InCARE Situational Analysis Topic Guide

Research Tool 1. Evidence Synthesis

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InCARE Situational Analysis Topic Guide	
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Acknowledgment

The current document has been developed on the basis of the *WHO Country Assessment framework for the integrated delivery of long-term care* (WHO Europe, 2019). The authors have adapted the content of the framework to better reflect the requirement of the InCARE project but also to capture important dynamics both at national and at regional level.

We further acknowledge the crucial contribution of the research tools developed as part of the *Strengthening responses to dementia in developing countries (STRiDE)* project (Comas-Herrara et al. 2020, 2021). Namely, the current document has closely followed the approach proposed in STRiDE research tool 1 (Comas-Herrera et al., 2021). Furthermore, throughout the document we refer the reader to STRIDE research tool 2 (Docrat et al., 2021a).

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Introduction

This document provides the topic guide for carrying out a situational analysis of the long-term care ecosystems in the three countries participating in the InCARE project (Spain, Austria and North Macedonia). The document has been developed as part of work package 2 (WP2) of the InCARE project, focused on Evidence synthesis and development of an evidence base for decision making.

The situational analysis will provide a comprehensive overview of long-term care system performance, collating data on sustainability, efficiency, accessibility, equity and quality of care for older people with cognitive and functional impairment. It will also carry out an in-depth analysis of demand for care, grounded in a detailed understanding of the demographic and epidemiological situation in each country. The analysis will cover information and dynamics both at national level and at the regional level relevant for pilot implementation.

The situational analysis will provide an evidence- base for identifying mismatches between demand and supply of care and the specific issues to be prioritized for policy intervention and for designing and implementing a relevant pilot intervention in each country. Its results will be complemented with findings from other evidence-building tools developed as part of the InCARE project:

- Mapping of data sources (WP2)
- Scoping review of evidence on social innovation in long-term care in Europe (WP1)
- Survey on attitudes to long-term care (WP1)
- Multi-stakeholder Theory of Change workshop (WP3)
- Policy toolkit (WP4).

What is a Situational analysis?

Situational analyses are used to assess the current state of affairs in order to be able to understand the multiple interacting factors that need to be considered for the design and updating of policies, strategies and plans, and also for the implementation of interventions (Murphy et al., 2019; Schmets, Rajan, & Kadandale, 2016).

The InCARE Situational analysis Topic Guide builds on the WHO Country Assessment framework for the integrated delivery of long-term care (WHO Europe, 2019) and the tools developed as part of the Strengthening responses to dementia in developing countries (STRiDE) project (Comas-Herrera et al. 2021; Docrat et al., 2021a, b).

The situational analysis will be carried out in four steps:

1. Desk review
2. SWOT analysis
3. Semi-structured stakeholder Interviews
4. Consolidation of findings and write-up

The **desk review** topic guide (this document) includes a series of questions to be answered narratively and complemented with excerpts from available data sources, in order to gather the information needed to describe support capacity and care needs in the community, long-term care service delivery, care system performance and system enablers. Its structure and focus follow closely the WHO Europe Country Assessment Framework for the integrated delivery of long-term care, also crucial adaptation have been implemented to support the creation of a strong evidence base on community strengths, user involvement, system readiness to change and innovation capacity.

Figure 1. WHO Europe Country Assessment Framework for the integrated delivery of long-term care
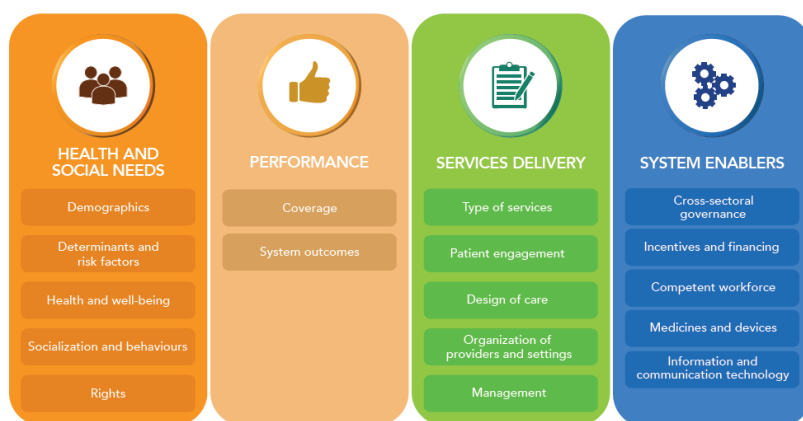
Source: Reproduced from World Health Organization (2019) Country assessment framework for the integrated delivery of long-term care. Copenhagen: WHO European Office.

Guidance on carrying out the desk review, including identifying resources using internet search engines and online databases; managing and presenting your references; and reading critically is presented in a separate document, developed by the STRiDE project (Docrat et al., 2020).

The Strengths, Weaknesses, Opportunities and Threats **(SWOT) analysis** will focus on identifying key gaps in knowledge and data availability and potential for innovation in each system.

Semi-structured interviews with purposefully selected stakeholders (3-5 policy stakeholders, 3-5 experts by experience and 3-5 researchers), will focus on collecting feedback on emerging findings from the desk review, filling literature/data gaps and refining reform priority areas.

Drawing on information gathered through the desk review, interviews and SWOT analysis we will **consolidate our findings** in three national short reports (in English) describing the long-term care landscape in each country and policy briefs summarizing key findings and policy recommendations (in national languages).

A separate **data mapping** tool in .xls format is provided together with this topic guide. Please keep track of all the data sources you have consulted and have found useful. Especially in cases where the level of data detail is too fine grained for presenting it directly in the situational analysis report, it is important we keep track of the databases and information sources where the detailed data is stored. Such data sources can include national statistics databases, census and administrative data, data sets collected through surveys and ad-hoc instruments.

You will note we have suggested, throughout the document, international data sources that you might find useful. Please do not limit yourself to these sources and attempt to find the most recent and most accurate information available. It is also not necessary to track the suggested sources/ databases in the data mapping tool – it will be sufficient to cite them appropriately, whenever you present data extracted from these sources.

Overview of the Situational analysis Topic Guide

This situational analysis desk-review topic guide has been developed in order to better understand the context, barriers and opportunities for improving long-term care in European countries. It aims to provide a comprehensive overview of the demand, supply and organization of care at national and regional level, in order to inform evidence-based decisions and support the implementation of innovative local initiatives.

The topic guide draws heavily on the WHO Country Assessment framework for the integrated delivery of long-term care and is based on the principles of people-centeredness and integrated care, life-course approach, healthy ageing, human rights, equity and systems thinking. While it is mainly intended as a policy-oriented framework it provides an equally informative overview for researchers, advocates and the general public. The guide emphasizes the necessity of designing care systems that are aligned with community needs and preferences, support high quality and equitable provision of care and are enabled by strong governance, financing and institutional mechanisms.

Based on this, the topic guide includes six sections, as illustrated in Table 1. A list of topics (sub-domains) covered under each core assessment domain (sections 2 to 5) are included in Table 2.

Table 1. Overview of the InCARE situational analysis topic guide

Topic Guide Sections	Content
1. Overview of country context	This short, introductory section aims to generate an overview of your country, in particular by describing the overall demographic, social, economic and political situation within the European context
2. Support-capacity and care needs in the community	This section explores the main demographic and epidemiological trends, the social and economic situation of older people and their support needs. It also explores the profile and needs of informal carers, measures to ensure rights and dignity protection and community support capacity. We attempt to answer the question *What are the strengths and support needs of older people, their families and local communities?*
3. Service delivery	This section focuses on mapping care services available to older people and their carers, as well as the procedures for accessing such services. It explores the profile of public and private service providers and the settings in which services are rendered. We want to understand *How are care systems organized and delivered?*
4. Performance	This section encompasses an appraisal of long-term care services coverage, accessibility and affordability. It reviews the quality and equitable distribution of long-term care services as well as the voice and control afforded to care users. We address the question: *How well do care services respond to population needs and how do they leverage existing strengths?*
5. System enablers	This section delves into the factors that are essential for care system functioning, sustainability and capacity to adapt: financing and governance, workforce, innovation and technology. The question we address is: *What key conditions (enablers) must be in place in order to deliver high quality, timely and sufficient care?*
6. SWOT analysis	This section develops policy and practice recommendations based on a table of strengths, weaknesses, opportunities and threats for the long-term care system at national and regional level.

Table 2. Summary of core assessment domains and sub-domains

SUPPORT-CAPACITY & CARE NEEDS IN THE COMMUNITY	SERVICE DELIVERY	PERFORMANCE	SYSTEM ENABLERS
Demographics	Types of services	Long-term care services coverage	Cross-sectoral governance
Socio-economic determinants and risk factors	Patient engagement in care	Access and affordability	Incentives and financing
Health, functionality and wellbeing	Design of long-term care	Quality of care for older people	Competent workforce
Social networks & Inclusions	Provider organization and care settings	Regional inequalities	Information and communication technology
Rights	Management	Shared decision-making with care users	

A basic shared lexicon

InCARE teams in three project countries will be carrying out situational analyses in parallel, working to describe care systems that share many characteristics but also diverge in very significant ways. We aim to produce results that are comparable across countries and understandable to broad and multi-disciplinary audiences throughout Europe and beyond. Therefore, it is crucial we base our work on a shared understanding of the key concepts that are relevant to long-term care provision and systems.

A full **glossary of terms**, providing concise definitions for all key concepts we will use throughout the situational analysis process, is included in a separate file. The glossary is extracted from the research tools developed by STRiDE (Comas-Herrera et al., 2021) and is presented as an individual file for ease of use. Please refer to the glossary as often as necessary and base your answers on these definitions. This will help us ensure that individual country teams generate harmonized and coherent information.

We single out for clarification five essential concepts that are crucial to a correct understanding of this topic guide and are often used in a loose and imprecise manner in research and practice:

- **Long-term care** (LTC) refers to activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.
- **Older people/ older persons** are individuals whose chronological age is above a certain threshold. In the EU context, the most widely used categorization is: <u>older people – aged 65 and above; very old people – aged 85 and above</u>. Please do not use terms that can be considered offensive or discriminatory when describing older population groups. Terms such as elderly, the aged, decrepit, demented or diseased should always be avoided.
- **Care services/ formal care** refers to all care services that are provided in the context of formal employment regulations, such as through contracted services, by contracted paid care workers, declared to social security systems.
- **Home and community-based care** refers to care provided to older people in their own homes and to care provided in dedicated facilities and institutions for people who mainly reside in their own home (e.g. community care, day care centres, home-based respite care).
- **Carer/caregiver** is person who provides care and support to an older person with support needs. Such support may include: a) helping with self-care, household tasks, mobility, social participation; b) respite care; and c) offering information, advice and emotional support, as well as engaging in advocacy, providing support for decision-making and peer support, and helping with advance care planning (for example for people with dementia).
  Carers may be relatives or extended family members as well as close friends, neighbours and paid lay persons or volunteers. We often distinguish between formal and informal carers and between paid and unpaid carers. The matrix below clarifies these concepts (Comas, 2021).

Carer types	**Paid** (Receives a wage)	**Unpaid** (Do not receive wage)
Formal has work contract and/or social security	Employed directly by person/family, or through an agency	Volunteers may have contracts
Informal no contract, no social security	Paid (usually cash) to provide care: e.g. migrant live-in workers, family members who are paid as "compensation"	Usually family carers, but also friends and neighbours

A few tips for ensuring clarity and understandability

To ensure we avoid misunderstandings and errors please avoid using abbreviations, wherever possible throughout the document. We generally use LTC to abbreviate long-term care, ADL and IADL for (instrumental) activities of daily living, EU for European Union and abbreviate the names of international organizations (e.g. WHO, OECD). Please use these well-established abbreviations but avoid other, less clear ones.

Furthermore, please avoid using statements such as 'recent data' or 'recent information' without adding the year of the data. The precision of adding the precise year will help should you want to revisit the topic guide in future years to see how the situation in your country has changed and whether new data may have become available. In addition, it provides the reader with clarity about the timeliness of the information. Please remember, the year in which the document cited was published does not necessarily reflect the year of data collection.

If you want to interpret the country specific data you have identified in an international context, please use the EU-27, the WHO European region or the OECD averages as the preferred comparison groups, in that order. Please avoid comparisons between individual countries.

If you cannot find any evidence for some of the questions listed in this guide, please write *No evidence found as of (date)* under the respective question. The addition of a date will help if you should revisit this question at a later stage so you know the timeframe in which to search for information that may have become available in the meantime.

1. Overview of country context

__Please keep this section very short__ – approximately 2 pages! It is intended to provide a broad, general context for the long-term system assessment. Under each subheading below, fill in one-two paragraphs of narrative text (where appropriate use tables, maps, graphs) highlighting those aspects that are most noteworthy.

A. Total population size and structure

B. Key geographical/demographic characteristics (e.g. population density, urbanisation)

C. Political organization and administrative structure (e.g. form of government, regional and sub-regional administrative division, type of welfare regime)

D. Socio-economic development

E. Key languages, ethnic groups and other diverse groups

When filling in this section you may find the following sources useful:

- *https://ec.europa.eu/eurostat/guip/introAction.do*
- *https://ec.europa.eu/eurostat/cache/infographs/economy/desktop/index.html*
- *For NMK: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Category:EU_enlargement_countries*
- *https://www.iom.int/countries*
- *https://www.ilo.org/empelm/pubs/WCMS_114060/lang--en/index.htm*

2. Support-capacity and care needs in the community

The Support capacity and care needs section is crucial for establishing a good understanding of the needs and demand for care in your country. You are encouraged to give narrative answers under each subheading below referring to and listing summaries of any available data.
You may want to use tables or graphs as part of the answers to some of these questions, particularly when you are presenting data for different groups (e.g. by age category, gender, region). If different estimates are available for some of the indicators of interest please choose the source that is more reliable and make a note of the differences.
We are interested here primarily in national level data and regional break-downs of key indicators. If detailed data sources (e.g. at province and municipal level) are available please keep track of them in the data mapping sheet but do not include the detailed data here.

2.1 Demographics
A.1 Population structure and dynamics

- Population size and age structure at national and regional level
Please provide data on population progress over the last decades and any projections that are available. In addition to country level averages, please include data broken down by region wherever possible. Please keep track of all identified resources in the data mapping tool.

- Fertility and migration trends
Please refer to the entire population when filling in this section and add any information available by age group

- Population density and level of urbanization
Please highlight how the age structure of the population varies between low and high population density areas and between areas with low and high levels of urbanization. Present your answer narratively, including references to key data.

When filling in this section you may find the following sources useful:
- *https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Population*
- *https://ec.europa.eu/eurostat/data/database?node_code=proj*
- *https://population.un.org/wpp/Publications/*
- *https://population.un.org/wpp/DataQuery/*

A.2 Current and forecasted life expectancy by gender

- Median age (by gender)
Please highlight any relevant differences between regions/ parts of the country

- Life expectancy at birth and at age 65 (by gender)
Please describe shortly the dynamics of these indicators (i.e. progress over the last decades) and any available projections

When filling in this section you may find the following sources useful:

- *https://ec.europa.eu/eurostat/web/products-eurostat-news/-/EDN-20200930-1*
- *https://www.who.int/gho/mortality_burden_disease/life_tables/en/*

A.3 Population ageing

- Share of population aged 65 and above
- Share of population aged 80 and above
  Please describe shortly the dynamics of these indicators (i.e. progress over the last decades) and any available projections.

When filling in this section you may find the following sources useful:

- https://ec.europa.eu/eurostat/statistics-explained/index.php/Ageing_Europe_-_statistics_on_population_developments
- https://ec.europa.eu/eurostat/en/web/products-statistical-books/-/ks-02-20-655

A. 4 Vulnerable or minority groups

- What vulnerable/ minority groups can be identified in your country? Consider ethnicity, migration status, race, religion, etc.
- Do these groups have different demographic structures and life expectancy than the majority population?
  Please answer these questions narratively highlighting key data.

When filling in this section you may find the following sources useful:

- https://fra.europa.eu/en/tags/minorities

B. How does the demographic landscape in your region differ from the situation at national level?

Please describe the main aspects related to the demographic landscape that set your region apart from the situation in the rest of the country. Do not restate all the information listed above! Mention only those aspects that are different, providing key data available and keeping track of data sources in the data mapping tool.

When filling in this section you may find the following sources useful:

- *https://ec.europa.eu/eurostat/web/regions/background*

2.2 Socioeconomic determinants and risk factors

Throughout this section you may find the following sources useful:

- https://ec.europa.eu/eurostat/statistics-explained/index.php/Ageing_Europe_-_statistics_on_population_developments
- https://ec.europa.eu/eurostat/en/web/products-statistical-books/-/ks-02-20-655
- https://ec.europa.eu/eurostat/web/income-and-living-conditions/data/database
- https://ec.europa.eu/eurostat/web/products-statistical-books/-/KS-DZ-18-001
- https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016

A.1 Living arrangements and family structure of older people

- Average family size;
- Average household size/ prevalence of intergenerational households.

Please reflect (shortly) in this section on how changes in the above indicators might impact patterns of community support. For example, is there a concern that care shortages might arise as the number of intergenerational households decreases (fewer parents living with their adult children).

A.2 Household income status and poverty rates of older people by gender

- Pension coverage
- Average income of older people (by gender)
- Percentage of older population at risk of poverty (by gender and region)

Please answer these sections narratively, including data by gender and region where available.

A.3 Socio-economic situation of vulnerable and minority groups among older people

Please describe shortly how the socio-economic situation of older people group belonging to ethnic and minority groups is different for that of the general population.

B. Employment and unemployment rates for the general population

Please include employment rates by age and gender), describing progress over the last decades and any projections available.

- *https://ec.europa.eu/eurostat/web/lfs/data/database*
- *https://ilostat.ilo.org/data/country-profiles/*

C. Lifestyle and behavioural risk factors of older people

Please keep this section short (a few paragraphs), presenting only remarkable/ important patterns in diet, physical activity, metabolic risk factors, behavioural risk factors that should be highlighted. There is no need to give a detailed overview of these aspects. Please keep track in the data mapping sheet of sources of data where further details could be accessed if needed.

D. How does the socio-economic landscape in your region differ from the situation at national level?

Please describe the main aspects related to the socio-economic landscape that set your region apart from the situation in the rest of the country. Do not restate all the information listed above! Mention only those aspects that are different, providing key data available and keeping track of data sources in the data mapping tool.

When filling in this section you may find the following sources useful:

- *https://ec.europa.eu/eurostat/web/regions/background*

2.3 Health, functionality and wellbeing

Throughout this sub-section, please include information on any available projections or forecasts (national or regional level) you identify during the desk review. Make sure to keep track of these sources in the reference list (for individual studies, reports) and the data mapping tool (for datasets and databases).
The following resources may prove useful:
- https://ec.europa.eu/health/state/country_profiles_en
- https://apps.who.int/gho/data/node.main
- https://ec.europa.eu/health/indicators_data/echi_en
- http://www.healthdata.org/results/country-profiles
- https://gateway.euro.who.int/en/country-profiles/

A. Health and social needs of older people

A.1 Mortality and morbidity trends

- Standardized death rates;
- Leading causes of mortality and morbidity (by age & gender)
- Prevalence and burden of significant non-communicable diseases (by gender)

Please keep this section short, highlighting only key statistics and cause of mortality trends at national level.

A.2 Brain health

- Prevalence of main mental health conditions (e.g. depression)
- Prevalence of neurological conditions that affect cognitive function (e.g. cognitive impairment and dementia)
- Awareness of mental and neurological conditions among care professionals and the general population

Please answer this section narratively, highlighting key data. As many European countries are currently not providing official prevalence figures you might have to rely on available estimates or individual studies.

B. Disability and functionality of older people (by gender and age group)

- Leading causes of disability
- Prevalence of functional limitations (ADL, IADL, mobility, sensory impairment)
- Disability adjusted life years / years lived with disability

Please provide a narrative answer of the main trends in disability and functionality, highlighting key statistics. Wherever possible, present data that is broken down by gender and age group (differentiating between older people and very old people).

C. Wellbeing of older people (by gender and age group)

- Self-reported measures of life satisfaction and happiness
- Quality of life
- Loneliness

Please summarize and report any available data, by gender and age group (i.e. differentiating between older and very old people). If national or regional data is not available, some information can be extracted from small scale studies and qualitative data sources.

D. How does the epidemiological landscape in your region differ from the national level?

Please describe the main aspects related to the health and wellbeing of older people that set your region apart from the situation in the rest of the country. Do not restate all the information listed above! Mention only those aspects that are different, providing key data available and keeping track of data sources in the data mapping tool.

2.4 Social networks & Inclusions

Throughout this sub-section, you might find it difficult to identify quantitative data and statistics. Please try to compensate with information from qualitative studies and reports. If this type of information is also scarce, we will try to compensate through the interviews.
The following sources may prove useful:
- https://ec.europa.eu/eurostat/en/web/products-statistical-books/-/ks-02-20-655
- https://www.eurofound.europa.eu/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2016
- https://www.eurofound.europa.eu/topic/care
- https://ec.europa.eu/social/BlobServlet?docId=19681&langId=en
- https://eurocarers.org/

A. Social inclusion and social networks:

- Share or older people who are widowed
- Share of older people living alone
- Size of social networks (i.e. social contacts and groups that extend beyond spouses and immediate families)
- Gender equality (index ranking or short narrative overview)

Please provide quantitative data and estimates if available. Alternatively, please answer narratively based on information extracted from reports or studies on patterns of marriage, cohabitation and size of social networks in your country more generally.

B. Gender stereotypes/attitudes related to care giving and receiving

In this subsection, please refer to any gendered social norms, roles, and relationships of and between groups of women and men that are specific to seeking and providing care. For example, are women seen as caregivers while men are not (daughters are caring for older parents more often than sons)? Are women providing unpaid care at earlier stages of their lives that limit access to economic resources (e.g. women provide care to parents whereas men provide mainly spousal care)? Do older women receive less formal care support as they are perceived to manage better?

Please highlight any quantitative data available from reports and studies. If that is lacking, you can refer to qualitative data only.

C. Profile of informal carers

- Number of informal carers (absolute numbers and share of the population)
- Average age of carers / Share of carers in specific population age groups
- Share of women out of all carers
- Carer's relationship to the older person (e.g spouse, child, other relative)

In this subsection, please refer exclusively to unpaid informal carers (see further information on carer types above). Please highlight any available quantitative data and statistics. As these might be scarce in some countries you can rely on qualitative data and interviews with experts.

D. Caring roles among minority and marginalized groups

Please describe shortly any specific norms or social roles related to care for older people that are prevalent among minority groups (if relevant in your country). You can rely on quantitative and qualitative information as available, or expert opinion collected during the interviews.

E. Are there any specific aspects related to social networks and inclusion that are particular to your region, with respect to the national situation?

Please describe the main aspects related to the health and wellbeing of older people that set your region apart from the situation in the rest of the country. Do not restate all the information listed above! Mention only those aspects that are different, providing key data available and keeping track of data sources in the data mapping tool.

2.5 Rights

In this sub-section, you are asked to identify legislation and legal norms. Please mention the name of the specific legal act in English and in the original language and provide a very short overview of its main provisions with respect to the rights of older people. There is no need to summarize the entire content of the laws and legal acts you identify.
The following sources may prove useful:
- https://eurocarers.org/portfolio-item/informcare/
- http://ennhri.org/our-work/topics/rights-of-older-persons/

A. Rights of older people

- Legislation for the protection of older people (e.g. against abuse, maltreatment, segregation)

B. Rights and needs of carers

- Legislation for the protection of rights and entitlements of carers (including pension credits, social security coverage)

C. Is there any regional/ local legislation specific to the rights of older people and carers that is particular to your region?

Please list only those regional/ local legal norms that are different from or add to the national legislation. There is no need to repeat the information in the previous sections.

3. Service delivery

__The Service Delivery section__ focuses on describing what care services are available to older people with support needs and their carers, how such services can be accessed, how care provision is organized and in which settings it is offered.

Identifying __data on service use and numbers of providers (as detailed as possible) will be essential__ to understanding if care service design and capacity is well-suited to respond to population needs. Therefore, please keep track of all data sources you identify in this section and present the key statistics and quantitative data in tables and figures in the text.

However, it is impossible to form a good impression about how care services operate from this information alone. We encourage you, throughout this section, to __respond narratively, describing to the best of your ability how different services are organized, how they operate and how they can be accessed.__

It is very likely you will not be able to obtain this information from desk research alone. As experienced care providers and experts in the long-term care system, InCARE partners are themselves a great source of information. Please draw on this experience as you fill in the topic guide. We will further use information from semi-structured interviews and discussion with key informants to fill remaining knowledge gaps.

The following sources may prove useful:

- https://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits/full-list-of-country-hits (dedicated section on LTC)

- https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=9185 (see country reports)

- https://op.europa.eu/en/publication-detail/-/publication/6f79fa54-1199-45e0-bbf3-2619c21b299a

- http://www.oecd.org/els/health-systems/health-data.htm

3.1 Types of services

In this sub-section, __please focus your answer on the national situation__, in general. For service mapping at the local level (municipality) we will use a more detailed tool (template provided separately) or a vignette approach (in case of very limited data availability).

Please provide short narrative answers, __describing those types of services that are available in your country (in each category mentioned below)__ and the governance level at which responsibility for service provision for each service type is held. Please add any available data on take-up (number of users or percentage of total older population) of services by type, if such exists.

If you are unsure what category a specific service belongs to, please mark it and we can discuss further where to best locate it.

A. Social services for older people, including:

- Support for personal care (e.g. personal hygiene, daily routines, eating)
- Support for household maintenance (e.g. support for cleaning, laundry, household maintenance and errands such as banking, grocery shopping)
- Fitness/strength training (e.g. balance exercises like Tai Chi, yoga, fitness)
- Driving and transportation (e.g. delivery of meals/medicines, drop in/out services)
- Support for social integration (e.g. community clubs, cultural programmes, leisure activities)
- Social support services (e.g. stress management, conflict resolution, detection of abuse)

B. Health and intermediate care services, including:

- Preventive care (e.g. annual check-ups, influenza vaccination, mental health risk assessment, counselling services for lifestyle, eye/ hearing exams)
- Follow-up services post hospitalization (e.g. post-discharge care, medicines reconciliation, nursing (home) care services, secondary prevention)
- Rehabilitation (e.g. physiotherapy, occupational therapy to support ADLs, speech language therapy, stroke recovery)
- End-of-life services (e.g. hospice services, pain management, advanced care planning)

C. Support services for informal carers

- Training programmes for informal carers for providing care, personal assistance and respite care
- Social support services for informal carers (e.g. programmes to prevent overburdening and burn-out, household support for cleaning, maintenance and errands)

D. Are there any important differences between the types of care services identified at national level and those available in your region?

For example, are there some services that are not offered at all in your region - e.g. palliative care? Or some that are particularly well developed with respect to the national average? Please list only those services that are particularly well- or under- developed in your region with respect to the national average. There is no need to list all services mentioned in the previous sections once again.

3.2 User engagement in care
A. Self-management support for older people

- Self-management and health literacy enhancing services (e.g. online services, patient portals)
  Self-management support is the care and encouragement provided to people with chronic conditions and their families to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviours.
- Publicly available & easily accessible information on services for older people (e.g. signposting & information services)

B. Peer-to-peer support and social inclusion for older people

- Peer mentoring programmes
  Peer mentoring programmes ensure one to one assistance and encouragement are provided to an older person by an individual considered equal and who possesses meaningful shared experience.
- Befriending/ friendship programmes
  Befriending services introduce older people to one or more individuals whose main aim is to provide them with companionship and additional social support through the development of an affirming, emotion-focused relationship over time.
- Learning programmes
- Support groups

C. Are there any notable particularities related to user engagement in care in your region?

Please list here only those aspects that set you region apart from the situation in the rest of the country. For example, are there any innovative user engagement initiatives implemented in your region? Has user engagement in care been recognized as an important priority by local or regional authorities?

3.3 Design of long-term care

A. Needs Assessment

A.1 Entitlements and means testing

Please describe the specific criteria imposed by current regulation for receiving in-kind care services and/or cash benefits. For example, are services available only for individuals of a specific age? Is eligibility dependent on disability or functional status? Please provide information on any means-tested benefits – that is, services/entitlements that are conditional on the household or the older person financial resources (more often than not, their income).

2. Needs assessment or protocol for assessing needs

Please describe what criteria or instruments are used in your country for determining that a person qualifies for care services). Are there any specific tools/instruments for needs assessment or legally recognized degrees or levels of dependency? And if so, are they used uniformly throughout the country? When answering please be brief, summarizing only the core information and keeping in mind to highlight differences in needs assessment tools and protocols between different types of care services.

B. Integrated service delivery

Please describe shortly what arrangements for multi-disciplinary work and joint delivery of health and social services are currently implemented in your country. For example, is the co-location (same facility) of health and social services practitioners common? How are health and long-term care professionals sharing information (e.g. shared of medical records)? Are multi-disciplinary teams common in long-term care provision and do they regularly consult with general practitioners?

C. Management of transitions

Care transitions can be defined as the movement of care users between health and social care practitioners and settings as their condition and care needs change. Interventions to improve transitions (also described as management of transitions or transitional care) are designed to improve the coordination and continuity of care as users move between different locations or different levels of care.

Please describe shortly any measures aimed at managing transitions between services and providers (e.g. between hospital and home-care) in your country. For example, are integrated health and social discharge care plans (e.g. protocols, templates, checklists) commonly used? Do primary care professionals offer follow-up services (e.g. referral feedback to primary care, follow-up assessment in primary care, follow-up calls)?

D. Care/ case management

- Availability of case managers
- Existence of care coordinators (e.g. care manager, liaison nurse or pharmacist)
- Mechanisms for users and carers to receive information on services (e.g. upon discharge)

Care management can be described as a continuous process of planning, arranging and coordinating multiple health-care services across time, place and discipline for patients with high-risk conditions or complex needs, in order to ensure appropriate care and optimum quality, as well as to contain costs, usually through the use of care coordinators and case managers (GDO Reference Guide, 2018). Please describe shortly in this section how common case management is in your national long-term care systems and what its main characteristics are.

E. Are there any important differences between the design of care services identified at national level and those available in your region?

Please describe here only those aspects that are significantly different from the information provided above at national level. For example, are needs assessment and entitlement different in any way from the national average? Is case/ care management more or less widespread than in other regions? Is multidisciplinary work more common?

3.4 Provider organization and care settings

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*In this sub-section, **please focus your answer on the national situation**, in general. Where data is available at regional level, summarize it in a table or a figure and keep track of the original source in the data mapping tool.*

*Please provide short narrative answers that give context and explain succinctly the data you present. Whereas in the section on Types of services (above) you focused on describing the types of services available in your country, in this section you are asked to **describe how long-term care providers are organized and in which types of setting they are providing care**. Please add any available data on number of providers (if possible distinguishing between private for profit, not-for profit and public), average size of providers (e.g. average number of beds in residential care setting), care capacity in each care setting (total number of users or percentage of total older population), if such exists.*

As long-term care systems in Europe have been undergoing important transformations over the last decades (e.g. a push towards deinstitutionalization and increasing community-based care provision) we encourage you to present any available data or include short, narrative description on how the organization of care has changed in your country.

A. Long-term care settings:

Please give narrative answers giving an overview of the long-term care provided in each setting and present any available data on number of providers, average size of providers, concentration of providers and overall capacity in each care setting. Please conclude this section with a short summative paragraph reflecting on how balanced the development in different care setting is currently in your country.
Please consult the glossary of terms if you need further clarification. If you are unsure where to include a specific type of service, please mark it for further review at the end of this sub-section.

- Outpatient and inpatient health and rehabilitation care
  Please refer only to those care institutions that provide long-term and rehabilitation care for older people, not all institutions that provide any type of care for older people (including acute, short-term, day care). For example, general hospitals, geriatric and psychiatric hospitals can have geriatric or other dedicated wards used for long-term institutional care of older people or palliative care units.
- Community based centres, day care centres, small community groups
- Day care services in residential institutions and support services in primary care facilities
- Residential long-term care facilities (health and/or social services) & nursing/care homes
- Home care
  Please consider here all formal care provided in the user's own home by care professionals or in-home informal paid carers (i.e. often migrant carers who provide both help with care and cleaning/ house maintenance). Do not include here information on unpaid informal care

> *offered by family members, friends or neighbours, as that has already been describe in a previous section.*

- Hospice (end-of-life care) and palliative care

B. Long-term care providers:

- Number of formal and informal long-term care workers (headcount)
  Please provide here a very short description of the balance between formal and informal care workers in your country and provide any data on their actual numbers (most recent estimate and any historical progress, if available)
- Types of health practitioners delivering long-term care services
  Please provide an overview of the specialization of different care professionals working in the long-term care system, adding data on numbers of professionals in each category where available. Consider the following types of professionals commonly involved with long-term care as well as any other categories that might be specific to your country: generalist medical practitioner, nurses, social workers, psychologists, geriatricians, gerontologists, community nurse/carers, occupational therapists, physiotherapists.
- Practitioners working at the interfaces
  Please describe very shortly which care professionals are primarily taking on the roles of coordinators of transitions and management of care at the interface between providers and settings (e.g. nurses as discharge managers, nurses/ social workers as case managers)
- Recognition of new professional categories and roles
  Please consider which new roles/ professions have been recognized or increased their relevance in long-term care provision in your country over the last years. Examples of roles that are becoming increasingly more common at European level include: nursing home doctor, dementia nurses, certified social and health care workers, community nurses/carers, care and case managers or care coordinators.
- Role of unpaid informal carers
  Please describe shortly in this section how care provided informally by family members, close friends or neighbours who provide support without direct remuneration complements formal acre provision. Do not repeat here information already provided in previous section, but rather refer to it (e.g. as described in more detail in section xxx).
- Role of migrant carers
  Please describe shortly the role of carer migration (i.e. the movement of care workers or immigrants involved in the provision of care assistance to older people) in your country's long-term care sector. Please refer only to <u>paid</u> care provision both formal (i.e. through an agency, care provider or recognized contract) and informal (e.g. privately remunerated live-in carers). If relevant for your country, consider not only the importance of inward migration flows but also that of outwards migration flows (i.e. nationals of your country emigrating to seek employment opportunity as carers abroad).

C. Social factors related to gender & perceptions of care work

Please describe shortly any gender roles and stereotypes that are prevalent in the formal care sector in your country. If the situation in the formal sector is very similar to that relevant for informal carers

please do not repeat the information listed in section 5.4 – simply mentioning no additional information to report (see further details in section xxx) will suffice.

D. Are there any important differences between the organization of providers and services at national level and in your region?

For example, are services in specific settings (e.g. in the users' home) more developed than in other regions? Is your region experiencing more acute shortages of human resources (formal and informal)?

3.5 Management

*In this sub-section, **please focus your answer on the national situation,** not on specific providers. If quantitative data is scarce you can rely on published reports, individual studies, qualitative information and expert assessment (collected through interviews) to fill in data gaps.*

A. Service provision management

A.1 Profile of human resources

- Staff composition
- Staffing gaps & use of agency staff
- Working conditions

Please refer in this section to any data available on the size and structure of the long-term care workforce. We are also interested in identifying capacity gaps so please mention any issues related to high staff turnover, low professionalization, working conditions.

2. Support services for workforce

Please mention briefly here any initiatives or services that are meant to support the long-term care workforce (e.g. training, mandatory leave, social support, crisis managers). Refer only to those initiatives (or pilot) that have sufficient coverage at national/regional level or those that are intended for scale-up. We are not interested in initiatives that disparate providers organize internally if these are exceptions within the national system.

3. Stability of the flow of funds that make up the budget of facilities

Please mention very briefly (no more than 1-2 short paragraphs) any relevant aspects related to the composition of long-term care provider budgets (public, private, voluntary contributions) and issues related to stability of funds for planning purposes. Please keep track of the sources of information you consulted should further detail be necessary at a later point

B. Quality management

1. Quality standards for the provision of long-term care across different settings

Please describe shortly any existing quality standards and accreditation mechanisms for long-term care provider, mentioning their scope of applicability (i.e. residential care, community care, home care). If such standards are set at regional, rather than national level please reflect shortly on their commonalities and differences across the country.

2. Quality assurance

Please describe shortly how quality standards in long-term care are checked and enforced. Please mention here which institutions have responsibility for LTC quality assurance (e.g. public bodies/ independent institutions at national/ regional/ local level) and provide an overview of enforcement measures (e.g. inspection, public reporting).

C. Are there any specific aspects related to the management of care services in your region?

Please describe here only those aspects that are significantly different from the information provided above at national level. For example, are quality standards and accreditation mechanism equivalent to those at national level? Are financing flows more stable than in other regions?

4. Performance

The Performance section reflects on the extent to which long-term care services are able to respond in a satisfactory manner to care needs in the population. This encompasses indicators of coverage, access and quality, while emphasizing an equity-perspective. The information collected in this sub-section will be essential to interpreting the data collected throughout the situational analysis and to formulating policy recommendations and the policy road map. Please report any quantitative data available and keep track of your sources.

The following terms are often used in the specialized literature and it is important to understand the concepts they define and the differences between them:

• *Availability of care refers to ensuring the existing supply of care is sufficiently developed to respond to the care needs of the population*

• *Accessibility of care refers to ensuring care services can be reached and used with reasonable ease by those who need them at the time they are needed*

• *Affordability of care (also described as economic accessibility of care) refers to the users' ability to cover the costs of needed care without being exposed to financial hardship or impoverishment*

• *Acceptability or adequacy of care refers to providing care that is consistent with the preferences, ethical principles and expectations of care users and their families*

• *Appropriateness denotes the fit between the services provided and the user's need, its timeliness, and whether the correct approach of care is given, including the professional and interpersonal skill of the staff*

• *Inequalities in (access to) care refer to systematic, avoidable and unfair differences in ability to access and use needed care, as well as in the quality and experience of care, across groups of people defined by a given social location (e.g. gender, age, income, geography). The specialized literature distinguishes between inequalities (meaning differences or disparities) and inequities (meaning differences in care use that cannot be ascribed to differences in care needs). However, the term inequalities is commonly used to cover both meanings.*

Ideally, you would touch on each of these aspects in your answers to the questions in the Performance domain.

A more detailed treatment of the terminology is available in Levesque et al. (2013).

The following resources may prove useful:

- https://www.eurofound.europa.eu/publications/report/2019/quality-of-health-and-care-services-in-the-eu

- https://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits/full-list-of-country-hits (include section on LTC)

- https://www.oecd.org/health/health-systems/social-protection-for-older-people-with-ltc-needs.htm

- https://www.eurofound.europa.eu/publications/report/2020/access-to-care-services-early-childhood-education-and-care-healthcare-and-long-term-care

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4.1 Long-term care services coverage

A. Access to care

Please provide a brief narrative overview of long-term care accessibility in your country and describe shortly any remaining barriers in access to care. For example, by providing information (quantitative data, if available) on waiting times, highlighting potential local differences in service availability and capacity and identifying underserved areas (e.g remote areas, rural areas).

B. Affordability

Please provide a brief narrative description of any financial barriers users' in your country might experience in accessing care. You can describe here any legislation on user co-payments and evaluate the burden they would place on older people. It is also important to reflect on the costs of private care provision (particularly if private providers contribute an important share of total care in your country) and how they impact on household finances for older people. For example, how do the average costs of services for intensive care-giving in the home compare to the average pension/income (in %)? Are certain types of care subject to higher private contributions from users' personal income (e.g. in many EU countries public residential care services are subject to lower user co-payments as compared to intensive formal care support in the user's home).

4.2 Quality of care for older people
A. Health outcome indicators

Please include here a short summary of any available health outcome indicators that reflect the performance of long-term care services. For example, rates of preventable hospitalization, ammenable mortality, (fatal) falls but also rates of re-hospitalization, average length of stay in residential care institutions.

B. User satisfaction: self-reported data regularly collected or as part of surveys

Please describe shortly any data collected regularly in your long-term care systems on user satisfaction with care. If providers report such data to national or regional authorities please include those statistics. Alternatively, refer to dedicated surveys carried out in your country or across Europe (the Eurofound European Quality of Life Survey reports include such information).

C. Care process indicators

Please describe shortly any indicators on the care processes, for example extracted from quality management systems standards. If this data is not available, you might be able to identify some qualitative information from reports and studies.

4.3 Regional inequalities
A. Regional variability

Please describe any key differences in system coverage and performance across regions, in your country. Give a general overview of how all regions compare to the national average (highlighting high and low-performers)

B. Main strengths and weaknesses in system performance in your region

Please *emphasize here the situation of the region where the InCARE pilot will be implemented, highlighting strengths and weaknesses, but do not repeat the information already included in the answer to the question above.*

4.4 Shared decision-making with care users

A. Legislation protecting user choice (e.g. in relation to care setting, preferred course of care)

Please describe shortly any legislation into force or currently being discussed as part of ongoing LTC system reforms. There is no need to provide an overview of the entire legislative acts – a mention of those provisions relevant to the protection of user choice is sufficient for our purposes.

B. Involvement of users and carers in decisions about their care plan (e.g. participatory decision-making procedures, supported decision-making tools for people with impaired capacity)

Please describe briefly any existing procedures and support tools currently in use in your country with the scope of ensuring users are involved in decisions about their care.

5. System enablers

__The System Enablers section__ focuses on describing those characteristics of care systems that foster high quality, sustainable and innovative care provision: governance, funding, adequate staffing and information technology platforms.

We encourage you, throughout this section, to __respond narratively, describing to the best of your ability how the care system is organized, how decision on priorities, funding and resource allocation are made and what workforce and technology issues are currently facing long-term care providers in your country.__ It is important in this section to mention all those policy documents and policy measures that are relevant for the organization of the systems – please refer both to those already in force and to those currently being discussed and planned for adoption in the near future. This will allow us to understand what reforms are underway or being planned.

It is very likely you will not be able to obtain all the relevant information required in this section from desk research alone. Please draw on your professional networks to access key information as you fill in the topic guide. We can further use information from semi-structured interviews to fill remaining knowledge gaps.

The following resources may be helpful:

- https://ec.europa.eu/info/publications/joint-report-health-care-and-long-term-care-systems-and-fiscal-sustainability-country-documents-2019-update_en

- https://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits/full-list-of-country-hits

- https://www.eurofound.europa.eu/publications/customised-report/2020/long-term-care-workforce-employment-and-working-conditions

- https://ec.europa.eu/info/publications/2021-ageing-report-underlying-assumptions-and-projection-methodologies_en

- http://www.oecd.org/els/health-systems/health-data.htm

5.1 Cross-sectoral governance

A. Prioritizing integrated long-term care

Please provide a brief narrative description of how care integration (i.e. health and long-term care services) is discussed and prioritized on the policy agenda in your country. If there are any LTC specific strategies or reform frameworks at national level in your country, please describe their focus and how care integration features in these policy documents.

B. Governance and accountability arrangements

B.1 Governance of long-term care

Please describe the roles of different institutional stakeholders at national, regional and municipal level in the governance of the national long-term care system. If appropriate, provide a description of how public, private and non-profit stakeholder participate in decision-making processes at national and regional level in your country. It is important to understand how priorities for care and reform are set, how services are planned and contracted.

B.2 Performance monitoring

Please describe shortly how care system performance is monitored by decision-makers in your country. For example, by mentioning any existing impact assessment studies of new policies and interventions or by monitoring users' assessments of care outcomes and quality. Do not repeat here any information already listed in the Performance section above.

C. Joint planning across sectors

Please provide short narrative descriptions in this section, pointing to any relevant policy documents. We are interested in understanding if both health and social workforce organizations are represented in decision-making bodies for long-term care at national level, if policy goals are aligned between the health and long-term care sectors and how resource allocation between the two systems compares. Please also reflect shortly on the flexibility of long-term care regulation in your country and if it as proven sufficient in order to respond to emerging long-term care needs.

D. Are there any aspects related to long-term care sector governance that are particular to your region?

Please describe shortly if your region is different in any significant ways from the situation described above, relative to the national context.

5.2 Incentives and financing

A. Provider payment

Please describe shortly how providers are paid for care services they provide in your country. Is the system based on capitation, fee-for-service financing or rather on outcomes-based financing (pay-for-performance)? If a combination of these approaches is used please explain how it works. Please comment shortly on any distortions or negative incentives the current financing system is having on care provision (e.g. incentives to shift the care burden to another care level).

B. Financial coverage

- System for financing long-term care
- Domestic spending on long-term care including home-care, nursing homes, specialist (ambulatory care), other services (e.g. rehabilitation, assistive devices)
- Support for carers (e.g. in cash such as care allowance, paid leave or in kind such as vouchers, respite services, social insurance contributions, unpaid care leave)

Please describe shortly how long-term care is financed in your country: we generally distinguish between five different approaches ranging from those who place most risk on individuals to those that shift risk primarily to the state. These are: 1) Private income, savings and assets; 2) (Voluntary) Private insurance (mainly complementary); 3) Public-sector tax-based support; 4) Social insurance and 5) Mixed: social insurance complemented by taxes. In practice, most countries operate a mix of

these arrangements and we are interested in understanding how they combine in your country. Please report as much quantitative data and statistics as possible on how resources are allocated to different types of services.

C. Are there any particular characteristics of LTC financing mechanisms in your region with respect to the national situation?

Please describe shortly any particularities of LTC financing in your region (if any), without repeating the information provided above.

5.3 Competent workforce
A. Planning, recruitment and staffing

Please describe shortly what methods are applied for allocating positions (e.g. standardized core competencies) and for recruiting (e.g. based on competencies) at the system level. Are there any certification procedure defined at national/regional level for the core work profiles in long-term care?

B. Workforce composition

Please describe in this section the composition of the long-term care workforce, bringing to bare any disaggregated data by gender, roles, migration status and education level. Please also include any available details on remuneration levels (as compared to average national incomes, for example), qualification requirements and conciliation of work and family life for formal carers. Please do not repeat information already listed in section 6.5 but rather refer to any results cited there, if relevant. In this sub-section we are interested in getting a system level overview of the long-term care workforce and any relevant issues and characteristics it might have.

C. Continuous professional development

Please describe shortly the range of continuous professional development opportunities available for long-term care workers in your country. Consider the availability of modular education and specialization, training and retraining courses, presenting any data available on number of participants and range of topics covered. Is there any form of professional development course on long-term care aimed at general practitioners, geriatricians and nurses? Are there any mutual/joint-learning opportunities across sectors, providers and between formal and informal carers?

D. Professionalization of long-term care role

Please describe shortly how current workforce competencies are matching the evolving care tasks and target groups facing long-term care provision in your country. What gaps are most relevant and how are current policies responding to closing these gaps. If any data is available on the number of licensed practitioners in home care and nursing homes (and its evolution over the last decade) in your country please summarize it here.

E. Is your region facing any particular challenges with respect to long-term care workforce or is implementing special policies and programs in this area?

Please describe shortly any particularities of the long-term care workforce in your region (if any), without repeating the information provided above.

5.4 Information and communication technology (ICT)
A. Data capture

Please describe briefly how data on care users and services is routinely collected in your country and what role ICT in the data collection infrastructure. Does your country operate electronic records or patient registries? Please also mention very briefly (no more than 1 paragraph) what measures for secure and safe data access and data protection are implemented in your country.

B. Application of new technologies and online platforms

- Guideline/strategy for encouraging technological innovation adoption
- Programmes for funding pilots of care technologies
- Online platforms and patient portals

Please describe shortly what initiatives and policies are in place in your country to encourage the adoption of ICT in long-term care.

C. Information exchange

Please describe very briefly (no more than 1 paragraph) what mechanisms are in place in your country to facilitate information transfer between health, long-term care and other social services.

D. Is your region a front-runner in ICT for long-term care? What are the particular initiatives or challenges that set your region apart from the national average?
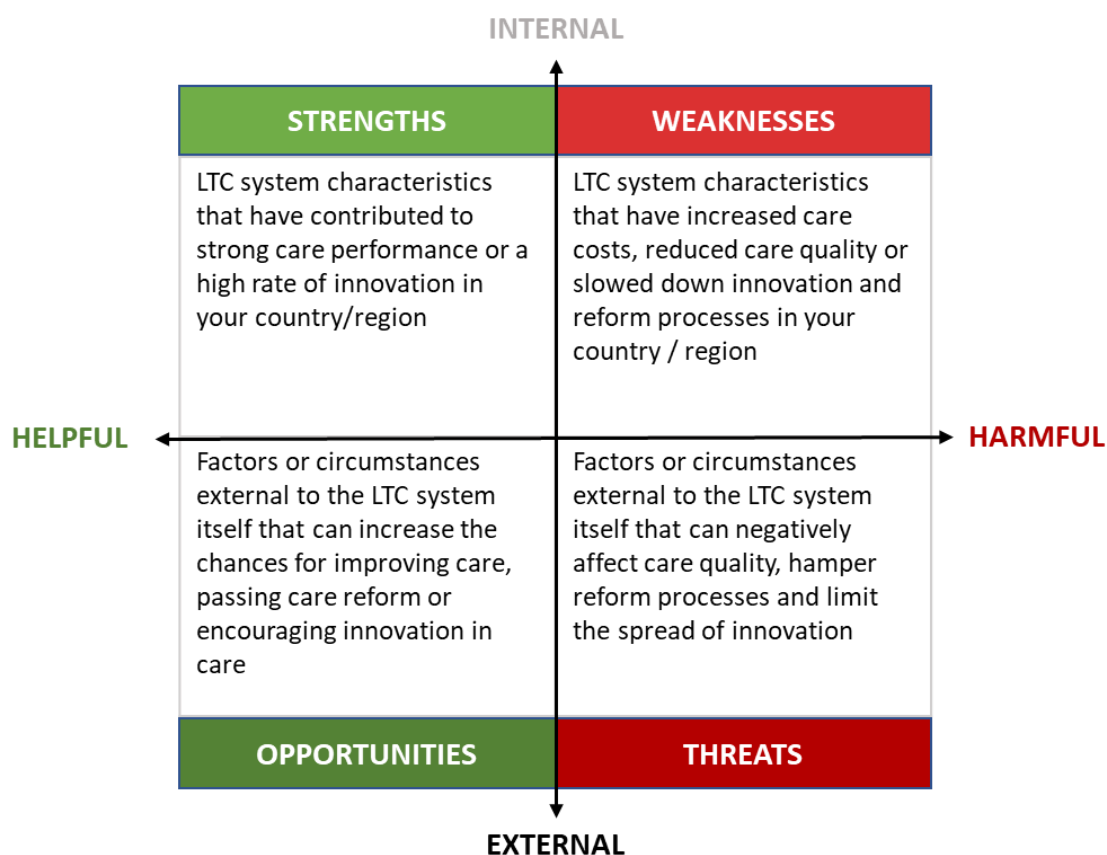
6. SWOT analysis

Once the Situational Analysis for each pilot country will be completed we shift our perspective from a descriptive approach to a more analytical one by carrying out SWOT analyses in each setting.

SWOT (Strengths, Weaknesses, Opportunities, Threats) analyses have been originally develop to support strategic planning in organizations but they have proved equally useful in guiding decision-making in the health, development and education sectors. We will use SWOT analyses as a planning tool to support us in identifying the internal and external factors that affect the likelihood of InCARE achieving its policy objectives (see Figure 1).

Strengths and Weaknesses refer to those characteristics of the LTC system that can contribute to better care performance, higher equity achievements and greater innovation potential in a national or regional care setting. To populate these categories, we would consider information collected in the Situational Analysis in areas such as human and financial resources, governance models and cross-sectoral integration, community empowerment and engagement, system infrastructure and use of technology.

Opportunities and Threats refer to factors or circumstances external to the LTC system itself but which can have far reaching consequences on LTC quality and equity performance, potential for innovation and readiness for sector reform. We would consider here factors which relate to the economic and political context in each country, the demographic landscape, cultural factors and the legislative background on social support, users' and carers' rights.

Figure 1. Defining Strengths, Weaknesses, Opportunities and Threats

The SWOT analyses will be carried out in a group brainstorming exercise including all national partners and their mentor organization and will be refined by national teams with support from technical partners.

For a more detailed description of SWOT analyses we encourage you to consult the following sources:

- Docrat, S., Lorenz K., Comas-Herrera, A. (2021) *STRiDE situational analysis: guidance on developing SWOT analyses from the desk review. STRiDE research tool No.4 (version 2)*, CPEC, London School of Economics and Political Science, London
- Renault, V. (2019). Section 14. *SWOT Analysis: Strengths, Weaknesses, Opportunities, and Threats*. Available at: https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/swot-analysis/main
- Giusti, A., Maggini, M. & Colaceci, S. The burden of chronic diseases across Europe: what policies and programs to address diabetes? A SWOT analysis. Health Res Policy Sys 18, 12 (2020). https://doi.org/10.1186/s12961-019-0523-1

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