal access within prevention and rehabilitation, quality and support for informal care, as this is closely connected to better visibility and co-ordination of these aspects and embedding them at the practice level.

Regarding ***legal frameworks***, Nies et al (2010) highlight that legal procedures are important and aim to safeguard fair services and equity among the care and service recipients regardless of their age. Though there are only few illustrations of laws or regulations that were created with the aim of improving LTC services, specific laws and acts have been launched in the past decades for health care and social services. LTC services have to operate within and between these systems and governmental layers and it is relevant therefore to search for good practice examples in this area, particularly in relation to combining LTC with prevention and rehabilitation, support for informal care and quality development.

In addition to this, Nies et al (2010) describe the relative merits of authorisation, accreditation and quality systems as legislative frameworks to improve LTC. Regulation and inspection are the most common and authoritative systems of assuring minimum quality standards and with accreditation, there are benefits in that service requirements are defined and compliance is assessed by expert consultants. In many countries, accreditation is a precondition for services to receive subsidies and/or reimbursement of service costs by public funds.

When it comes to workforce planning, it is becoming increasingly imperative to consider the ways in which governments are acting to guarantee a qualified LTC workforce. Not only are informal carers' contributions to caregiving are likely to be reduced in the future, but also recruitment and retention of the formal workforce is problematic with far from encouraging forecasts (Triantafillou et al 2010) . Thus these aspects warrant inclusion as key issues.

The European papers suggested that negotiating ***governance mechanisms*** can prove to be a barrier to delivering integrated services in LTC especially in relation to our topic areas. According to Nies et al (2010), the effects of competitive and economic measures on care quality are hard to measure so the relevance of incentives become evident. Where incentives induce competition with a specified goal, such as to enhance good local integration or for more resources, overall care quality should increase. This would be through strategic contracting and financing of services in a way that care providers collaborate and form multi-level partnerships, thus increasing potentially the quality and efficiency of the output. However, a local guiding and commissioning organisation with enough financial or regulatory power and legitimacy needs to be in place.

Connected to governance mechanisms are steering capacities, and making them visible within our examples is also important. Kümpers et al (2010) for instance identified that local steering

institutions to promote access have been developed to varying degrees; countries with strong local steering capacities seem to provide a better context for the development of collaborative 'integrated care' approaches in LTC especially in overcoming fragmentation of prevention and rehabilitation.

2.1 Policy

This sub-theme refers to the key messages within policy papers that relate to LTC, such as from national, regional or local policy levels; from the EU level and other international countries. Examples must describe at least one of the following key issues:

a) policy barriers and opportunities in terms of linking social and health care (eg rhetoric as opposed to more achievable opportunities and results, workforce planning)

b) policies addressing continuity and mechanisms to overcome barriers at the interfaces between social and health care

c) policies addressing continuity and mechanisms to overcome barriers at the interfaces between formal and informal care, in particular to set the balance between caring informally and working

d) policies addressing continuity and mechanisms to overcome barriers at the interfaces between prevention/rehabilitation and cure/care

e) policies addressing continuity and mechanisms to overcome barriers at the interfaces between care at home and residential care

f) implementation strategies

g) policies addressing issues of diversity and equal access, i.e. considering differences according to gender, culture, disability and/or social inequalities

2.2 Legal Framework

A legal framework is a set of rules or procedural steps through which judgements can be made in a legal case. It is also an instrument of policy implementation, together with funding and verbal communication. It may also outline the legal actions that will be taken if contractual obligations or agreements are not met. Examples describe what a legal framework for LTC can look like and must include at least one of the following key issues:

a) legislation which explicitly addresses LTC with respect to informal carers

b) legislation which explicitly addresses LTC with respect to interfaces between health and social care

c) legislation which explicitly addresses LTC with respect to workforce planning

d) legislation which explicitly addresses LTC with respect to authorisation, accreditation, quality systems

e) legislation which explicitly addresses LTC with respect to co-ordination or integration of facilities or services

2.3 Governance Mechanisms

A governance mechanism is a specific procedure associated with decision-making, performance or control of formal and informal long-term care providers. Examples must include at least one of the following key issues:

a) institution building to support and emphasize LTC as a specific area of concern (eg quality assurance agencies, insurance system, awareness campaigns)

b) incentives linked to contractual and financial mechanisms

c) incentives to provide LTC by addressing multi-level governance

d) a description of steering mechanisms concerning access and eligibility criteria

2.4 Visibility of key topics

Examples in this sub-theme look at how the core areas of prevention and rehabilitation, quality and informal care are represented in policy and governance. Key issues thus include:

a) Programmes and initiatives to promote prevention and rehabilitation

b) Programmes and initiatives to promote informal care

c) Programmes and initiatives to promote quality development

d) Programmes and initiatives to promote user empowerment

3 Pathways and Processes

This theme focuses on the manner by which older people and informal carers enter and leave care processes. It gives examples of the processes that need to be in place to address needs. Pathways and processes go hand-in-hand: a *pathway* refers in a longitudinal way to the diversity of settings the older person and informal carer will encounter from the moment they enter LTC to the time they leave it. *Processes* refer to all professional activities that take place in and at the interface of the organisations involved or at the service delivery level.

Threaded throughout the key issues in this theme, the principles of choice, involvement in decision-making and carer's interests are clearly visible. Overview papers noted that in some countries freedom of choice for users and carers is valued as a fundamental right, and this is complemented by the notion of taking individual decisions and responsibility for one's own health. Yet this is often restricted and a facade of inclusivity is maintained, when in reality there is discrimination. Thus searching for good exemplars of where these principles are upheld within the grass root level of pathways and processes of care is important.

All papers assert that ***accessing services*** for the vulnerable and heterogeneous group of older people is a crucial policy imperative throughout Europe. Kümpers et al (2010) confirm the evidence from the national reports that lack of equity and limited access of older dependent people to integrated services results in a loss of opportunities and choice for this target group. They suggest that organisational issues and adequate transport as well as other discriminatory factors such as culture and gender are important reasons for such disparities, which can have significant impact on health outcomes. Examples that overcome these barriers are therefore sought.

Intrinsic to the success of care pathways and processes are comprehensive methods of ***assessing needs***. European partner countries identified a number of integrated assessment formats in use, many based on a multidisciplinary assessment where comprehensive treatment regimes and individual plans for remobilisation and reintegration are offered to the patient (Kümpers et al 2010). Needs assessment is vital for the creation of economically efficient tools for planning, standardising and analysing transition processes across health and social care services (Nies et al 2010) and through independent needs assessments, older people can have the freedom to develop a person-centred plan of services.

With a focus on informal carers, Triantafillou et al (2010) agrue that there is strong evidence at the service delivery level that there may be conflicts between the older person's and the informal carer's needs and expectations, i.e. the older person's choices may not always be in line with the needs or expectations of their informal carers and vice versa. This raises the issue of whose needs are being addressed and how to optimally link carer's needs into overall pathways of care.

The overview papers indicated that with increasing managerial tasks placed on professionals, there is less time for contact with service users. With the spotlight on ***discharge and terminating professional contacts***, and in response to the rising demand, roles have been developed to accommodate requirements in an effort to improve continuity and quality in care for service users (Kümpers et al 2010; Triantafillou et al 2010). The most common innovation in job profiles has been the development of discharge managers whose task consists of facilitating the transition between hospital and home care services. These roles have brought to the fore the importance of

follow up, information sharing between professionals and users as well as investigating and ensuring funding for care continuation.

Interdisciplinary work is a strong feature of integrated care and vital to ensure seamless care across the service gaps and interfaces. Kümpers et al (2010) have identified that multidisciplinary, nurse-led teams for example are seen as good practice across settings in many of the European partner countries, particularly for those older people with complex needs and dementia. Having a mix of skills through collaboration, optimal knowledge and information exchange, and clear lines of responsibility are all important ingredients to interdisciplinary work.

Added to this, professionals are working across more settings and performing activities which are not strictly within their professional profile and as a consequence, professional roles are blurring and, as with the development of discharge managers, new roles are emerging (Kümpers et al (2010; Triantafillou et al 2010). Coordination of care for example can enable a joint venture on the professional level, which aims to follow and evaluate the care given to the client. Though still quite exceptional there is a growing tendency to assign 'boundary spanners' as cross-functional liaisons. These individuals' task is to integrate different profession, and combine the roles of case managers and primary nurses.

Interdisciplinary work also includes the role of informal care. Triantafillou et al (2011) state that gaps and tensions exist in the way professional and informal carers work together and share responsibility for supervising and implementing the care process, and good practice in this area needs to be made visible.

3.1 Accessing services

At a certain point in their lives, many older people will require care. This is a crucial phase in which the needs of the older person and the informal network are identified to ascertain which needs must be met, to what timescale, in what ways, where and by whom. Examples of how pathways and processes work must include at least one of the following key issues:

a) case finding through routine screening services (eg preventative home visits)

b) transfer of information to users and carers and about users and carers between services or agencies

c) the older person's and carers' interests and involvement which should consider rights, information, choice, and entitlements

d) how services deal with diversity and equality of access, considering culture, disability, gender, sexual orientation and class to counter discrimination

e) performance management/indicators that relate to service access

f) ethical guidelines

3.2 Assessing needs

Once in the LTC system, needs must be assessed and then reassessed at regular intervals to identify and provide the correct pathways and processes through LTC to make sure there is a good fit between professional input and needs. Examples must provide a description of how

assessment for eligibility of services/benefits as well as within organisational structures is operating and include at least one of the following key issues:

a) multidisciplinary assessment (protocols, tools and instruments)

b) assessment tools and instruments (older peoples' and/or informal carers' needs), protocols, (and electronic records)

c) follow up of needs assessment (transfer of information)

d) older peoples' and/or informal carers' rights: information, shared decision making, consent, privacy regulations, complaints, second opinion

e) dealing with diversity (cultural and socio-economic inequalities, disability specific issues)

3.3 Discharge, terminating professional contacts

At a certain time contact is terminated or a new care setting is chosen. In many cases the main responsibility of care delivery is transferred to another service or professional; in some cases to the informal care network. In a small number of cases the older person regains independent living. Examples must include at least one of the following key issues:

a) how professional and or informal follow up is properly communicated, available and well prepared

b) how older people's and carers' rights are ensured (user-friendly information, shared decision making, consent to care, privacy regulations, complaints, second opinion)

c) how information (files, care plans) and responsibilities are transferred (logistics issues)

d) how information to and dialogue with older people and their informal network are facilitated, and how capacities are enabled and strengthened

e) how funding of next stage care and service delivery is ensured

f) how outcomes are assessed

3.4 Interdisciplinary work

LTC requires interdisciplinary working, as needs of older people and their informal care networks are usually complex. Often these professionals work in different organisational structures. This raises a number of issues regarding how interdisciplinary and inter-organisational work can best be ensured in order to foster a common understanding of comprehensive pathways. Examples must include a description and evidence of at least one of the following key issues:

a) fostering a culture of collaboration (requirements, training, team building)

b) inter-professional exchange/development/agreement about views on care and pathways

c) transfer of information (joint care plans, registers/files)

d) accountability, responsibilities, dealing with hierarchies and professional-cultural clashes

e) new ways of involving older people and/or informal carers

4 Management and Leadership

Innovation and progress regarding linking mechanisms within a comprehensive LTC system as well as between LTC and health and social care require sophisticated and innovative approaches in management and leadership, such as organisational development, human resource management and inter-organisational relations. There should also be a focus on quality development, the integration of older peoples' and informal carers' perspectives and of preventive and rehabilitative orientations.

Within the European overview papers, Nies et al (2010) highlight that when considering ***management and leadership competence and skills***, it is necessary that respective training and leadership approaches are supported to maintain high standards. This is particularly so for maintaining quality systems; for example in Finland there is compulsory training for managers two times per year. Nies et al add that a clear devolution of responsibilities is important in order to achieve and maintain a level of quality in LTC that can correspond to agreed standards or improvement targets. Kümpers et al (2010) and Triantafillou et al (2010) also note that building competencies around the management of networks is vital to facilitate and harmonise the co-ordination of disparate activities such as those that often constitute prevention and rehabilitation and support for informal carers.

Aspects relating to ***quality assurance at the workforce level*** in LTC are becoming increasingly important, as care needs increase and workforce patterns change (Triantafillou et al 2010). Nies et al (2010) comment that a professional's ability to carry high quality care in LTC depends on skills, competencies and how to collaborate within an integrated team. Outcomes also depend on the right skill mix of professionals working together to meet users' needs. With the introduction of new professional roles, such as case managers or facilitators of multidisciplinary working across services, additional skills and training are also required.

Kümpers et al (2010) note that in addition to professional training, certain categories of health care professionals also require official authorisation, accreditation or a license to practice their profession. Vocational training, education and professional qualifications are increasingly recognised as being relevant for the LTC sector. The relatively new phenomenon to supplement family care by employing migrant carers has spread, triggering a series of measures and initiatives that will reinforce training needs, such as compulsory training for employed migrant carers (Di Santo & Ceruzzi 2010). In general, the connection between LTC systems and the quality of informal care, such as care and support by volunteers, remains poorly developed, even if some first steps can be identified (Triantafillou et al 2010).

The ***contractual bases of pathway links*** is fundamental to ensure managerial and organisational agreement between services and therefore warrants inclusion (Nies et al 2010). Some examples are evident in Europe: Kümpers et al (2010) for example identified that as a result of the last health care reform in Germany, an integrated care concept based on contracts with two health insurance funds has been developed. A key feature of this contract is intensive rehabilitative care provision combined with the organisational support of a bridging person, with the aim to enable people to live at home again.

How agencies are ***ensuring relationships with stakeholders***, such as older people themselves, their carers and advocacy groups is important to ascertain. Kümpers et al (2010) identifed some countries or regions who were developing a shared vision of stakeholders, and have started to engage in such a process by involving multiple actors, interest groups and categories of

stakeholders in order to reach priorities and define goals. The involvement of concerned groups in civil society, whose voice may not usually be heard, is often necessary for identifying appropriate ways across health and social care not only to deliver services but to evaluate their suitability and promote high levels of quality. This was found in a few countries only.

Nies et al (2010) note that in the participating countries, some service users and informal carers have started to become active in ensuring the quality of care through shared decision making and consent, choice, satisfaction surveys, and increased information seeking. User involvement, in terms of shared decision making is not a common practice in LTC. In addition, Triantafillou et al (2010) state that a clear distinction must be made between involvement of older people and informal carers; as the boundaries between formal and informal care have become increasingly blurred, informal carers do not always represent the same interests as the older person being cared for.

While true involvement and meaningful activity in this area has yet to become widespread, examples across Europe show that informal carers and users are getting a stronger voice, when it comes to quality assurance (Nies et al 2010). In spite of practical and methodological difficulties, users' opinions are heard more often. Although these are often subjective and individually determined, it is worthwhile to investigate principles and perspectives that are shared by many older people and their representatives.

When it comes to ***quality management***, Nies et al (2010) intimate that a rather patchy pattern emerges across Europe, as many LTC systems are just emerging or 'under development'. In some cases existing systems are being restructured in order to achieve mechanisms that ensure quality, access, financial and labour market sustainability, but these are unclear. Setting goals for defining and evaluating the quality of passages or transitions from one part of the system to another, aspects relating to choice, information, breadth of evaluation, and multi-disciplinary input into decisions has not yet become common practice. Across Europe, there appears to be a movement from minimum quality standards towards quality that aims at excellence. This tendency is more evident in the acute sector, but also in individual LTC services, the first signs of this trend have become visible.

In several countries quality management has become an explicit job profile in the area of LTC, with instruments such as RAI HC, E-Qalin® or EQ-5D as methods explicitly designed for LTC services. The use of audits, benchmarking, performance indicators and National Frameworks are also in use. Client satisfaction surveys as a method for measuring quality are used widely in the participating countries. The validity of satisfaction scores is often limited, but when used in conjunction with other user-based measures, they can be an informative source for improvement. While approaches to quality management can take different tracks, they must work from an holistic perspective with a view on citizens' enhanced quality of life as an outcome. To achieve this goal, all stakeholders have to constantly assess, measure and improve their structures, processes and results.

4.1 Management and leadership competence and skills

Management approaches are needed to develop and maintain management and leadership competence and skills. Leadership expertise within LTC is essential for innovation and

organisational and professional development. Examples describe possible approaches including at least one of the following key issues:

a) foster leadership and management using appropriate training

b) establish management and leadership competences in organisations through mentorship, secondment and shadowing

c) establish leadership competencies regarding the management of networks

4.2 Quality assurance at workforce level

LTC staff need to be comprehensively trained, qualified and supported, so that specific functions and tasks can be fulfilled by designated people, teams, groups or partners (departments) with different roles, responsibilities, expertise and competences. Examples must include at least one of the following key issues:

a) training of professionals in interdisciplinary/interprofessional working

b) enabling interprofessional knowledge transfer

c) fostering diversity-sensitive knowledge and attitudes of staff, promote and make use of multi-ethnical teams

d) shaping job profiles, fostering and mutual understanding of comprehensive pathways

e) establishing competence regarding preventive and rehabilitative LTC

f) establishing competence and providing capacity for supporting and negotiating with older people and/or informal carers at their level

4.3 Contractual bases of pathway links

Those contractual instruments that enable functions to link together should be identified and examples include at least one of the following key issues:

a) using contracts or agreements to enable and sustain processes between services and/or organisations

b) contracts or agreements that link between services professionally and managerially

c) contracts or agreements that specify funding across services

4.4 Administrative support at interfaces

Administrative support is vital to ease the professional burden of bureaucracy within and between services. Examples must describe at least one of the following key issues, i.e.

a) how organisations foster enabling administrative patterns as well as processes between services or organisations, making administrative systems compatible, reducing administrative burden

4.5 Ensuring relationships with stakeholders

Relations with older people and informal carers with other agencies in and outside of LTC need to be facilitated. Examples must describe at least one of the following approaches (key issues) that:

a) enable participation of older people and carers' representatives in shaping pathways and appropriate linkages

b) ensure conditions for older people's and carers' shared decision-making

c) mobilise volunteers' organisations, and ensure their participation

d) consider socio-economic, socio-cultural, disability and gender differences of older people and carers

4.6 Quality management

Quality management should play an integral role within and between LTC to ensure an improvement in processes, structures and outcomes of care through management cycles. These include defining goals, planning and organising services to meet objectives, evaluating results and implementing changes. Quality management techniques can include, for example, reflective and reflexive quality circles with staff, reviewing care pathways, etc. Examples must consider at least one of the following key issues:

a) approaches for promoting and facilitating the quality of mechanisms in relation to linkage, networking, cooperation, coordination or integration of agencies and organisations

b) approaches to ensure diversity-suitable structures and processes

c) approaches to ensure high quality structures and processes involving users/informal carers

d) approaches to shape preventive and/or rehabilitative structures and processes

e) approaches focusing on quality of structures, processes *and* results of LTC providers

f) approaches to measure and consider user satisfaction

5 Organisational Structures

Organisational structures provide LTC services at various stages along individual care pathways. Often two or more services (eg home-help, acute medical treatment and rehabilitation) provided by different organisations and often in different settings have to be available at the same time. Therefore organisational structures need to take on *interlinking and coordinating approaches*, which foster inter-professional and cooperation between organisations and allow them to match specialised services to comprehensive personal needs of older people and informal carers at the same time. The implementation of such interlinking and coordinating approaches represents a crucial precondition for seamless LTC pathways and processes, and can take place within different settings. Each sub-theme in this theme represents a LTC setting or facility, as these exist in most, if not all, European countries providing a necessary structural basis and 'building block' for innovative approaches and integration in LTC.

While the other sections have focused on providing a rationalisation within subthemes, this section will focus more on the key issues and provide justification of their inclusion using a transversal approach. Represented in the list of key-issues for each subtheme are approaches which have been newly implemented or developed, and which permit the 'upgrading' of existing structures in a defined setting (e.g. community/hospital/transitory/residential care). This had been achieved through developing more comprehensive and multidisciplinary services in order to improve the quality of existing services and to bridge gaps to neighbouring settings and structures (Kümpers et al., 2010).

Such approaches are closely connected to ***communication, coordination*** **and** ***collaboration*** and are a prerequisite for seamless transitions that contribute to preventive and rehabilitative approaches within LTC (Kümpers et al., 2010; Ruppe 2009). In practice, this requires individual structures to actively develop networks with other stakeholders involved (see also 'Processes & Pathways') and to integrate rationales such as ***multi-disciplinary (team) work, flexibility*** **or** ***diversity management*** as decisive features of their quality. These key-issues have only just started to become part of quality management and quality assurance mechanisms (Nies et al., 2010). Practice examples will therefore illustrate first steps to ***integrate discharge and follow-up planning*** in hospitals, and ways to preserve and ***maintain relationships with family and other informal carers, including volunteers*****.**

Finally, the necessity of coordinating structures that address problems at the interfaces between health and social care, and between formal and informal care (Triantafillou et al., 2010), has resulted in the purposeful development of intermediary structures and functions such as case and care management centres or transitory care facilities. By their very nature, these structures should have adopted multi-professional and multi-disciplinary working to ***facilitate coordination and cooperation with other formal and/or informal care*** in planning, working and further development. As independent providers or entities, e.g. for case management, they still often lack own resources for ***care planning and coordination between different kinds of services***. These experiences will, however, help further development in defining clear responsibilities and professionalising coordination and inter-agency cooperation, as for instance recommended by Allen et al., 2011, in European LTC systems.

5.1 Nursing and residential care homes

Examples of this type of institutional care include a consideration of the approaches listed below. The question to be answered is: how do care homes organise approaches such as these in order to promote seamless care? Examples must include at least one of the following key issues:

a) multi-disciplinary teams

b) structures that facilitate individual and multi-professional care planning

c) integrated access points (eg concerning referral, financial issues, payment regulation, one-stop-shops)

d) programmes integrating prevention/rehabilitation/reintegration

e) facilities that help preserving and maintaining informal family relationships

f) structures that facilitate free choice and access to additional external services including medical (own GP), social (own hairdresser, friendships) or voluntary services

g) diversity-friendliness: recognition of the specific care needs of hard-to-reach groups, especially their specific needs for information, coordination and support to access available services and benefits

5.2 Care within a hospital setting

This sub-theme includes the role of general or geriatric hospitals, specialised wards (eg palliative care), or out-patient services for people in need of LTC. How do hospital settings organise approaches such as those in the list in order to promote seamless care? Examples must include at least one of the following key issues:

a) multi-professional teams for assessment, care and treatment

b) flexible out-patient/out-reach services/ geriatric ambulatory teams

c) integrated prevention, rehabilitation/remobilisation/reintegration programmes

d) access points (referral, one-stop-shops)

e) day clinic services

f) structures that facilitate communication and planning with existing formal care resources and informal carers

g) structures that facilitate integrated discharge and follow-up planning

h) diversity-friendliness: recognition of the specific care needs of hard-to-reach groups, especially their specific needs for information, coordination and support to access available services and benefits

5.3 Transitory care facilities

These include temporary care within an institution or facility such as respite care, day care, intermediate care or rehabilitation units. How do these facilities contribute to promote seamless care? Examples must include at least one of the following key issues:

a) structures that facilitate communication and planning with formal care resources and informal carers

b) access points (referral, one-stop-shops)

c) structures that facilitate re-assessment and follow-up planning

d) structures that facilitate individual and multi-professional care planning

e) integrated prevention/rehabilitation/remobilisation/reintegration programmes

f) diversity-friendliness: recognition of the specific care needs of hard-to-reach groups, especially their specific needs for information, coordination and support to access available services and benefits

5.4 Assisted living arrangements

These can be described as sheltered or warden assisted accommodation, and may be seen as a halfway house between living at home, in a nursing home or in residential care. How do assisted living arrangements organise approaches such as those in the list in order to promote seamless care? Examples must include at least one of the following key issues:

a) structures that facilitate individual and multi-professional planning of care and living arrangements eg care communities, small units, service housing, sheltered housing (ie without care facilities)

b) access points (referral, one-stop-shops)

c) structures that facilitate preserving and maintaining informal family relationships

d) structures that facilitate free choice and access to additional external services including medical (eg own GP), social (eg own hairdresser, friendships) or voluntary services

e) structures that facilitate coordination with formal care resources (eg prevention and/or rehabilitation)

5.5 Formal care in the home and community

These care services are those that are provided at home and in the community in order to maximise independence and prevent admission to institutions. They include mobile or outreach teams, palliative care, migrant care, and will also include community-based innovations between LTC and health and social care, such as care farms, meeting centres for people with dementia and other care needs. In addition, general practitioners, therapist and independent practitioners are also included. How is formal care in the home and community organised and structured to promote seamless care? How are public, private for profit and non-profit organisations contributing? Examples must include at least one of the following key issues:

a) access points (referral, counselling, one-stop-shops)

b) flexible and adaptable services to suit individual needs and individual lifestyle

c) multi-professional teams (eg preventive/rehabilitative measures)

d) structures that facilitate coordination and cooperation with other formal and/or informal care (including mobility and transport)

e) structures that facilitate communication, planning and care delivery with informal carers

f) practitioners in independent practice as gate keepers and/or personal case and care managers

g) diversity-friendliness: recognition of the specific care needs of hard-to-reach groups, especially their specific needs for information, coordination and support to access available services and benefits

5.6 Specialised case or care management centres

This sub-theme refers to specialist centres or discrete groupings within organisations that specialise in case or care management. How do they organise approaches such as those in the list in order to promote seamless care? Examples must include at least one of the following key issues:

a) access points (referral, counselling, one-stop-shops)

b) structures that facilitate multi-professional and inter-agency care planning and coordination

c) structures that are responsible for care planning and coordination between different kinds of services (as independent provider)

d) diversity-friendliness: recognition of the specific care needs of hard-to-reach groups, especially their specific needs for information, coordination and support to access available services and benefits

6 Means and Resources

This theme addresses crucial aspects of funding (including funding mechanisms and budgeting) and human resources in LTC as well as IT and other technical support mechanisms. Because LTC expenditures are set to rise over the coming decades, it will be of utmost importance to use resources as effectively and efficiently as possible – designing shared funding mechanisms and allocating financial and human resources will thus be key issues to guarantee support for people with LTC needs.

With regard to the visibility of ***funding*** issues in the European overview papers, Allen et al (2011) remark that there are few separate national systems or budgets for LTC. This creates a problem for those monitoring and planning finance, whereby information can slip into the silos of health and social care sectors and the real financial and funding activity for LTC remain hidden. Kümpers et al (2010) and Allen et al (2011) report that the question of which authority should control the individually granted funds for purchasing care and support is answered differently among the countries. This varied between personal budgets more state-protective policies, or defined by levels of assessed needs and levels of (co-financed) support. Difficulties in accounting for LTC expenditure also arise from the fact that different stakeholders (e.g. municipalities or regional states) may be responsible for the governance and financing of different components of LTC

Allen et al (2011) also add that the financial sustainability of LTC depends also on the degree to which health care and other components of social LTC services will be integrated in comprehensive reform steps. The country examples point towards a variety of possibilities to pool various funding sources, such as integrating health and social care at a local level, and referring to case management as a means to improve cooperation between ambulatory and residential care, as well as between medical and social services.

With reference to ***enabling, allocating and funding human resources***, Allen et al (2011) comment that at national levels within the partner countries, concerns over the sustainability of LTC relate not only to its fiscal sustainability (i.e. to what extent public expenditure will remain contained), but also on assuring that dependent older people will be able to access adequate care. Primary concerns include how to prevent care gaps from occurring as informal care may reduce in the future and hiring qualified staff for the care sector may become increasingly difficult.

In addition, Triantafillou et al (2011) add that the low status and low level of professional recognition of care workers in the field of LTC, although rarely explicitly acknowledged, is linked to a corresponding difficulty in the recognition of informal carers as a new type of worker with training needs. The authors add that in addition to their professional training, formal care staff also need training in how to assess the needs of and provide support to informal carers.

When it comes to ***supporting informal carers as a resource for LTC***, Triantafillou et al (2010) state that there is evidence that in most European countries, informal carers still provide most of the care delivered to older people in need of LTC, including hands-on care. Their financial contribution is estimated to range from 50 to 90 % of the overall costs of LTC, thus surpassing the contribution of the formal care system. There is also evidence that, in the near future, informal carers will not be as available as they are today. This prediction, linked to the fact that LTC financial sustainability is threatened by the growing needs of an ageing population, has led to the introduction of direct or indirect cash benefits as an important tool of LTC policies.

Allen et al (2011) also note that *'muddling-through'* and incorporating informal care is a type of governance that relies on informal care, with consequences such as 'illegal' migrant care. The extent to which countries 'muddle through' or are developing governance approaches which acknowledge and support the input of informal carers is variable. They state that National governments face a series of related challenges, including how to balance national reliance on informal care with progressive employment policy; how to recognise informal carers as 'partners' or 'co-providers' of care, improve the status of this role and give them a voice in relevant decision-making processes; how to best support carers in their everyday work, in particular older carers and those that have significant care needs themselves; and how to approach regulations for migrant workers within informal care.

The lack of data on tangible ***financial indicators*** of LTC at the organisational and systems level has been criticised in all relevant studies over the past decades. Taking provision of LTC services as an example, Allen et al (2011) note that expenditure alone does not provide the full picture, and it is almost impossible to establish the number of beneficiaries/users who will receive one or more services. This is in part due to the services often being distributed from a number of different providers. Furthermore, data do not reflect the amount of service hours received by individual users, though it must be assumed that, in most cases, formal home care has to be backed up by informal or family carers (Triantafillou et al 2010). So while datasets are available in some form, they can only give impressions at this stage.

When it comes to ***outcome indicators***, Nies et al (2010) state that agencies must be transparent and concerned with putting measures into place to evaluate the effectiveness and quality of services. There is a distinction whether the measures and systems are compulsory or voluntary. In order to verify that quality standards at organisational level are met, different tools of control and evaluation have been created, such as inspection, certification, or more specific approaches like E-Qalin® Quality Management System.

In general, there is a tendency across the participating European countries for responsibilities in quality assurance to move from control and inspection by public administration towards responsibilities of the care providers themselves by means of self-assessment and self-regulation. The general tendency is to assess and monitor not only quality of care, but also aspects that reflect quality of life. There is also a shift from monitoring aspects of structure and process (or: input and throughput) to results (output and outcomes) and a shift from organisation and profession oriented approaches to person oriented measures.

Kümpers et al (2010) add that the recent implementation of quality management instruments are seen as a promising approach to regulating competition. These are being implemented and used for LTC improvement in several countries. Also, Allen et al (2011) summarise a range of responses such as greater governance roles for service users and carers; greater user and carer involvement with quality systems, service design and evaluation; and the creation of disease specific, pathway-focused quality indicators. They suggest that these visions, guidelines and indicators have the potential to address the links and interfaces between health and social care and the various types of organisations and stakeholders involved in LTC.

The ***role of information technology*** is expanding in LTC and there was evidence of its uses to enhance the quality and safety of the lives of older people and their carers. Kümpers et al 2010 also note that there has been a growing trend towards using electronic or web based assessment systems to improve the communication of patient information between professionals in different

settings. Electronic web based systems improve the timeliness of information transfer and allow different professionals to amend patient information in real time.

6.1 (Shared) Funding

This sub-theme is about funding and funding mechanisms explicitly designed for LTC services, facilities and financial support schemes. Examples should be provided for all countries as this will be important background information for other themes and sub-themes, in particular if reforms have focused on incentives to pool social and health care funding. Examples include at least one of the following key issues:

a) types of funding (insurance-based vs. tax-based; co-payments)

b) financial incentives between different levels of funding (national vs. regional or local; health vs. social; formal vs. informal levels; the role of insurance companies/agencies)

c) commissioning and contracting with individual or pooled budgets

6.2 Enabling, allocating and funding human resources

This sub-theme should highlight means and mechanisms to educate and train professional staff for LTC services, but also to allocate and retain staff in this sector. What are the successful mechanisms to select and retain staff in LTC services? Which role does the level of payment play in retention policies at the organisational level? Examples must include at least one of the following key issues:

a) recruiting staff (including ethical international recruitment)

b) levels of payment of staff in LTC

c) (new) job profiles in LTC

d) innovative education or career patterns

6.3 Supporting informal carers as a resource for LTC

This sub-theme will underpin the need for specific support for informal carers who are and will remain the most important resource for people in need of LTC. This should not only include examples that describe financial off-set against professional expenditure, but also those that describe financial or other benefits to informal carers. Examples must include at least one of the following key issues:

a) financial support schemes for informal carers and their funding

b) funding of services, training and other in-kind support directed at informal carers

c) funding of initiatives to reconcile work and caring

6.4 Financial indicators

. While reliable datasets for financial indicators are difficult to obtain, basic indications on an organisational and/or systems level are available and examples should be presented with a view

to trends and tendencies so that debates may be based on additional evidence and national practice can be assessed using contextual evidence. Most of these indicators do exist and will be exhibited in comparative tables. Examples must include at least one of the following key issues:

a) expenditures for LTC as a percentage of GDP

b) percentage of population over 65 with LTC needs in residential care as opposed to home care

c) percentage of population over 65 with LTC needs using community care services

d) number of staff working in LTC (as a percentage of total work-force)

e) percentage of funding by stakeholders (public, private out-of-pocket, other)

6.5 Outcome indicators

We are looking for examples that are on the pathway to developing and assessing outcomes or at least results-oriented indicators at an organisational or even a systems level. Which results-oriented indicators are used to show effectiveness of LTC services? Examples must include at least one of the following key issues:

a) initiatives that strive to develop and implement outcome indicators

b) costs of different services in relation to number of users

c) methods and indicators used to measure quality of service

6.6 Role of information technology

Information technology (IT) has played an important role in the development of health care over the past few decades. This includes technology in surgery and other applications as well as administrative and management applications (E-health). With some delay, social care and LTC services have also started to implement IT solutions in organising services and in improving housing environments – from mobile phones with care management applications to 'smart homes'. What is included in IT solutions for overcoming blockages and problems at the interfaces between health and social care organisations? Examples must include at least one of the following key issues:

a) IT solutions in ambient assisted living and smart housing

b) IT solutions in LTC management including electronic records

c) IT applications at the interfaces between health and social care professionals

d) IT applications at the interfaces between health and social care administrations

e) IT applications at the interfaces between formal and informal care

The INTERLINKS template to describe and analyse practice examples

The following template will be used to describe and analyse practice examples, focusing on the themes, sub-themes and key issues stipulated above. It will be used as a separate WORD-file by all partners to fill in their practice examples. It will also be the basis for the back-end of the INTERLINKS web site – the text in italics below each category heading provides prompts and additional information that will not be shown in the front-end. For some categories a restricted number of words was specified.

Theme	
Subtheme	
Key issue(s) *Which key issues are addressed?* *Choose from key-issues from INTERLINKS Framework (web: drop down menu)*	
Title	
Summary of this example *Use this section for addressing the following aspects: Where is the example taking place (local, region, country)? In what settings (e.g, individual organisation, across organisations, whole system)? Why was the example developed? What are/were the main results?* *Max. 150 words, no headings*	
What is the main benefit for people in need of care and/or carers?	
What is the main message for practice and/or policy in relation to this sub-theme?	
Links to other INTERLINKS practice examples	
Country	

Status *Choose from the following: pilot project (terminated), pilot project (ongoing), project (terminated), project (ongoing), implemented practice (restricted areas), widely spread practice/rolled out.*	
Keywords	
Why was this example implemented? *Use this section for addressing the following aspects: What were the reasons for starting this example? Which interfaces or gaps does the example address? For which target groups?* [3] *No headings, max. 200 words*	
Description of the Example *Use this section for addressing the 'what' of the example (the type of intervention, service, policy measure, policy paper, legislation). Who are/were the people involved and who is/was driving the example forward (initiator, supporter, promoter, users and carers)? How does/did it affect the person in need of care and/or the carer? Was there user involvement? How is/was it carried out (include also costs, resources), when, where?* *Max. 300 words with hyperlinks, with more specific information*	

[3] See list of terms in appendix

What are/were the effects? *Use this section to describe the effects based on evidence: How well did the example address the gaps and improve the interfaces? How were the benefits for older people and informal carers evaluated? What were the demonstrated or potential effects on older people, informal carers, formal carers, organisation/ inter-organisational collaboration, costs? To what extent did the example change the way that LTC is provided across systems or services? Has the example proved to be sustainable, or mainstreamed? Has the example been implemented elsewhere?*[4] *Max. 300 words*	
What are the strengths and limitations? *Use this section to give your reflection on strengths, weaknesses, opportunities and threats, intended or non-intended outcomes/effects. Include any doubts whether the outcomes were caused by the measure/intervention/service. Consider the perspective of the person in need of care and the informal carer.* *Max. 200 words*	
Credits *Author and organisation, reviewer, example verified by....and organisation (if available, refer to key person of the example)*	Author and organisation: Reviewer 1: Reviewer 2: Verified by: Organisation:

[4] Based on evidence. For categories of evidence see INTERLINKS Discussion Paper #4 (J. Billings: What counts as evidence in INTERLINKS); references will be given on the website by hyperlinks; in the meanwhile use Harvard references.

Appendix - Terminology

In order to have homogeneous terminology we propose to use the following terms:

- Themes/subthemes/key issues (see introduction)
- Older people: the service users or target group for whom the services in LTC are working; while acknowledging that LTC also serves other groups, INTERLINKS has the focus of older people, especially those who are at risk of or are already suffering from frailty, dependency, longstanding consequences of diseases (e.g. dementia, strokes, Parkinson's Disease)
- Informal carers: those who care for older people on a regular basis because of emotional affiliation, being next of kin, feelings of obligation being spouse, child or parent of older person, neighbours, friends, volunteers
- Formal carer/professionals: those who care for older people in a paid for relationship; those who have had middle or higher education are referred to as 'professionals'.
- Interfaces: mechanisms, tools and organisational structures to overcome organisational and professional discontinuities and inconsistencies between services that are a barrier to optimum care for older people.