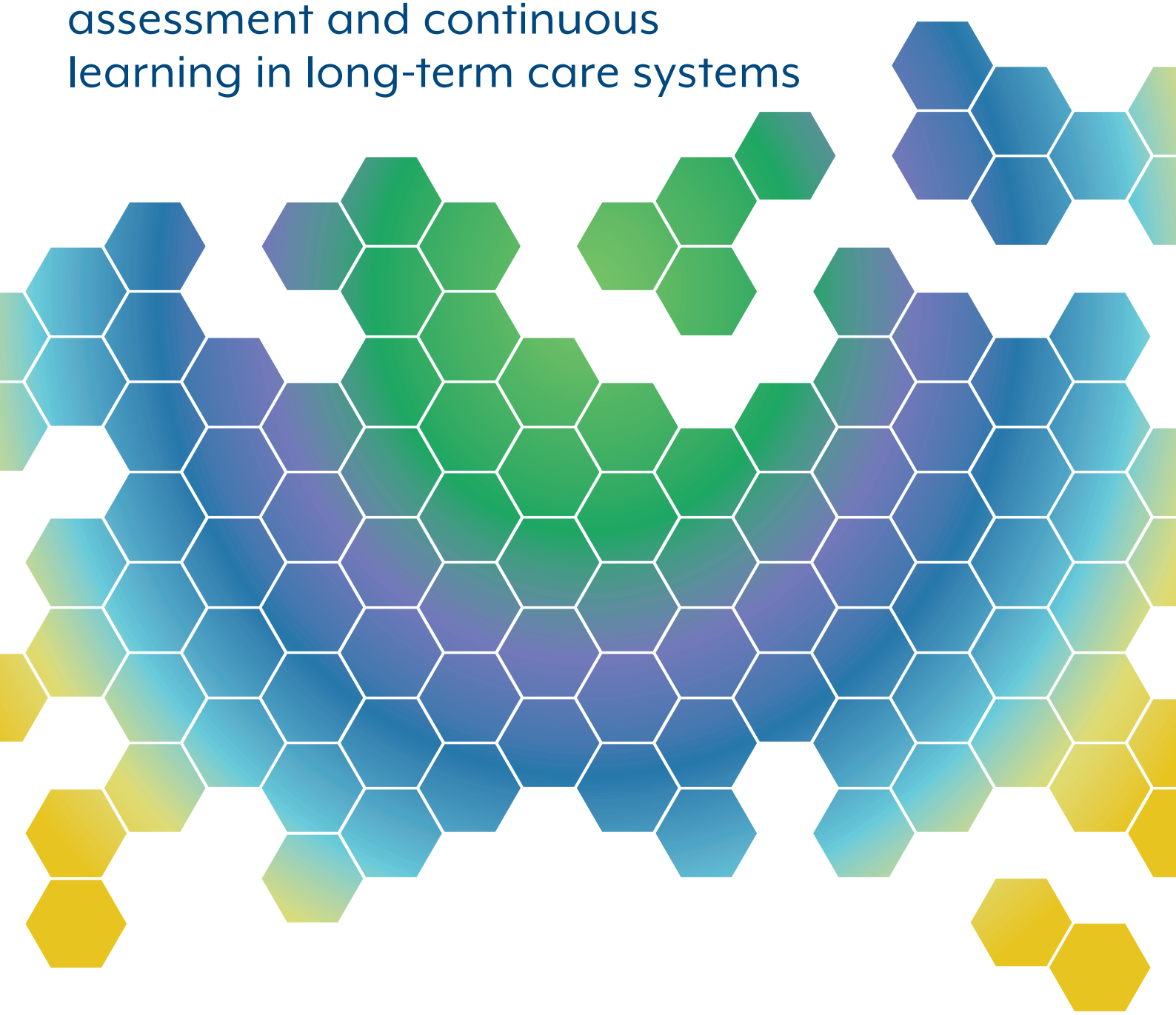
State of long-term care

A conceptual framework for assessment and continuous learning in long-term care systems



World Health Organization
European Region

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Abstract:
The State of Long-term Care (State of LTC) Toolkit is designed to support policy- and decision-makers in their efforts to reform and transform long-term care systems by promoting learning, collaboration and trust. It proposes a conceptual framework and a methodological approach to knowledge generation, grounded in participatory governance. The conceptual framework focuses on five key components – population care needs, system inputs, outputs, outcomes and population-level impact – disaggregated into 25 analytical domains. Rooted in a person-centred approach and emphasizing that individual care needs, preferences and expectations should inform system design and reforms, the conceptual framework links in a causal chain structure the available resources in the system to the outputs the system produces and the system-level outcomes obtained. The State of LTC Toolkit is a key deliverable of the European Care Strategy and aims to support the implementation of the *Council Recommendation on access to affordable high-quality long-term care*.

KEYWORDS: LONG-TERM CARE, AGEING, HEALTH POLICY, SOCIAL POLICY, HEALTH CARE REFORM, INTERSECTORAL COLLABORATION, TRUST

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List of abbreviations

ADL	activities of daily living
COVID-19	coronavirus disease
EU	European Union
IADL	instrumental activities of daily living
LTC	long-term care
SDGs	Sustainable Development Goals
UHC	universal health coverage

Executive summary

The State of Long-term Care (State of LTC) Toolkit is designed to support policy- and decision-makers at national, regional and local levels, in their efforts to reform and transform LTC systems by promoting learning, collaboration and trust. It proposes a conceptual framework and a methodological approach to knowledge generation grounded in participatory governance. The State of LTC Toolkit consists of a conceptual framework (detailed in this report) and an Implementation guide, which itself includes a detailed a Data-collection template.

The conceptual framework for evidence gathering and system-level assessment considers five components – population care needs, system inputs, system outputs, system outcomes and population level impact – further disaggregated into 25 analytical domains. The State of LTC framework places people at the centre, recognizing that individual care needs, preferences and expectations should inform the design of LTC systems, the processes of care delivery and the direction of reforms. The long-term care system itself is represented in a results chain structure, linking in a causal sequence the resources that are available in the LTC system (both tangible and non-tangible, financial and human resources), with the outputs the system produces (e.g. the capacity and quality of care services and supports) and the outcomes that are obtained at the LTC system level.

The State of LTC Toolkit also emphasizes broad engagement of diverse stakeholders, both as a precondition for ensuring a balanced and comprehensive analysis of the existing knowledge base and as a mechanism for promoting trust, dialogue and consensus among national stakeholders.

Applied regularly or institutionalized into national monitoring and evaluation mechanisms, the State of LTC approach will enhance learning in LTC systems and empower all stakeholders to use, enhance and share their knowledge and expertise.

The Toolkit, produced by the WHO Regional Office for Europe in collaboration with the European Commission Directorate-General Employment, Social Affairs and Inclusion, is a key deliverable of the European Care Strategy and aims to support the implementation of the *Council Recommendation on access to affordable high-quality long-term care*.

1. Long-term care (LTC) as a key component of social policy

Every country in Europe is experiencing population ageing; that is, median age is increasing as fertility rates decline and life expectancy rises. This trend is projected to continue and will have effects on every aspect of society – from economic and financial markets to all public and welfare programmes, as well as social relationships, solidarity, family structures and intergenerational dynamics. In light of continued population ageing and the increase in prevalence of diseases with a high burden of disability, the need for LTC in Europe has been growing at an accelerated pace and far exceeds the availability of care services.

Increasing longevity is a measure of societal progress and a testament of success for health and social welfare interventions over the decades. Whether it also becomes a challenge for our societies will depend on how people age and how countries respond to population ageing. Investment throughout the life-course in healthy ageing (that is, the process of developing and maintaining the functional ability that enables well-being in older age) is not only a prerequisite for enabling growing numbers of older people to maintain dignity and to be and to do what they value, but also an investment in thriving economies, social cohesion and sustainable development.

LTC encompasses activities that 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" *(1)*. This broad definition from WHO covers continuous or intermittent care services, delivered in a variety of settings to address the health, personal care, and social needs of individuals and with the goal of recovering (whenever possible), maintaining or optimizing their functional ability.

The *Council Recommendation on access to affordable high-quality long-term care* proposes a similar definition, whereby **LTC consists of a range of services and assistance for people who, as a result of mental and/or physical frailty, disease and/or disability over an extended period of time, depend on support for activities of daily living (ADL) and/or are in need of permanent nursing care** *(2)* (Box 1).

As limitations in intrinsic capacity can arise at any point during the life-course, LTC services are needed and relevant for every age group. However, in the context of population ageing a large share of users are older people who experience functional decline as they age.

LTC can be delivered by remunerated care workers (formal care services) or by informal caregivers, in the care users' home, in the community or in residential care settings. LTC delivery should include – or be well coordinated with – a spectrum of health and care services ranging across various domains, from screening and health promotion, rehabilitation of function, assistance and maintenance of independence, to provision of palliation and end-of-life care. It focuses on the functioning of an individual, irrespective of the disease(s) and conditions which may lead to declines in functional ability.[1] This is achieved through an emphasis on empowering people who use care to manage their health conditions, adapt to and compensate for changes in functioning and maintain as much independence, autonomy and quality of life as possible, at every life stage. LTC often requires support from others (such as caregivers) to carry out ADL[2] and instrumental

[1] These are the health-related attributes that enable people to be and to do what they have reason to value; it is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individual and these characteristics.

[2] Including activities such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet and/or controlling bladder and bowel functions.

activities of daily living (IADL[3]) and to maintain social participation, as well as to access assistive technology, adequate housing, caring and age-friendly communities.

One of the main targets set through the 2030 Sustainable Development Goals (SDGs) is the pursuit of universal health coverage (UHC), whereby all people should have access to the full range of high-quality health services they need, when and where they need them, without financial hardship. The vision of UHC covers the entire continuum of health and care services across the life-course, and includes health promotion, prevention, treatment, rehabilitation, and assistive and palliative care. Aligning LTC service delivery with the broader agenda on universal access and equity in health is essential to promote accessibility, high-quality, integration and sustainability of health and care services and resources, as well as to amplify population-level impact (see Box 1).

Box 1. Global and regional commitments driving LTC policy

The *Council Recommendation on access to affordable, high-quality long-term care (2)* calls on Member States to improve access to affordable, high-quality LTC for all people who need it. This entails ensuring the adequacy of social protection for LTC; continuously aligning the offer of LTC services to the respective needs; ensuring that high-quality criteria and standards are established for all care settings and applied to all providers; supporting high-quality employment and fair working conditions in the sector; improving the professionalization of care work; and addressing skills needs and worker shortages, while also supporting informal carers in their caregiving activities.

The United Nations Decade of Healthy Ageing (2021–2030) is a global collaboration, aligned with the last 10 years of the SDGs, to improve the lives of older people, their families and the communities in which they live *(3)*. The Decade addresses four action areas, one of which focuses on ensuring equitable access to LTC of high quality, so that people experiencing decline in their physical and/or mental capacity can maintain their functional ability, enjoy basic human rights and live with dignity.

The 2030 Agenda is a plan of action for people, planet, peace and prosperity *(4)*. It mobilizes a global partnership to end poverty in all its forms and to ensure that all human beings can fulfil their potential in dignity and equality, as well as in a healthy environment.

The WHO Global Network for Age-friendly Cities and Communities has brought together cities, communities and organizations worldwide with a common goal of enabling age-friendly environments that empower every person – regardless of age or health status – to maintain and enhance their functional abilities. In 2024, 1542 cities and communities across 51 countries were part of the Network.

According to projections from the baseline scenario in the *2024 Ageing report (5)*, the number of people with LTC needs in the 27 Member States of the European Union (EU) is expected to rise from about 31.2 million in 2022 to 33.2 million in 2030 and 37.8 million in 2050; an overall increase of over 20%. In the absence of sustained public investment and reform to strengthen LTC systems, the unmet needs that result from the mismatch between demand and supply of care limit the ability of European countries to meet their commitments to ensuring an inclusive and equal society, as enshrined in Article 3 of the Treaty on the EU (to promote the well-being of its peoples and the sustainable development of Europe, aiming to achieve full employment and social progress) *(6)*. Inequitable and limited access to high-quality care also constrains opportunities to ensure healthy lives and promote well-being for all, across all ages (SDG 3). It can thwart social and economic development and remains a considerable barrier to social justice and protection, equality between women and men and solidarity between generations.

[3] This includes activities such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

The same values are reflected in the European Pillar of Social Rights *(7)*, especially Principle 16 (Everyone has the right to timely access to affordable, preventive and curative health care of good quality) and Principle 18 (Everyone has the right to affordable long-term care services of good quality, in particular home care and community-based services). Transposing these principles, the European Care Strategy *(8)* and the accompanying *Council Recommendation on access to affordable high-quality long-term care (2)* chart a way for local, regional, national and European-level actors to join forces and ensure all those who need and who provide care are protected, supported and empowered to use and provide high-quality, affordable and accessible care services.

In support of these efforts, the Directorate-General for Employment, Social Affairs and Inclusion at the European Commission and the WHO Regional Office for Europe have established a strategic partnership to support Member States in strengthening their LTC systems and improving the quality, resilience and sustainability of service delivery. The partnership aims to improve access to affordable, high-quality LTC for all people who need it and to promote well-being, autonomy and quality of life for growing numbers of people living with functional limitations and for their caregivers. The partnership works to enhance capacity for assessment and monitoring of LTC systems and reforms to help accelerate sustainable, evidence-based and inclusive system transformation.

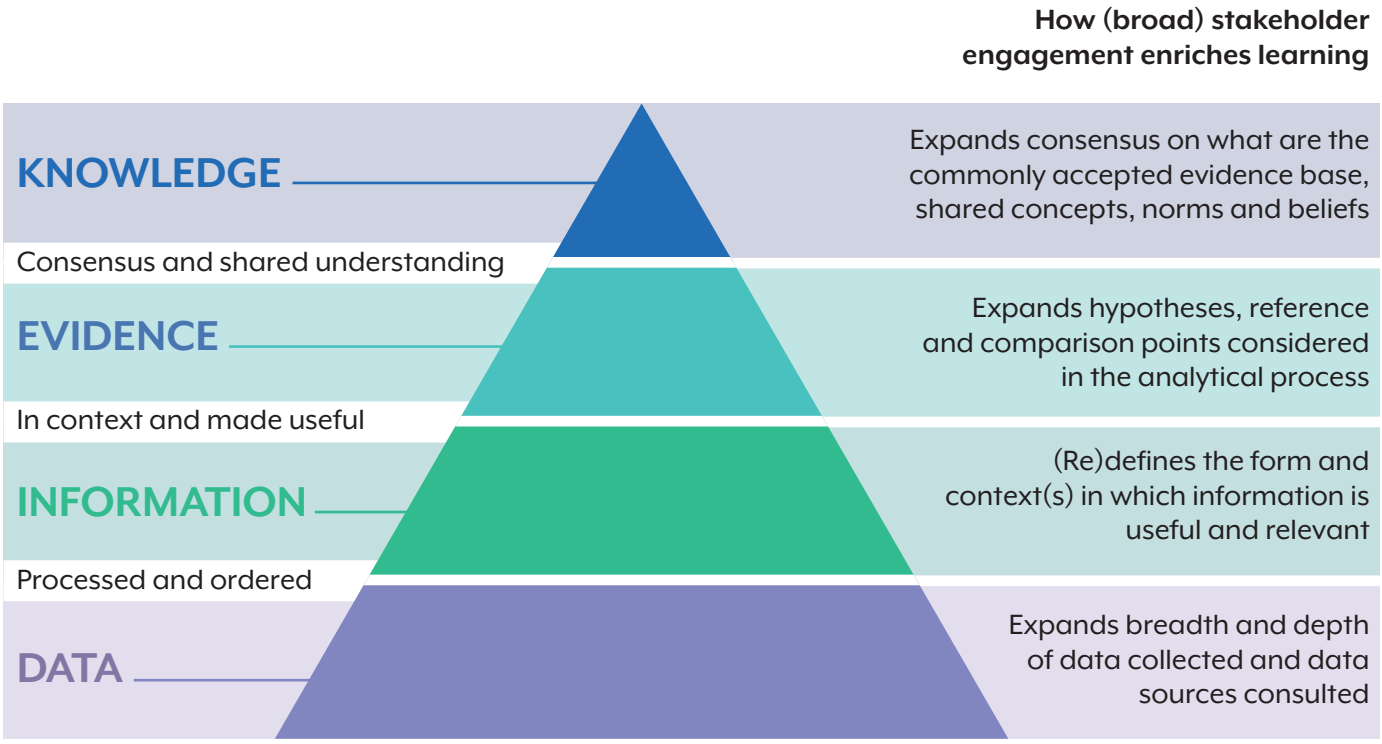
2. The State of LTC Toolkit for monitoring and assessment

What it is and what it isn't

The State of LTC Toolkit aims to develop a **conceptual framework** and propose a **methodological approach grounded in participatory governance**[4] to facilitate development and transformation of LTC systems through learning, collaboration and trust. It builds on insights derived from systematic data collection and analysis, validated and supported by multi-stakeholder engagement and dialogue, in order to facilitate national reform processes and improve alignment and synergies with European or global processes.

The State of LTC approach proposes a systematic and flexible methodology to balance the development and synthesis of evidence and knowledge (**learning**) with broad stakeholder engagement in support of evidence triangulation and consensus-building (**trust and collaboration**). Participation and broad multisectoral engagement enrich every phase of knowledge generation (as depicted in Fig. 1) and can **facilitate change management, leadership, planning and transparency** as part of health and LTC system reforms. The State of LTC Toolkit offers an approach for facilitating dialogue and consensus between stakeholders across the health, LTC and social protection systems, who often work in silos.

Fig. 1. The role of stakeholder engagement in the knowledge generation pyramid



Source: adapted from the work of Dammann *(9)*.

[4] Participatory governance is understood as empowering people, communities and civil society through inclusive participation in decision-making processes that affect health across the policy cycle and at all levels of the system. It is also synonymous with multi-stakeholder participation and social participation.

The State of LTC Toolkit for assessment and continuous improvement consists of:

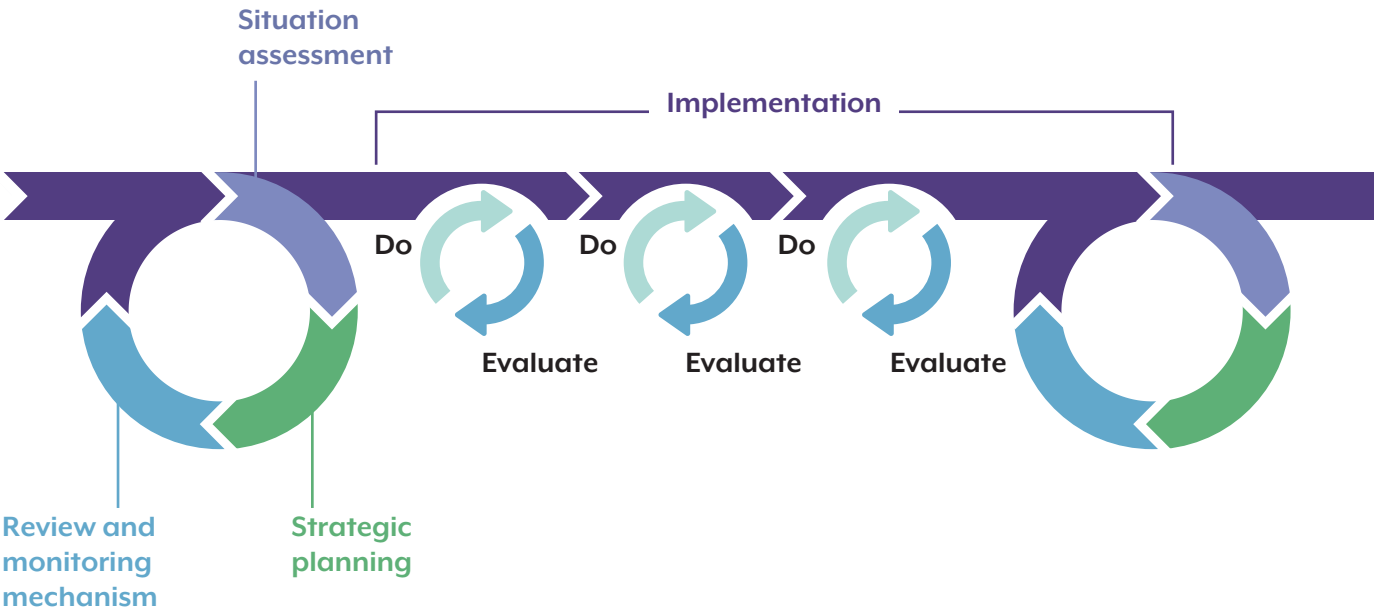
- a **conceptual framework** for LTC system strengthening practices – described in more detail in Section 3 of this report – and a detailed **Glossary** of terms in the web annex to this report *(10)*;
- an accompanying operational **Implementation guide**, which provides guidance on all steps of the assessment process *(11)*; and
- a **Data-collection template** for systematic evidence synthesis *(12)*, available as a separate web annex to the Implementation guide. This aims to provide a broad, although not exhaustive set of indicators and measures that can be used to collect information on any of the domains considered in the conceptual framework.

The State of LTC Toolkit focuses on **monitoring change over time within a country** rather than between countries or regions. It aims to track and recognize progress, wherever it has been achieved in the LTC system, and to promote further improvement and innovation, in relation to key system outcomes. Therefore, it is not a benchmarking tool.

The Toolkit is much **broader in scope than an indicators framework**. It attempts to complement data from statistical sources with insights from evidence and information that are not and cannot be fully captured by quantitative indicators. The depth and scope of information recommended for collection – including that of a qualitative nature – allows for capturing the subjective and contextual elements of LTC systems as means to understand the origins of bottlenecks and challenges. A **flexible evidence-gathering approach** is essential to the breadth and depth of analysis and to generating a strong knowledge base in an emerging field like LTC, which is in the process of clarifying concepts and boundaries, and refining its identity, scope of practice and goals in many European countries.

The State of LTC Toolkit is accompanied by three country reports, which exemplify what insights can be derived from applying this approach as part of a national-level LTC system assessment. Once the assessment has been completed, it can inform strategic planning processes, efforts to strengthen the evidence base and accountability, and the development of a continuous monitoring and evaluation loop to promote performance management. It can be thought of as one component of a cyclical process of assessment, planning, implementation and evaluation that should underpin reform and policy development processes (Fig. 2).

Fig. 2. Cyclical strategic policy/reform planning process



Source: adapted from WHO *(13)*.

The application of the State of LTC Toolkit generates policy conclusions and options for action to improve LTC systems which can feed into – but, crucially, not replace – strategic planning at national or regional levels. Similarly, while the assessment will generate data that can be used over the medium to long term to track system-level progress, it cannot be a substitute for the development of monitoring, evaluation and accountability mechanisms at the appropriate governance levels.

The assessment process set targets to be achieved; nor does it define policy goals. It is built to **generate learning and consensus** on how available resources, processes and structures in LTC systems can be optimized to achieve key predefined system-level outcomes and population-level impacts. To this end, the State of LTC conceptual framework links, in a causal chain, the key population needs, inputs and outputs that are crucial for strengthening and transforming LTC systems. It is designed to make use of all available evidence, while providing insights into the remaining data gaps. Completing the State of LTC assessment is a way to **map existing evidence and raise awareness of remaining gaps in data and knowledge generation, which may impede or entirely prohibit evidence-based decision- and policy-making**.

The Data-collection template focuses on the outcomes and impact identified as strategic priorities in the European Pillar of Social Rights *(7)*, the *Council Recommendation on access to affordable high-quality long-term care (2)*, the 2030 Agenda for Sustainable Development *(4)* and the United Nations Decade of Healthy Ageing *(3)*. However, the template can be adapted in the process of self-assessment to track alternative or additional indicators and outcomes of interest, which should be defined by national or regional stakeholders in alignment with relevant policies and objectives.

Who it is for

The State of LTC Toolkit has been developed primarily to support governments and policy-makers with responsibilities for regulating, planning, financing, organizing and delivering LTC services at the national or subnational levels. Further, the Toolkit can be used by stakeholders across health and LTC systems (including housing and social protection policies) and, depending on the particularities of each setting, may include insurance organizations, educational institutions responsible for workforce training, regulatory bodies and service managers working in public and/or social partnerships, civil society organizations and social economy entities, among others.

It can be used by governments and policy-makers in many ways, in line with national context and priorities. Among the variety of possibilities, the tools may be used to:

- guide development and monitoring of national strategies and action plans, notably to support the implementation of the *Council Recommendation on access to high-quality affordable long-term care*;
- support decision- and policy-making on priority areas for reform and investment (such as national programmes on the care workforce or informal carers);
- guide, strengthen and/or expand national monitoring efforts relating to LTC system performance and outcomes;
- support reporting on LTC system performance to the EU or other international stakeholders;
- strengthen participatory approaches to policy-making and LTC delivery, including meaningful engagement of people with care needs, their families and their communities;
- build collaboration and trust between stakeholders with responsibilities in the LTC system;
- support mutual learning and knowledge exchanges across countries and regions; and
- support targeting of European/national/international investment and funding for development and technical support.

The different components of the Toolkit may also prove informative and useful for academics, researchers and advocates in the LTC field, and can guide and encourage increased consistency across their efforts at subnational, national and European levels.

How it was developed

The State of LTC assessment Toolkit builds on existing guidance and system assessment tools and publications focusing on integrated delivery of LTC, care continuum and health systems, produced by WHO. Among them:

- *Country assessment framework for the integrated delivery of long-term care* (2019) *(14)*
- *Framework for countries to achieve an integrated continuum of long-term care* (2021) *(15)*
- *Rehabilitation in health systems: guide for action* (2019) *(13)*
- *Health system performance assessment: a framework for policy analysis* (2022) *(16)*
- *Long-term care for older people: package for universal health coverage* (2024) *(17).*

The Toolkit was developed by WHO Regional Office for Europe and European Commission teams, with a view to adapting pre-existing tools to better capture and address the long-term effects of demographic change, shifting morbidity patterns, environmental change and global health emergencies like the coronavirus disease (COVID-19) pandemic on health and care systems. It recognizes the need to plan and design health and care systems with a focus on improving adaptability, promoting continuous learning and improvement, enabling resilience, investing in preparedness and enhancing readiness to mobilize stronger responses to unfolding and emerging challenges.

At the same time, the Toolkit is designed to help plan implementation measures in line with the *Council Recommendation on access to affordable high-quality long-term care (2)* and the European Care Strategy *(8)* and to track progress at national and regional levels.

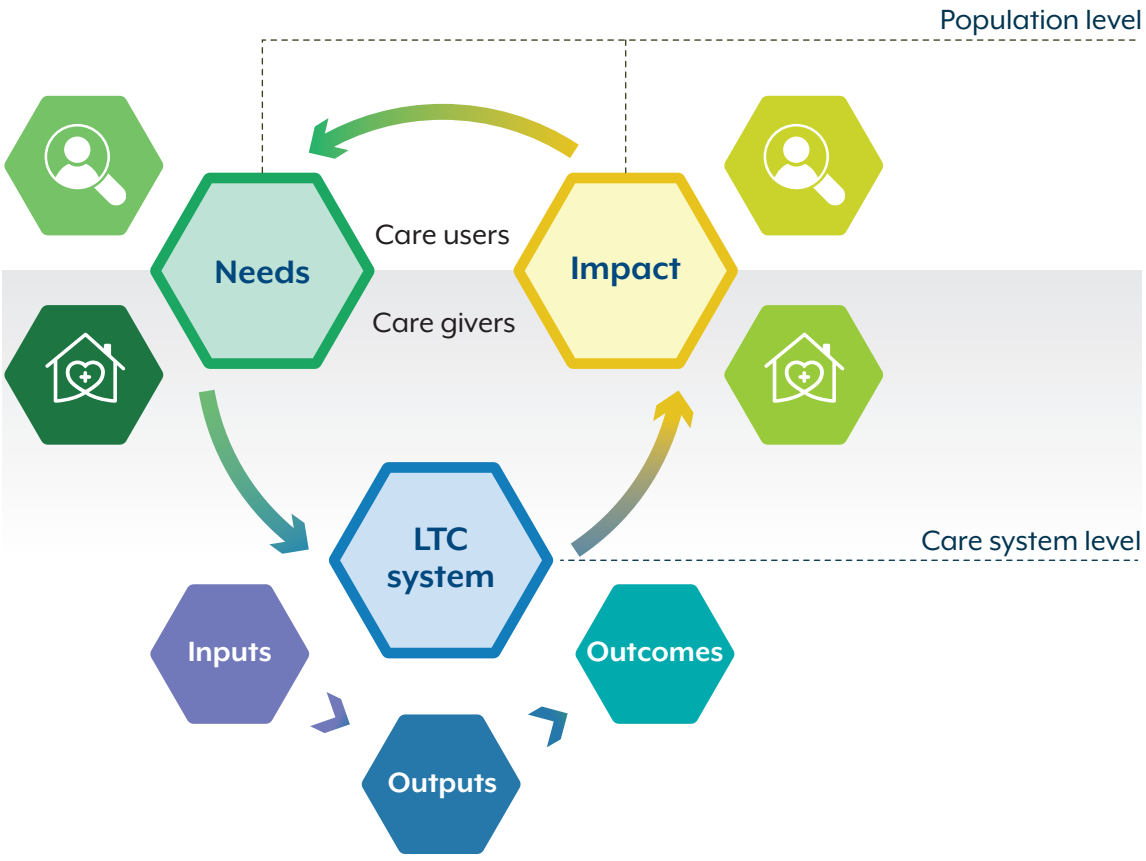
The conceptual thinking is rooted in the synthesis of global evidence and experiences on LTC system development, preparedness and resilience, while the structure of the Toolkit, the operationalization of the dimensions proposed, and the selection of indicators are informed by the *Council Recommendation on access to affordable high-quality long-term care* and the availability of key information in comparable, international databases.

The Data-collection template relies (where possible) on statistics and data sources that are regularly and reliably collected across all EU countries or at global level. Where this is the case, the data sources are signposted in the Implementation guide *(11)*.

3. State of LTC conceptual framework

The State of LTC Toolkit proposes an approach to LTC system monitoring and assessment that considers five components (needs, inputs, outputs, outcomes and impact) and places people at the centre of the analysis, recognizing that individual care needs, preferences and expectations (aggregated at population level) should inform the design of LTC systems, the processes of care delivery and the direction of reforms. Furthermore, it emphasizes that the performance of LTC systems is defined primarily in relation to its impact on individuals at the population level – that is, reflecting individual rights and flourishing – but also taking into account societal level goals, such as well-being, social cohesion and economic development (see Fig. 3).

Fig. 3. Conceptual mapping of LTC systems in a results chain structure



Source: authors' own compilation.

Within this conceptual framework, the LTC system is called on to respond to care needs in the population in a person-centred way and expected to co-produce positive impacts for and with the same population. The population of interest is understood, in line with the *Council Recommendation on access to affordable high-quality long-term care (2)*, to include both people in need of care and those who engage in the provision of needed care, whether formally or informally, and who themselves may need support. Similarly, the desired impact should be thought of in terms of both improved well-being and better individual outcomes for people with care needs and for all those who contribute to care and caregiving among the wider population. Box 2 outlines the types of caregivers involved in providing LTC to various individuals in need.

Needs and impact are themselves interdependent within a long-term perspective. For example, improved well-being, control and autonomy for individuals will translate into reduced need for care services over their life-course, while improved social protection and better opportunities to reconciliate work and care will lead to lower rates of socioeconomic vulnerability for caregivers. Understanding and effectively promoting positive impact at the population level is the main goal of LTC systems, and through its role in preventing and reducing LTC needs in the future, this is also an essential contributor to the sustainability of LTC systems.

Within the State of LTC Toolkit, the LTC system itself is modelled along a results chain structure, widely used in programme monitoring and evaluation. It begins by identifying the key populations in need, their care and support needs, and other key population factors that are relevant for consideration in the design and delivery of LTC systems (see Fig. 3). The results chain traces a pathway for change, linking in causal sequence the resources that are available in the LTC system (including both tangible and non-tangible financial and human resources) with the outputs the system produces (that is, the capacity and quality of care services and supports) and the outcomes that are obtained at the LTC system level (namely, ensuring equitable access to affordable and cost-effective care that is sustainable and resilient to emergencies and shocks).

Box 2. Types of caregivers involved in the provision of LTC

While the broad diversity of caregiving experiences and care arrangements defy simple categorization, in this report the terminology is used to distinguish between different types of care and caregiving.

(Informal) caregivers are people in the social environment of the person in need of LTC, who provide care for a member or members of their family, friends or community. They may provide occasional, regular or routine care, or be involved in organizing care delivered by others, most often without pay and always outside the remit of an employment arrangement or formal service-provision agreement. In this sense, informal caregivers are distinct from (formal) care workers, since they are not employed by organizations entitled to coordinate and deliver services.

Formal care workers (for example, personal care workers, home care aides, care assistants, physicians, social workers, nurses, physiotherapists and personal assistants) are people who are paid within the remit of an employment contract, often hold professional qualifications or have received basic training for the roles they fulfil and are usually associated with formal service delivery (by certified or accredited providers).

Live-in carers, domestic workers or 24-hour carers provide care based on an agreement with the person needing care or their family, although such agreements are not always declared or regularized as formal employment. They are remunerated for the care provided but are rarely recognized as care workers (with a few exceptions whereby pathways for certification and formalization of such care roles exist), which limits access to education and training as well as protection and monitoring of working conditions.

Note. The Glossary in the web annex to this report contains further details on the terminology used in the State of LTC assessment *(10)*. These categories may be defined differently in various countries and contexts.

A separation of the population-level targets and indicators from the system-level analysis does not indicate the LTC system can or should be separated from the individuals and communities it serves. On the contrary, communities are an integral part of care systems, contributing in myriad ways to their functioning and effectiveness, but also directly to maintaining the health, independence, social participation and quality of life of people in the community *(18)*. This is recognized in the conceptualization at every level of analysis (care needs, inputs, outputs, outcomes and impact), through the explicit recognition of the dyadic nature of care, the role of caring communities and age-friendly cities and communities *(19)*, the interdependencies between formal and informal care provision and the imperative to ensure collaboration and balance between them. Importantly, while informal care remains the backbone of LTC systems, formal service provision is called upon to complement and facilitate it, ensuring every individual is afforded meaningful choice of whether to provide care, when to provide it and at what intensity. Similarly, while local communities can and do self-organize to ensure the necessary support structures are available, it is imperative that public investment is directed towards the development of such supportive community structures and that their key role in LTC systems is adequately acknowledged in policy and governance. Investing in national programmes that develop and support age-friendly cities and communities by fostering healthy ageing, improving access to health and social care services and supporting the participation of people in their communities can directly promote the health, well-being and autonomy of the population and further support the community's role *(19)*.

A system analysis in a results chain structure has the considerable advantage of allowing a narrower focus on identifying levers for policy intervention, by drawing the direct links between the resource investment, the system processes, the services produced and the outcomes of interest. While it is possible to track and monitor key system outcomes, they are rarely amenable to direct policy interventions, especially within the time frame of political cycles, and often must be interpreted in the context of evolving population needs, preferences and priorities. Conversely, targeted interventions, investments and transformation of inputs, processes and outputs can be pursued directly by policy-makers, on more accelerated time frames.

For example, the objective of improved continuity and coordination of care resources is a common challenge and policy goal across European countries. Policy-makers can, in principle, pass legislation that mandates all care providers to implement processes for better coordination across care settings. However, such legislation is unlikely to be impactful if the key conditions for achieving this outcome are not in place, including appropriate training and up-skilling of health and care workers, investment in data sharing and digital technologies that favour coordination, and high-quality management frameworks and financing models that incentivize multidisciplinary work, care user, family and community engagement and collaboration across stakeholders, among others. Furthermore, policy interventions to optimize financing, training and quality-management models will have positive impacts on multiple system-level outcomes (including equity, cost–effectiveness, sustainability and resilience), which are important to consider in a robust evaluation of the value of a policy intervention or the cost of inaction.

Component 1. Population needs

In line with the *Council Recommendation on access to affordable high-quality long-term care* and WHO guidance *(2,14,15)*, the State of LTC Toolkit recognizes the need for long-term support for all individuals (i.e. care users) experiencing or at risk of decline in intrinsic capacity and functional ability due to health conditions (*(2)*: Article 1), as well as psychosocial needs and social inclusion. This includes the need for assistive care (i.e. responding to limitations in functional abilities) but also the need to prevent functional decline (maintaining function and delaying further decline). This can be achieved through the prevention and management of health conditions associated with losses in functionality, as well as through rehabilitation and reablement.

Furthermore, the need for care can extend beyond the individual with limited functioning to their caregivers, who are at increased risk of detrimental mental and physical health effects, poverty, social isolation and loneliness, especially when providing intensive or frequent care (*(2)*: Article 9). LTC systems should identify caregivers who are at risk of or experiencing care burden or detrimental effects on their health and well-being and deploy appropriate support services to prevent and minimize such effects (Fig. 4).

Fig. 4. Care needs in the population

Source: authors' own compilation.

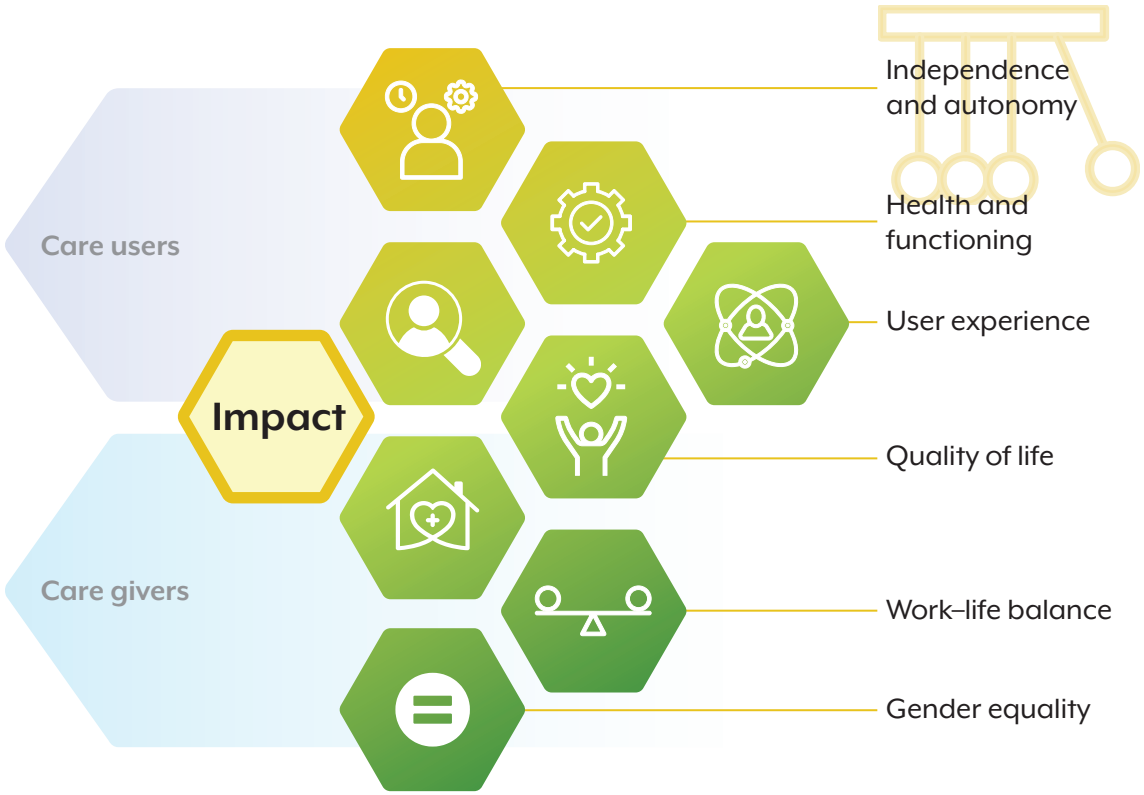
Applying a person-centred approach, which places care users and their families at the centre of LTC systems, the needs for support must be understood in the context of a right to choose and aligned with the values, cultural underpinnings and preferences for care of individuals and communities. The LTC system is called upon to provide care that reflects the expectations of both the people who use it and the caregivers alike, offering services that are acceptable to their personal goals.[5]

Component 2. Population impact

Similar to the definition of needs, the population-level impacts considered in the State of LTC Toolkit include the perspective of people with care needs, of caregivers and of communities more broadly in terms of the gender-equity and work–life balance implications of care systems (Fig. 5). LTC systems aim to contribute to improving quality of life for all and optimize health and functioning in the population, for people who use care, caregivers and all members of communities. For care users, quality of life is closely linked to improving independence and autonomy, having meaningful relations with others, having sufficient support, and a sense of fulfilment. This means all people experiencing functional decline should be able to maintain choice and control over their living environment, social interaction and personal dignity, often reflected in remaining in their homes for as long as possible. The care services and support available to them should be satisfactory and adapt flexibly to their expectations and preferences, as these evolve through time or at various stages throughout the life-course.

[5] This is emphasized by Article 5 of the *Council Recommendation on access to affordable high-quality long-term care (2)* and the quality principle of person-centredness described in the Glossary (in the web annex to this report *(10)*).

Fig. 5. Population-level impact



Source: authors' own compilation.

From the perspective of caregivers, a balanced distribution of care responsibilities and support in ensuring care can be reconciled with other personal, social or economic activities is essential to allow all individuals to reach their full potential and maintain the highest possible quality of life. For informal caregivers, quality of life as linked to their caring role means maintaining social relations, having sufficient support, and spending time as one would like.

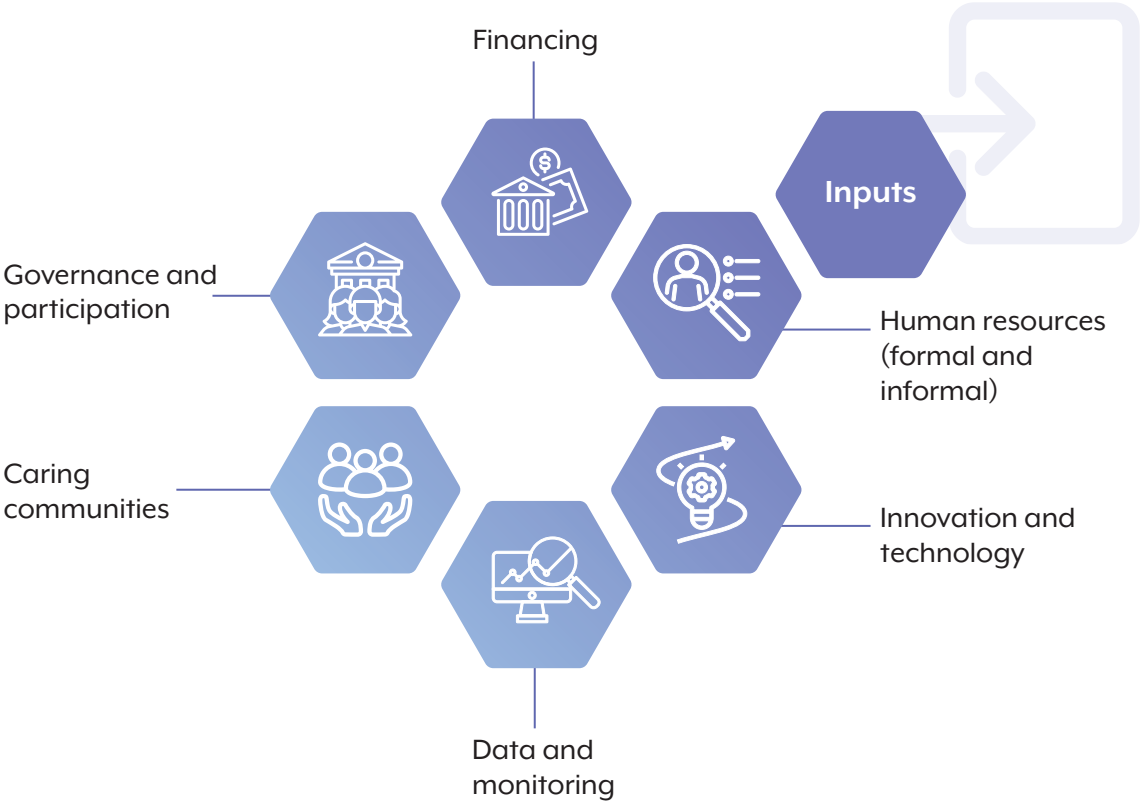
Recognizing the gender imbalance in the provision of care, both formal and informal, and the important spillover effects on cohesion and social and economic development, the State of LTC assessment takes a transversal gender-equity perspective. The gender dimension is emphasized in the analysis across care needs, system inputs, outputs and outcomes. It is monitored as a population-level impact and should be explicitly considered in all recommendations for policy and practice.

Investing in high-quality, accessible and affordable LTC systems that are integrated and coordinated along the continuum of care has widespread positive effects, including on the health care system by reducing the burden on acute care services and facilities, preventing the unnecessary use of more costly services and improving coordination. This contributes to promoting efficiency of the health care system and a more sustainable use of resources, as well as improved quality of life of the population by improving coordination and outcomes. Similarly, LTC systems that prevent and delay the onset of care needs and that support informal carers can contribute to improving productivity and labour participation, thus supporting economic growth. Finally, investing in LTC systems supports families and communities, promotes social participation, and builds trust in public institutions, all contributing to social cohesion at the population level *(19)*.

Component 3. LTC system inputs

The inputs component includes all tangible and non-tangible resources required for the functioning of the LTC system and amenable to policy intervention. This includes material, financial, human, informational and other types of capital, organized under six domains (see Fig. 6). The State of LTC Toolkit abstracts from the contribution of people who use care as a direct input into the care process. This role in the co-production of care – while significant for the care process and for care outcomes – is not immediately subject to policy intervention or the target of reforms.

Fig. 6. LTC system inputs



Source: authors' own compilation.

Governance and participation in decision-making processes reflect the roles and involvement of relevant stakeholders in the preparation, implementation, monitoring, regulation and evaluation of LTC policies and reform and are essential to ensuring they are evidence-based, value-driven, informed by user preferences, consistent and coordinated across sectors and at national, regional and local levels (*Council Recommendation on access to affordable high-quality long-term care* (*(2)*: Article 10) as well as the quality principles of comprehensiveness and continuity described in the Glossary in the web annex to this report *(10)*). The governance domain includes information on leadership and allocation of responsibilities across key stakeholders, bodies and strategies for integrating and coordinating all levels of the LTC sector, and regulation on delivery and procurement of services and assistive technologies. Relevant legislation guiding entitlements for LTC provision and benefits is also a key element of governance, and while often rooted in a reactive approach – addressing already present care needs – a shift to a prevention-oriented approach is needed, which can identify and target those at risk of developing care needs.

Supporting and investing in **age-friendly, healthy and caring communities** is also recognized as a means for holistically meeting the needs of individuals while preserving their autonomy, independence and right to live in the place of their choosing. Age-friendly environments provide ecosystems for implementing programmes and initiatives that foster healthy ageing in urban and rural areas, including addressing social isolation, and

promoting healthy activities and diets. As defined through the prism of functioning, the need for care emerges from the interaction of individuals' intrinsic capacity and their environment, understood as both their personal home environment and the wider community environment. In caring communities – that is, enabling, age-friendly and supportive environments – people with limited functionality are able to manage more tasks, independently, as well as engage more deeply with community activities and choose on an equal basis with others, without having to rely on care services and support to facilitate their participation.

The **financing** domain covers information on the amount of and on the approaches used to mobilize and allocate financial resources for LTC activities, including responsibility for organizing and overseeing the budget for LTC, raising revenue, pooling resources, and resource-allocation mechanisms across services and providers. Ensuring sufficient and stable financial resources are available for the development and provision of LTC services is an essential function of the system, but equally important are mechanisms for deciding how (public) resources are mobilized, allocated and distributed to different types of services and benefits, care settings and providers, subnational constituencies and user groups. Such environments may also reduce the reliance on informal caregivers.

Given the considerable implications for access, equity and efficiency of high reliance on private financing in LTC, the financing domains pays particular attention to the balance between public and private resources in LTC financing. Furthermore, the design of financing mechanisms at all governance levels instils incentives for purchasers, providers and users of care services, which should be accounted for and aligned with broader LTC system and policy goals (e.g. fiscal sustainability, incentivizing prevention and diversity in the care services provided, facilitating care use in less intensive and most appropriate care settings). Public procurement rules can play a key role in this respect in promoting efficient resource allocations, quality of care and good working conditions for care workers.

The **human resources** domain recognizes the value and contributions of both formal and informal activities to the delivery of LTC. It is a typical characteristic of LTC that a considerable majority of care and support has been traditionally provided by informal caregivers, including family members, friends, neighbours and communities. In addition to efforts to increase the capacity of formal LTC services, aligning with growing LTC needs in an ageing population, it is important to ensure appropriate support for informal caregivers and their integration with formal care delivery structures. Reflecting the duality and need for integration of human resources for care, the human resources domain includes information relevant to the assessment and planning of human resources for care (including size, structure, demographics, characteristics, stability, mobility, working conditions, safety and development of the workforce), as well as the processes and mechanisms that support the development of skills and competencies (professionalization, capacity-building, access to training, opportunities for continuous development, and so on). Investment in and protection of informal caregivers includes activities such as identifying informal caregivers, facilitating cooperation with formal care workers, supporting access to relevant information and training, providing adequate access to social protection and improving the reconciliation of caring responsibilities with work, social participation and economic opportunities.

In recognition of the continued reliance on domestic care workers in European LTC systems, the human resources domain also tracks the frequency, conditions and protections available for such carers, who often have a migration background, are women, and carry out undeclared care work. This includes evidence generation on challenges faced by vulnerable groups of care workers, policies to disincentivize undeclared care work and pathways to regularization.

While an implicit focus on gender equity is found across all components considered in the framework, the human resources component explicitly considers available evidence and policy interventions aimed at reducing the gender imbalance in care work, as well as in social and financial protections. These indicators attempt to capture not only the over-representation of women in caregiving (both formal and informal), but also the pathways

through which gender inequity in the distribution of care tasks and responsibilities contributes to persistent gendered patterns in socioeconomic status, opportunities for personal development and vulnerability over the life-course.

The **information and monitoring** domain collects indicators on processes and mechanisms for generating relevant knowledge to inform decision-making at all levels in the LTC system. This is achieved by ensuring sufficient capacity for collecting, systematizing, analysing and using reliable data in a timely and regular manner and it crucially depends on the availability of well-functioning, integrated (or at least interoperable) information systems. Strong information and monitoring capacity underpins performance and the ability to plan for all other domains. As a result, carrying out the State of LTC assessment is indirectly an assessment of the breadth, depth and capacity of the national information system for health and LTC. This includes an overview of: surveillance mechanisms in LTC settings and availability of data to track, estimate and anticipate care needs; the capacity for monitoring and planning delivery of care services across settings and providers; and the transparency of data collection, use and public reporting.

Finally, the **innovation and technology** domain of the inputs component encompasses measures of the capacity to create, adopt, adapt and scale up innovation (both technological and social), to promote independent living, improve and facilitate care delivery and other core system functions. This includes analysis of system orientation towards promoting more innovative and efficient care models that are better aligned to population needs and preferences, as reflected in the legislative framework, in the incentive structure of key stakeholders, in priorities for strategic investment and the allocation of funding, and in mechanisms to promote partnerships with the private sector, innovators and communities. Research, innovation and digital technologies should be inclusive, driven and co-produced by people who use care and their caregivers, and deployed with a strong focus on equity and accessibility.

Component 4. LTC system outputs

The delivery of care services is the core function of LTC systems. It results from the combination of the resources described in the inputs components[6] and their interaction with the individual and unique contributions to the care process of people who use care. Within the governance framework of the system, human, financial, informational and technological resources are constantly mixed and transformed to create care interventions that should be matched as closely as possible to the care needs and preferences of the target population groups (both people who use care and caregivers). In the interest of simplicity, within the results chain structure of the framework, the relationship between inputs and outputs is mostly described as unidirectional. However, it is important to recognize that service delivery processes feed back to influence governance, financing and human resource management – therefore, long-term strategic planning for LTC systems should consider the ways in which the input and output components shape and impact each other.

While the shorthand term "care services" is often used – both in this report and in the specialized literature – LTC systems produce a constellation of interventions, including formal services delivered directly by care professionals to care users and informal caregivers, financial and non-financial benefits, and the provision of assistive and digital technologies to aid self-care and self-management of conditions which impact functional ability (Fig. 7). Even this broader definition abstracts from LTC-sector contributions to myriad community- or society-wide interventions that shape the risk, prevalence and intensity of care needs. To reflect this diversity, the outputs component of the State of LTC Toolkit attempts to capture not only the quantity of interventions produced but also their type, settings in which they are provided and characteristics of the providers.

[6] Service delivery represents "the combination of inputs into a production process that takes place in a particular organizational setting and that leads to the delivery of a series of interventions" *(20)*.

Fig. 7. LTC system outputs

Source: authors' own compilation.

Crucially, all formal **outputs** of LTC systems can be provided along a spectrum of quality and should respect at least a minimum standard of safety and adequacy, captured by indicators of quality of service delivery. A more encompassing conceptualization of quality of care would include both indicators focused on the outputs of the LTC system, and measures of the outcomes and impacts of care services, captured in the Toolkit under those respective components.

The **care services** domain surveys the availability of a mix of care services, as described by WHO's extended package of long-term care interventions *(17)* and covering the continuum of care from promotive and preventive care to assistive and rehabilitative care, palliative and end-of-life care and caregiver support. These services respond to health, social and palliative care needs and have been selected for their essential role in protecting, restoring, and optimizing the functional ability of people who have a significant loss of intrinsic capacity and need long-term support. The list further includes caregiver support services, as means for empowering informal carers in their role and protecting their own physical and mental health.

Depending on the organization and development of the LTC systems of each country, some of these services will be delivered within the traditional boundaries of health systems (e.g. in primary care, or through specialized health programmes), while others will be provided within LTC and social care programmes, with yet others spanning the boundary between health and social care and being duplicated in different settings. While, ideally, this continuum of LTC interventions would constitute support through some form of public coverage, persistent gaps in coverage remain a pressing concern across the European Region. To explore this complexity, the care services domain incorporates indicators for the structure of service provision across different care settings (home-based, community-based or residential care (see Box 3)) and the profile of public and private care providers.

Box 3. Various care settings in LTC service provision

Home-based care includes services provided in the private home of the person with care needs, by one or more professional LTC workers.

Community-based care includes care services delivered in specialized centres, usually located close to the homes of the service users, such as day care centres, palliative day centres, community and recreational centres.

Facility-based/residential care includes all services and interventions delivered in facilities that provide accommodation alongside services. This ranges across a spectrum of intensity of care commensurate with care needs and types: common models include chronic care units in specialized hospitals, assisted living facilities, nursing homes or skilled nursing facilities, residential homes or care homes, and inpatient palliative care facilities.

Note. The Glossary in the web annex to this report contains further details on the terminology used in the State of LTC assessment *(10)*. These categories may be defined differently in different countries and contexts.

The **assistive technology and environmental adaptation** domain is grounded in the recognition that an individual's functional ability results from their interaction with their environment and that the characteristics of the environment will determine their ability to navigate it and their independence. Access to assistive technology[7] and accessible infrastructure helps maintain and improve functioning and independence, thereby promoting the health and well-being of individuals and reducing LTC needs. Availability of high-quality assistive products, as well as delivery and maintenance services, without undue financial burden is recognized as an essential component of UHC. This is documented in the State of LTC Toolkit through tracking the availability of a subset of products included in the Priority Assistive Products List *(21)*.

Assistive technology – such as sensor systems, lifts and medical beds – can also facilitate care tasks and improve the user's safety in their home environments. Interventions to develop enabling, age-friendly and inclusive communities contribute to ensuring that people who experience decline in intrinsic capacity can function independently and participate in social activities for longer periods of time. Similarly, investing in and continuing to support financially home adaptations for people with LTC needs can be instrumental in allowing individuals to remain comfortably in their homes for as long as possible. Policies and programmes that improve the accessibility of private and public environments and promote innovative housing models play an important part in building community-based LTC resources. Whether they are organized within LTC systems or as part of cross-sectoral strategies to promote equity and inclusion, they should be considered in the assessment as essential facilitators for more effective LTC delivery.

In addition to direct access to care services, LTC **benefits** can also be provided in the form of monetary transfers provided to people in need of care or their caregivers. Such cash benefits can either be flexibly used by recipients with no specific requirement on their allocation, or may be restricted to the purchase of specific types of care. Cash benefits for care are common across European countries and can allow people with care needs more flexibility in choosing the type and intensity of care they use (for example, to compensate informal caregivers, purchase assistive products or cover the costs of privately provided care)[8].

[7] Assistive technology is an umbrella term including the systems and services related to the delivery of assistive products – such as hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers, and various memory aids. More detail is provided in the Glossary (in the web annex to this report *(10)*).

[8] While general welfare benefits (e.g. pensions, poverty alleviation measures, disability payments, etc.) are often used to cover the costs of care in the absence of care-related cash benefits or a formalized LTC system, the State of LTC framework focuses strictly on cash benefits that are awarded on the basis of being assessed as having LTC needs.

Therefore, the uptake, type and generosity of cash benefits and how these are commonly used is crucial for understanding and developing LTC systems. However, cash benefits improve access to care only if the capacity, quality and distribution of care services are adequate, and should therefore be interpreted in conjunction with indicators on developing care services.

The **quality of care services** domain covers quality definition(s), quality-measurement (both quantitative and narrative), quality-assurance and quality-improvement mechanisms, across care settings and services. It includes measures to identify whether the necessary resources, processes and legislative structures are in place to influence, monitor, manage and incentivize improvement of the quality and safety of all care services. Grounded in comprehensive and standardized needs assessment, a quality-management system should include an evidence-based[9] set of quality criteria and standards (adapted to the characteristics of different care settings), clearly defined and transparent processes, dedicated resources for quality assurance and a national framework of incentives, programmes and policies for promoting continuous quality improvement. In line with the *Council Recommendation on access to affordable high-quality long-term care (2)* (see Box 4), the State of LTC Toolkit takes a broader approach to the quality of care services delivery. It emphasizes mechanisms for prevention, reporting and recourse of all forms of abuse experienced by people who receive care, as well as the importance of regular collection of information on user-reported outcomes and acceptability of care services, with a view to promoting person-centeredness and ensuring human rights are respected.

Given the importance of care users' own contributions to what constitutes good care and subjective assessment of quality of life and dignity, measures should be put in place to strengthen participatory and inclusive processes to define, refine and update quality standards; enhance capacity to address ethical issues in decision-making processes and care practices; allow flexibility to recognize the outcomes that matter to everyone using care; and facilitate meaningful user engagement in quality management.

Box 4. LTC quality principles

The *Council Recommendation on access to affordable high-quality long-term care* identifies that the following principles should guide the development of quality frameworks for LTC, irrespective of the legal status of care providers and the care setting in which they operate.

- Respect
- Prevention
- Person-centredness
- Comprehensiveness and continuity
- Focus on outcomes
- Transparency
- (Adequate) workforce
- (Adequate) facilities

Source: annexes to the *Council Recommendation on access to affordable high-quality long-term care (2)*.

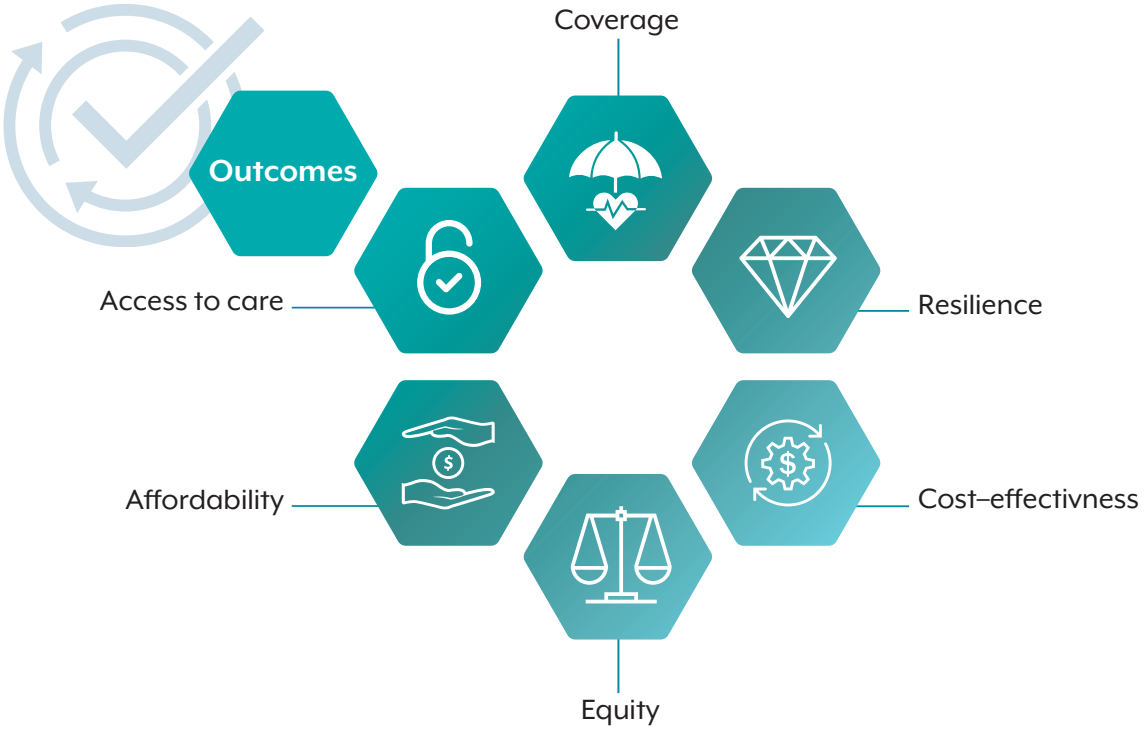
[9] What constitutes sufficient and reliable evidence should be adequately adjusted to respect and reflect the specificities of LTC provision in different care settings and recognize the co-production of care with people who need care, their caregivers, families and communities.

Component 5: LTC system outcomes

System-level outcomes are intermediary objectives, directly related to population-level impact and grounded in the explicit goals of LTC programmes and policies. They result from the interaction of needs in the targeted population groups with the outputs created by the LTC system, through the use of care services and interventions.

System outcomes can be influenced by – but are not directly under the control of – decision-makers in the LTC system. The outcomes considered in the State of LTC framework are grouped under six domains (Fig. 8), modelled in line with the *Council Recommendation on access to affordable high-quality long-term care* and aligned with the vision of the United Nations Decade of Healthy Ageing and the 2030 Agenda for Sustainable Development *(2,3,4)*. They are neither exhaustive nor comprehensively described by the indicators selected under each domain. Complementary outcomes and objectives or additional and alternative indicators can be used to measure specific objectives set by national or regional authorities in each specific setting.

Fig. 8. LTC system outcomes



Source: authors' own compilation.

The **coverage** domain groups together indicators that attempt to quantify the depth, breadth and comprehensiveness of public LTC interventions and programmes, including the share of the target population covered, the diversity of care services included in public programmes and the level of financial protection that public programmes afford users.

Access to care refers to the opportunity to reach and use appropriate care services, whenever such services are needed. Access presupposes understanding on the part of the potential care user that they have a need for care and that a specific care service can be helpful in addressing that need. Furthermore, the person with care needs must have the ability to seek and reach LTC services, which they consider acceptable. The access domain aims to track the frequency of situations in which these conditions are not fulfilled, resulting in care needs being postponed (e.g. waiting times) or unmet by service provision entirely.

Affordability is one of the most important challenges faced by people in need of LTC services. This domain tracks the share of the population with care needs who report financial reasons for foregoing care and the share of costs covered by public programmes in different care settings.

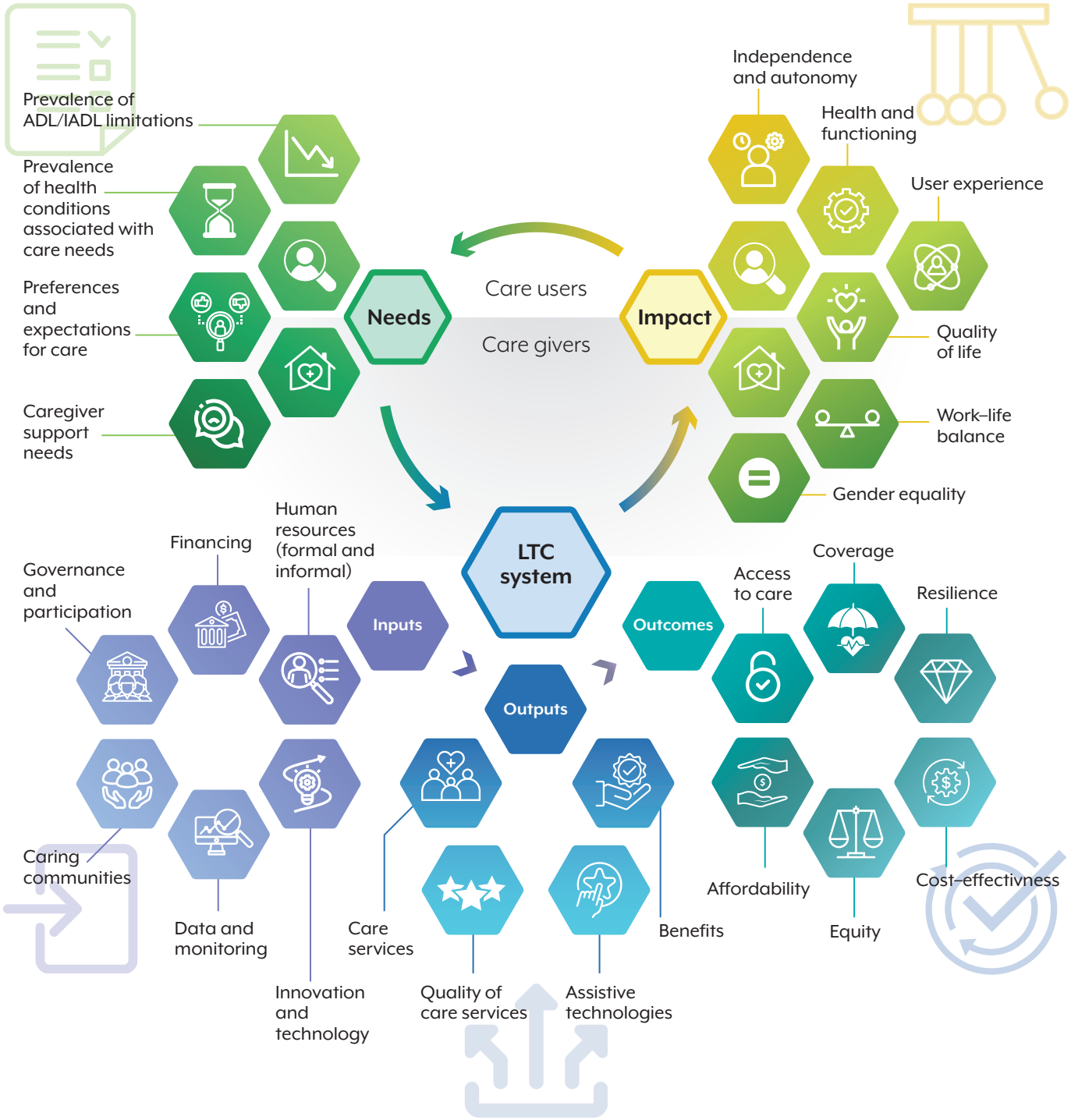
The **equity** domain focuses on the distribution of publicly covered LTC services and resources across population groups, with specific attention to identifying inequalities in access across key demographic and socioeconomic dimensions (e.g. gender, education, occupation/income). Given the high degree of decentralization of some LTC systems in Europe, the equity domain also collects information on differences in entitlement, eligibility and generosity of public benefits at subnational level.

An overview of measures and processes on the allocation of resources at system level are grouped under the **cost–effectiveness and sustainability** domain. This includes indicators of allocative efficiency and the shift of resources towards lower-intensity care settings (share of resources allocated to community-based versus facility-based care services; share of individuals opting for cash versus in-kind benefits), as well as indicators of the efficiency of care processes, reflected in measures of continuity of care (based on having a care plan upon discharge from acute care settings).

Resilience encompasses all measures to anticipate and effectively respond in the face of shocks and emergencies. Recent health emergencies, namely the COVID-19 pandemic and humanitarian crises, have re-enforced the importance of developing plans to respond to emergencies, to ensure the continuity and safety of LTC. The State of LTC Toolkit includes measures that track the availability of dedicated LTC plans, training or surveillance mechanisms, as well as the recognition and integration of LTC into broader, cross-sectoral emergency preparedness plans.

Pooling together all the strands, the State of LTC Toolkit collects and systematizes information on care needs, LTC systems and population-level impacts, across 25 analysis domains grouped under five components (care needs, impact, inputs, outputs and outcomes), along a results chain structure (Fig. 9).

Fig. 9. Overview of the State of LTC assessment structure



Source: authors' own compilation.

4. Participatory processes for LTC reform and system transformation

Strong leadership and participatory governance at national and subnational levels are essential to promoting trust and transformation in health and LTC systems. Responsibilities for financing, organizing and delivering LTC services are often split, with porous boundaries and overlaps between the health and social protection sectors, between national, regional and local authorities and between public, private, social partners and civil society organizations *(22)*. Cross-sectoral partnerships, broad stakeholder engagement and meaningful participation of care users and caregivers are key enablers for positive change, as they promote equity, consensus, the definition of common identity and sense of joint purpose *(23)*. Because its aim is primarily to facilitate learning and support LTC system reforms, the State of LTC assessment methodology emphasizes broad engagement of diverse stakeholders, both as a precondition for ensuring a **balanced and comprehensive analysis of the existing knowledge base** and as a **mechanism for promoting trust, dialogue and consensus** among national stakeholders. The emphasis of the State of LTC approach on participatory governance and broad stakeholder engagement aligns with the resolution on Social participation for universal health coverage, health and well-being endorsed at the 77th World Health Assembly, which recognizes the crucial role of social participation in fostering respect and trust, while making health systems more responsive, equitable and resilient *(24)*.

Firstly, the breadth of assessment domains, along with the purposeful blending of quantitative and qualitative measures and prompts for expert input ensure that contributions from care providers and professionals, care users and their families, civil society organizations, research and academic bodies, civil partners and community representatives can be included in the analysis and complement evidence from national statistical sources. Each stakeholder group has a distinct perspective on the LTC system, and none has a full overview of its structure and dynamics. In addition, each stakeholder group may have different priorities, experience diverse challenges, produce and disseminate evidence in various ways and have different opportunities to shape care delivery and policy. Each perspective is relevant and valid, and creating a platform for collecting and sharing these different perspectives is essential for understanding where disconnects occur and how inclusive solutions can be defined. Allowing all stakeholder groups the opportunity to participate actively in the evidence-gathering process, to define what constitutes relevant knowledge and to share information and data that they consider important, helps build trust and buy-in for consensus-building processes. Promoting engagement and participation of stakeholders in these processes should be as inclusive as possible, ensuring that participation is possible for individuals with different functional abilities.

Secondly, the State of LTC approach aims to create opportunities for dialogue and exchange among diverse stakeholder groups, with the goal of promoting trust and working to refine a shared vision for LTC system transformation. The perspectives of care users, their families and communities are equally important in refining this shared vision in line with a person-centred approach, to ensure that reforms are rooted in the needs and preferences of the individuals the system aims to serve. After having provided available evidence and input in the data-collection phase, stakeholders are invited to come together and refine, as a group, the priorities for the State of LTC assessment itself (e.g. stakeholders discuss and agree on which system outcomes will be considered for analysis and which policy interventions are key to their achievement) and for LTC system reform more generally. Such opportunities for exchange can take the form of national or regional policy dialogues, multi-stakeholder workshops, and working sessions and consultations with invited experts. By creating spaces for open discussion, finding common ground and co-creation of desired

solutions, this fosters trust, transparency and the development of broad coalitions which can catalyse ambitious reforms.

The benefits of the multi-stakeholder participatory approach at the heart of the State of LTC assessment include the creation of:

- shared terminology and a shared identity around LTC, which can facilitate communication and collaboration;
- meaningful engagement of people with care needs, their families and communities in policy- and decision-making processes, which can bring the design of LTC systems, the processes of care delivery and the direction of reforms closer in line with the preferences of the populations they aim to serve;
- a shared vision of what defines a high-performing LTC system, which is essential to mobilize broad support and the necessary resources for change;
- a common understanding of priorities for action to achieve this vision and shared commitment to action at different levels of the LTC system;
- opportunities for interaction and exchange between stakeholders, which help improve coordination and establish coalitions of people willing to work together for LTC system transformation;
- a platform to track, acknowledge and celebrate progress, with a view to continuing to build on strengths and resources as well as accelerating the pace of positive transformation; and
- a sense of shared accountability and opportunity to transform LTC systems, which can help catalyse support and accelerate reform processes.

5. Incorporating the State of LTC approach into national performance management processes

The State of LTC approach to continuous improvement and system assessment brings together and places equal focus on developing a strong evidence base – informed by the State of LTC conceptual framework – and on building consensus and common ground through multi-stakeholder engagement. It brings together three components, each designed in a modular structure and with in-built flexibility: this conceptual framework (including a Glossary of terms in the web annex to this report *(10)*), an Implementation guide *(11)* and a Data-collection template *(12)*, as a separate web annex to the Implementation guide. Taken together the different components of the Toolkit can accompany and support national policy-makers to further develop, adapt, adopt and implement the State of LTC approach in their countries, at national or subnational levels, in ways that best reflect their priorities.

It is strongly encouraged to employ the State of LTC Toolkit in its entirety when carrying out the assessment, due to its considerable benefits in supporting LTC reform and transformation processes. Providing a global overview of the LTC system, grounded in diverse sources of evidence and knowledge, it can facilitate ambitious, system-wide reforms. Furthermore, the State of LTC approach can help identify where data gaps remain, thus informing target areas for improving monitoring and evaluation efforts. It can provide strategic insight into where policy intervention can have the most substantial impact and support system-wide consensus to encourage wide adoption and facilitate implementation. Repeated at regular intervals to monitor progress and changes across all domains considered in the conceptual framework, the State of LTC Toolkit can form the backbone of change management and a continuous improvement process for LTC systems. Carrying out the full State of LTC approach requires sufficient time and resources, an assessment team with the specialist knowledge and competencies, and openness among national authorities to engage in evidence generation and stakeholder dialogue.

The State of LTC Toolkit can also be used in a modular fashion, for example by focusing on a particular policy area of the LTC system, or using only one component of the Toolkit (e.g. the Data-collection template or stakeholder engagement process). For example, the Toolkit can be used to inform and support quality-management and monitoring processes, to complement workforce planning and strengthening, or for developing targeted interventions to protect and provide support for informal caregivers. While these adaptations to the methodology are possible and can have their benefits, such approaches should be balanced with potential risks and drawbacks (see Table 1).

Table 1. Potential benefits, risks and drawbacks of using different components of the State of LTC Toolkit and process on their own

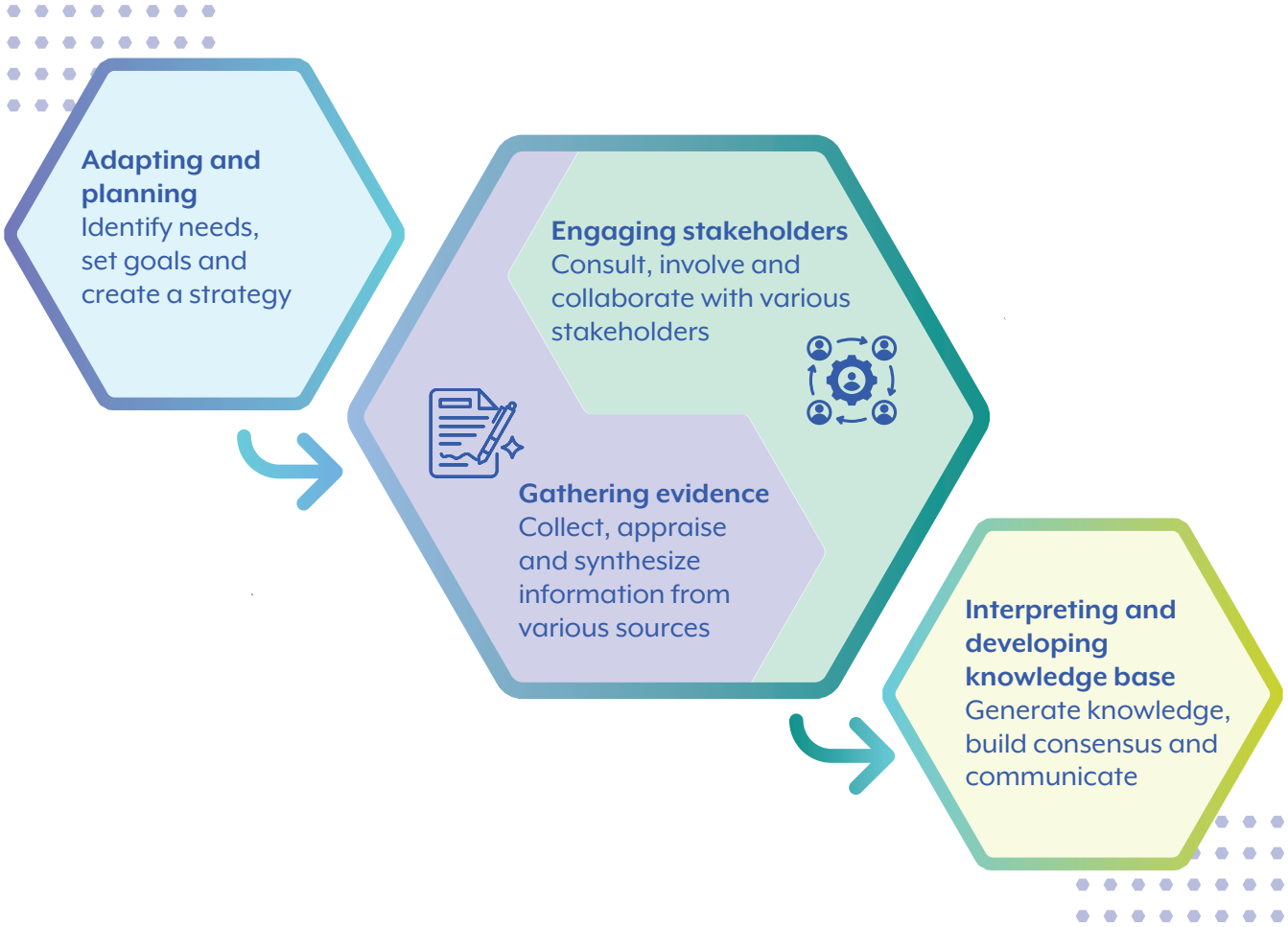
Using individual components of the State of LTC Toolkit	Potential benefits	Risks and drawbacks
Using the State of LTC approach and Toolkit for targeted assessment of priority policy areas	> Allows for in-depth analysis > Supports formulation of detailed and highly specific recommendations for policy interventions > Less time and resource consuming (depending on the level of granularity of evidence gathering)	> Disconnected from other relevant policy areas within the LTC system, the assessment can lead to incomplete – if not misleading – results > Narrow focus of analysis on only certain policy areas can make consensus-building difficult, if stakeholders are concerned that their main interest areas are not even considered
Using only the multi-stakeholder engagement elements of the State of LTC approach	> Outlines an easy-to-follow approach to meaningful engagement of stakeholders in change management and policy design > Adaptable, and can be easily incorporated into other policy-making and research processes > Builds trust and a sense of shared responsibility for system transformation	> The disconnect from conceptual framework and data-collection structure may require appropriate adaptations of the participatory and interactive activities > May be less effective as a consensus-building tool, given that participation in evidence-gathering activities is essential to building trust
Using only the Data-collection template/structure for evidence gathering	> Provides an overview of a set of comparable indicators collected across the EU to measure different aspects of LTC > Results in a set of key information most important for policy- and decision-making that is evidence based and expert informed	> Provides no interpretation of existing policies > May still require adaptation and adjustment to capture specificities of national contexts

Source: authors' own compilation.

6. Carrying out the State of LTC assessment

The State of LTC assessment and continuous improvement approach proposes a systematic process of evidence gathering and knowledge generation in support of complex LTC system reforms, which can be broken down into four key activity areas (depicted in Fig. 10): (i) adapting and planning, (ii) evidence gathering, (iii) stakeholder engagement and (iv) development of a knowledge base in support of change and reform processes. These are described in detail in the companion Implementation guide *(11)*.

Fig. 10. The State of LTC assessment process



Source: authors' own compilation.

The assessment process begins with an initial planning phase, which should include outlining the goals and objectives, adapting the State of LTC approach to best respond to those objectives, setting up the assessment team, defining the assessment timeline and mapping core data sources and stakeholders.

Evidence-gathering and stakeholder-engagement activities are closely intertwined and form the core of the assessment process. Data-collection and evidence-gathering activities require filling out the Data-collection template, by sourcing literature and information

through a desk review, but also through input from experts involved in LTC organization, planning and delivery.

Expert consultations take place simultaneously to further contextualize the information uncovered and to provide an analytical view of the bottlenecks and challenges. These activities lead to a policy dialogue event, which brings together all engaged stakeholders in an interactive, consensus-building workshop. Through exercises aimed at idea generation, collaborative unpacking of complex concepts and causal chains, as well as group-based and individual prioritization, participants co-produce a vision and pathway for transformative LTC system reform.

A period of interpretation and analysis follows these stages of the State of LTC process to develop a set of recommendations for policy interventions, generate knowledge products (such as publications and information materials targeting various audiences) that respond to the needs of diverse stakeholders, disseminate findings and reflect on the assessment process itself, as well as considering the next steps.

7. Promoting learning and enhancing trust in LTC systems

> "Learning in health [and care] systems [...] occurs by making the link between past actions, the effectiveness of those actions, and future actions. In making that learning link, the knowledge within a system is restructured or enhanced as they anticipate, prevent or solve problems."
> *(Sheick & Abimbola (25))*

LTC systems, like all complex and adaptive systems, are constantly faced with the need to respond to change, adjusting and evolving. When feedback and experiences of past changes are codified as actionable knowledge, the system is better equipped to transform the lessons of the past into the evidence base needed to guide decisions for the future. Learning in LTC systems is grounded in the regular generation of knowledge and feeding that knowledge back into the design and management of all system functions.

Investing in continuous learning and in strengthening the evidence base for policy and reform processes is key to improving population care outcomes, as well as the effective deployment of limited resources and the sustainability and resilience of LTC systems. Continuous evidence generation and analysis (**learning through information**) requires investment, but this is more than offset by gains in quality and effectiveness linked to evidence-based practice and increased capacity for adaptation, innovation and self-reliance *(25)*. At the same time, dialogue, reflection and collaboration are needed to interpret and contextualize information, to create a shared understanding and reach consensus around needed actions (**learning through deliberation**). Finally, learning can be experiential and occur through action and practice (**learning through action**). Often tacit and highly specific, such learning is experienced and shared by various stakeholders across the LTC system.

The State of LTC Toolkit is designed to leverage and to promote all three types of learning through a blend of activities, including information gathering, evidence synthesis and stakeholder engagement. Applied regularly or institutionalized into regular monitoring and evaluation structures, the State of LTC approach and components will enhance learning in LTC systems.

Participation, wide engagement and dialogue are as important for learning as they are for building trust and consensus for LTC system transformation. Convening 15 years after the signing of the Tallin Charter and with consideration of the legacy and lessons of the COVID-19 pandemic, European countries identified "trust and co-creation between stakeholders [are] the key ingredients to empower people and communities to drive the transformation of systems" *(26)*.

Deficits of trust, exacerbated during the COVID-19 pandemic, affect all parts of health and LTC systems. The share of Europeans who do not trust that the type of care they prefer will be available and affordable when they will need it is growing, while changes in the (public) supply of LTC services do not reflect evolving preferences and expectations among the population *(27)*. Caregivers – whether informal or active as health and care workers – and their essential contributions to LTC systems and societies continue to be undervalued *(28)*. Underinvestment, and the associated slow progress on improving working conditions, protection and support for caregivers contribute to a looming human resources crisis in health and LTC, while fatalistic prognoses on the unsustainable burdens of population

ageing and a perception of high polarization may discourage policy-makers and the public from supporting meaningful LTC reforms and dedicating effort to consensus building.

Through dialogue, deliberation and co-development, and through its wide definition of stakeholders in the LTC ecosystem, the State of LTC approach aims to provide a blueprint for addressing such deficits of trust. However, building trust – as much as building continuous learning systems – requires sustained investment and deliberate effort and will hinge on the ability to scale and institutionalize the participatory approach to evidence- and consensus-building that the State of LTC methodology exemplifies.

The State of LTC Toolkit proposes learning, collaboration and trust as the lenses through which to view LTC system transformation and the levers with which to advance reforms on access to affordable, high-quality LTC for all those who need it. Developing system capacities for continuous learning and change management is a route to accelerating progress, empowering all stakeholders to enhance and use their knowledge and skills, and ultimately to promoting well-being, autonomy and quality of life for growing numbers of people living with functional limitations, as well as for their caregivers.

8. Methods

The development of the State of LTC Toolkit was led and coordinated by the Human Resources and Service Delivery Unit at the WHO Regional Office for Europe, with support from the European Commission's Directorate General for Employment, Social Affairs and Inclusion between May 2023 and Sept 2024.

The development of the conceptual framework grounding the State of LTC Toolkit builds on guidance and system assessment tools on the integrated delivery of health care and LTC previously developed by WHO, aligning these analytical approaches to the vision for LTC system development outlined in the *Council Recommendation on access to affordable high-quality long-term care*. A scoping review of international literature was carried out to support the refinement of the structure and domains of the State of LTC Toolkit, including guidance documents, global and regional reports, policy documents, case studies and academic literature on assessment, monitoring and continuous development in LTC systems.

This global evidence was synthesized and interpreted to define the core concepts, dimensions and indicators relevant for monitoring and strengthening LTC systems, while the availability of key data in global and European comparative databases informed the development of the Data-collection template.

Two rounds of expert consultations for refinement and validation of content took place with the support of a technical advisory group consisting of global experts in LTC. Members were purposefully selected to represent different perspectives on LTC policy, practice and lived experience (the full list of members can be found in the Acknowledgements).

To test and improve the coherence and ease of implementation of the State of LTC approach, the Toolkit was piloted in two European countries (Ireland and Lithuania) in collaboration with national coordinating partners and numerous local stakeholders.

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