Developing EU statistics on long-term care

Workshop of the EAPS Health, Morbidity, and Mortality Working Group, Bilbao, 25-27 September 2024

Session 11 - Invited methodological note, 27 September 2024
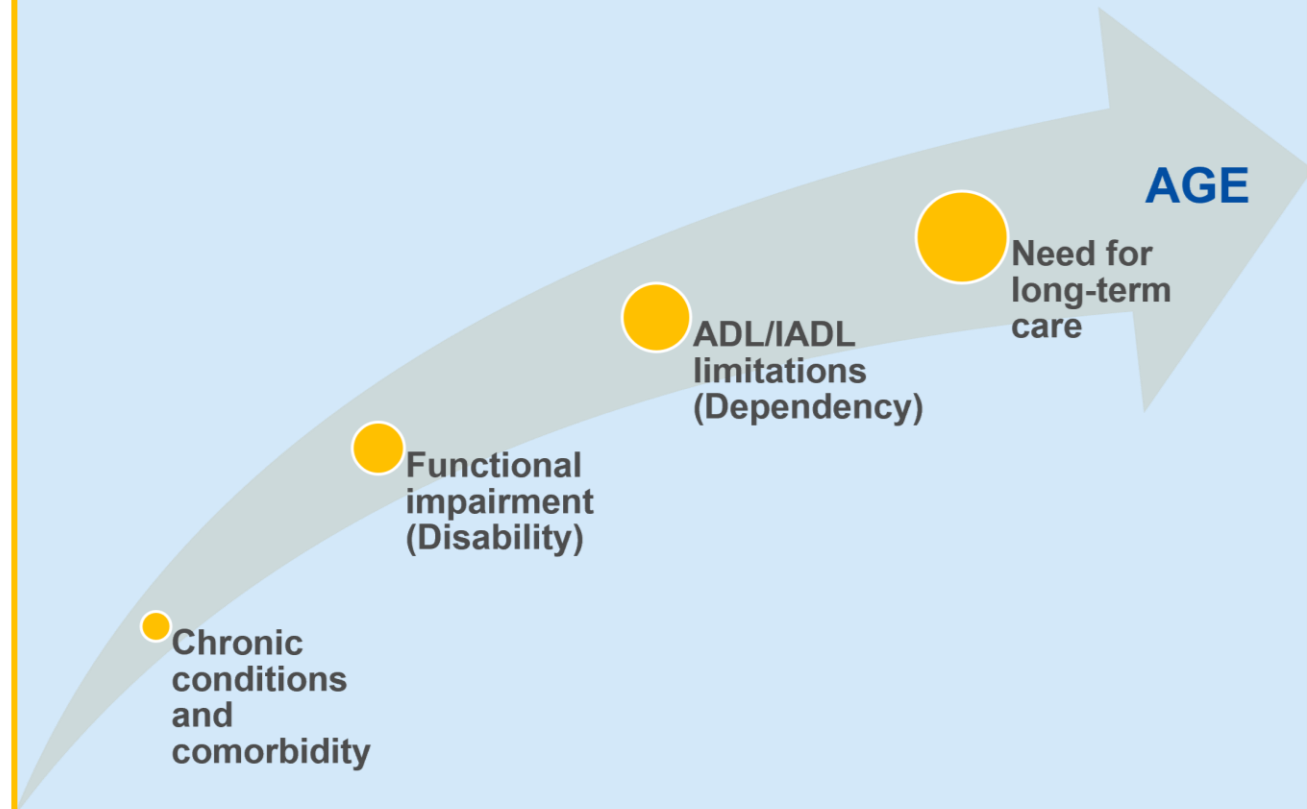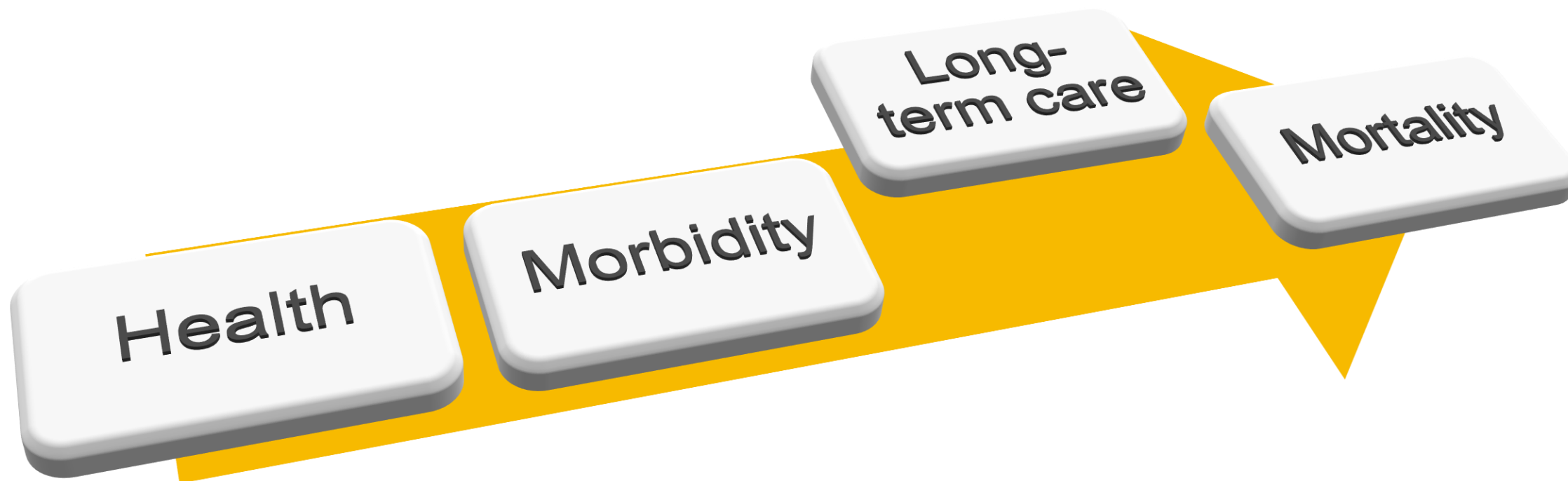
Giampaolo LANZIERI

Eurostat

What 'long-term care' is and why we should care (for long) about
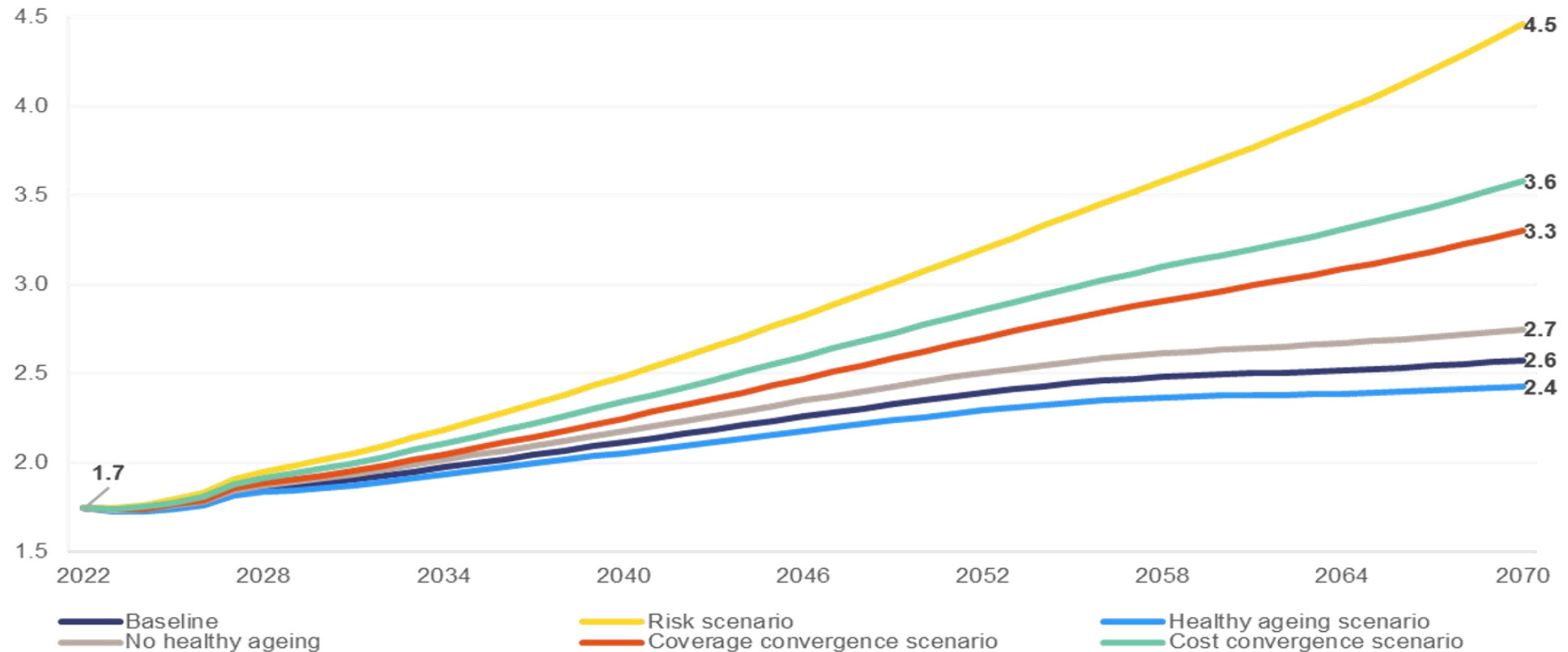
European Commission

As from EU Rec.:

"'long-term care' means 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 daily living activities and/or are in need of some permanent nursing care"

3

AGE

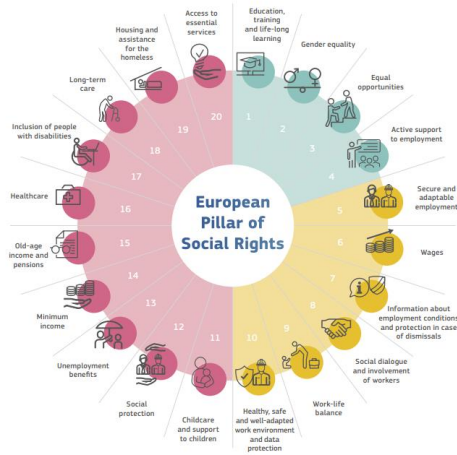Need for long-term care

ADL/IADL limitations (Dependency)

Functional impairment (Disability)

Chronic conditions and comorbidity

A missing tile?

European Commission

LTC budgetary projections as % of GDP: baseline and alternative scenarios

5

LTC in social policy-making: some milestones

Principle 18. Long-term care: *Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.*

European Pillar of Social Rights

2017

European Care Strategy & LTC Council Recommendation

2022

COVID

2014
1st EC-SPC Report on LTC

2021
2d EC-SPC Report on LTC

2027
EC Report to the Council

European Commission

LTC beginning in EU official statistics

- In latest years, growing interest on LTC data by various EU stakeholders. Scattered data availability, potential for further harmonization.

- Decision by the '**European Directors of Social Statistics**' (DSS) Expert Group of the European Commission to set-up a dedicated <u>Task Force on Long-Term Care statistics</u> (TF LTC).

- On 7 September 2022, the European Commission launches the **European Care Strategy** for "*high-quality, affordable and accessible care services with better working conditions and work-life balance for carers*".

- **Council Recommendation** on "*access to affordable high-quality long-term care*" adopted on 8 December 2022 (2022/C 476/01).

  - Art.12: "*The Council welcomes the Commission's intention to: …(d) work with Member States to enhance the availability, scope and relevance of comparable data on long-term care at Union level, building on the forthcoming results of the* **Commission task force on long-term care statistics***;…*"
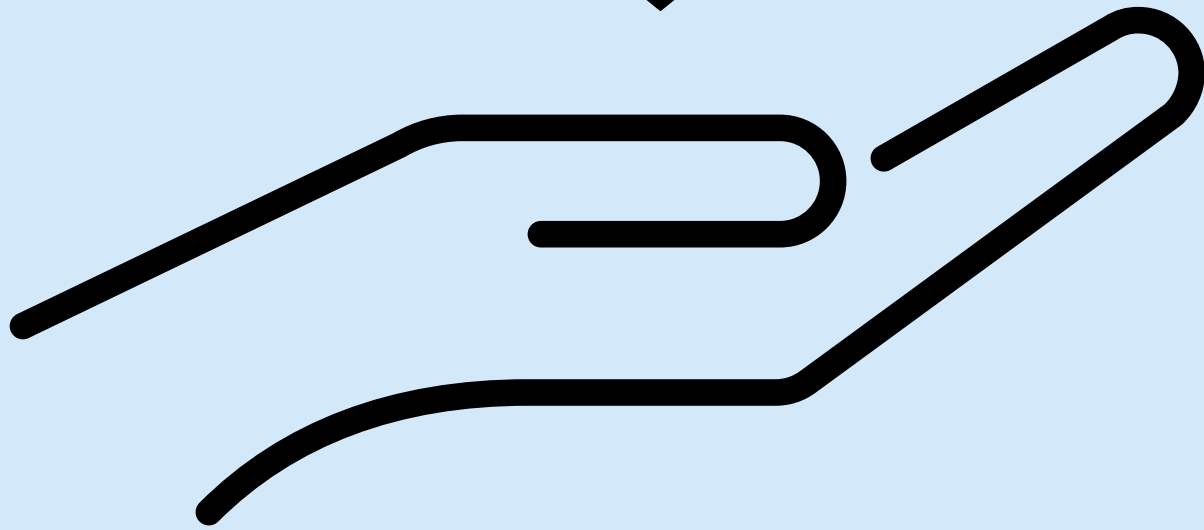
European Commission

Actions relevant for LTC statistics

Task Force on LTC statistics (TF LTC)

- Formally a *subgroup* of the Commission Expert Group of the European Directors of Social Statistics – DSS (E01552/4).

- Kick-off meeting: February 2023

- Conclusion of work: end 2025

Initiatives in the EU social surveys

- New variables relevant for long-term care

- Expanding coverage to population living in (health-related) institutions

- Dedicated survey modules (Health, Access to services, Mental health and wellbeing)

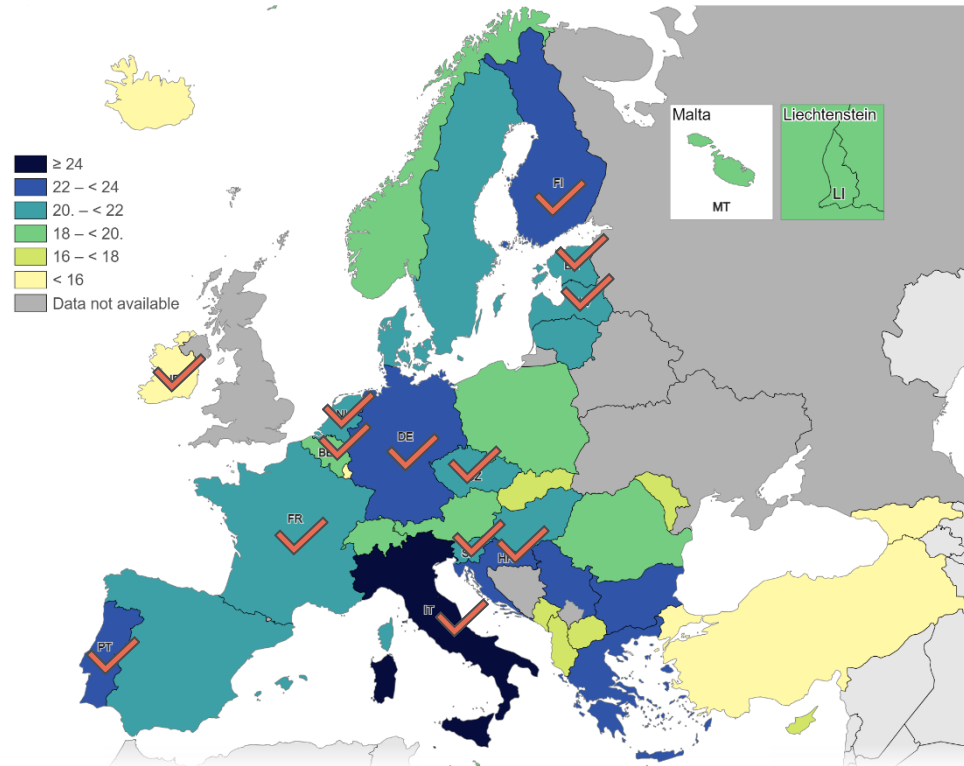European Commission

The Eurostat Task Force on Long-Term Care statistics

Composition of the TF LTC

Members from 13 EU countries

Percentage of population aged 65 years and more
Europe, 1 January 2023

≥ 24
22 – < 24
20. – < 22
18 – < 20.
16 – < 18
< 16
Data not available

Eurostat (online data code: demo_pjanind)

Administrative boundaries: © EuroGeographics © UN–FAO © Turkstat
Cartography: Eurostat – IMAGE, 09/2024
*This designation is without prejudice to positions on status, and is in line with
UNSCR 1244/1999 and the ICJ Opinion on the Kosovo declaration of independence.

Chair and Observers

- Chair: **Eurostat.** Other Commission services also following the work (EMPL, ECFIN).

- Observers: **ILO**, **OECD**, **WHO**, European Foundation for the Improvement of Living and Working Conditions (**Eurofound**), European Institute for Gender Equality (**EIGE**), and International Social Security Association (**ISSA**).

Diverse contexts, expertise and institutions

10

European Commission

Areas of work of the TF LTC

- <u>Overall aim</u>: **to develop comparable EU statistics on long-term care**

- "*To study solutions and provide methodological guidance in*" statistics on: LTC need, recipients, workforce, informal carers, expenditure and financing, etc.

- <u>Guiding criteria</u>: sustainable approaches for regular production, minimum burden on data providers, <u>European Statistics Code of Practice</u>

- Over 20 working papers on different LTC topics produced so far by the TF LTC as input to discussions (here the <u>list</u>)

Excerpt from Terms of Reference

(1)	to produce guidelines on the boundaries and scope of long-term care: beneficiaries, providers (institutional settings, households,…), treatments, financing, amongst others,
(2)	to improve availability, quality and coverage of long-term care statistics:
(a)	for long-term care health and social expenditure based on the System of Health Accounts 2011,
(b)	for health long-term care, non-expenditure such as data on health activities, health employment, physical resources,
(c)	for non-health long-term care providers and activities,
(d)	for exclusion from long-term care health and social services, due to financial burden and non-affordability of LTC.
(3)	to investigate links across different domains and methodologies,
(4)	to support the cooperation at national level amongst the different national institutions and bodies involved in the provision of LTC related statistics,
(5)	to support the discussions in the different technical groups in order to support member states in developing methods of estimation:
(a)	the informal long-term care services provided by households,
(b)	the long-term care services financed from households budget,
(6)	to investigate the feasibility for a potential legal basis for a data collection dedicated to long-term care.

European Commission

First basic questions addressed

- What is the statistical definition of 'long-term care'?

- How many persons need long-term care?

- How many persons are 'working' in this domain?

- How much is spent in assistance for the independent living of persons in need of long-term care?

How many are receiving long-term care (formal or informal)?

European Commission

Some issues discussed in definitions

- Which level of activity limitation (ADLs) / participation restriction (IADLs) would require long-term care – should 'mild' to 'moderate' be included?

  - Current orientation: only cases with severe to complete level

- Coverage of IADLs in the case of no limitation in ADLs?

  - Current orientation: to take into account IADLs even if without ADLs

- Relation with concepts such as disability, frailty, etc. and other international conceptual frameworks

  - Development of a statistical conceptual framework and tentative mapping

European Commission

Need of long-term care

- Various **measures** tested, including new ones

- Data source(s): **EHIS**, **EU-SILC**

- Some **issues**: population under-coverage (persons in 'institutional households'), incomplete age profiles, frequency of surveys, relation with measures of related concepts (e.g., disability)

- Tested **statistical modelling** approaches: age profile and data frequency

- **Pending**: institutionalized population, variability between survey waves

14

European Commission

Discussion on LTC workers
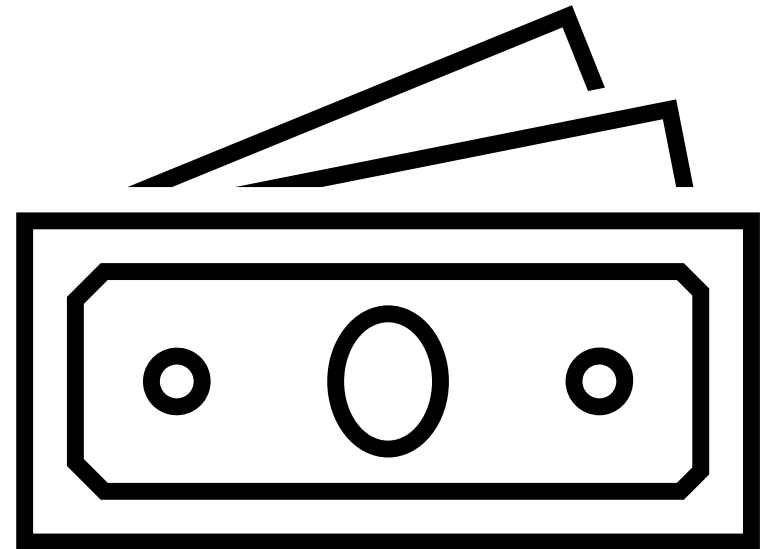
'Formal' carers

- <u>Workforce</u>: LTC providers for pay or profit as main job

- Data source: **EU-LFS**

- Identification: **NACE-ISCO cross-classification**. Some categories included partially.

- Blanked LFS values: estimation based on less granular cross-classification
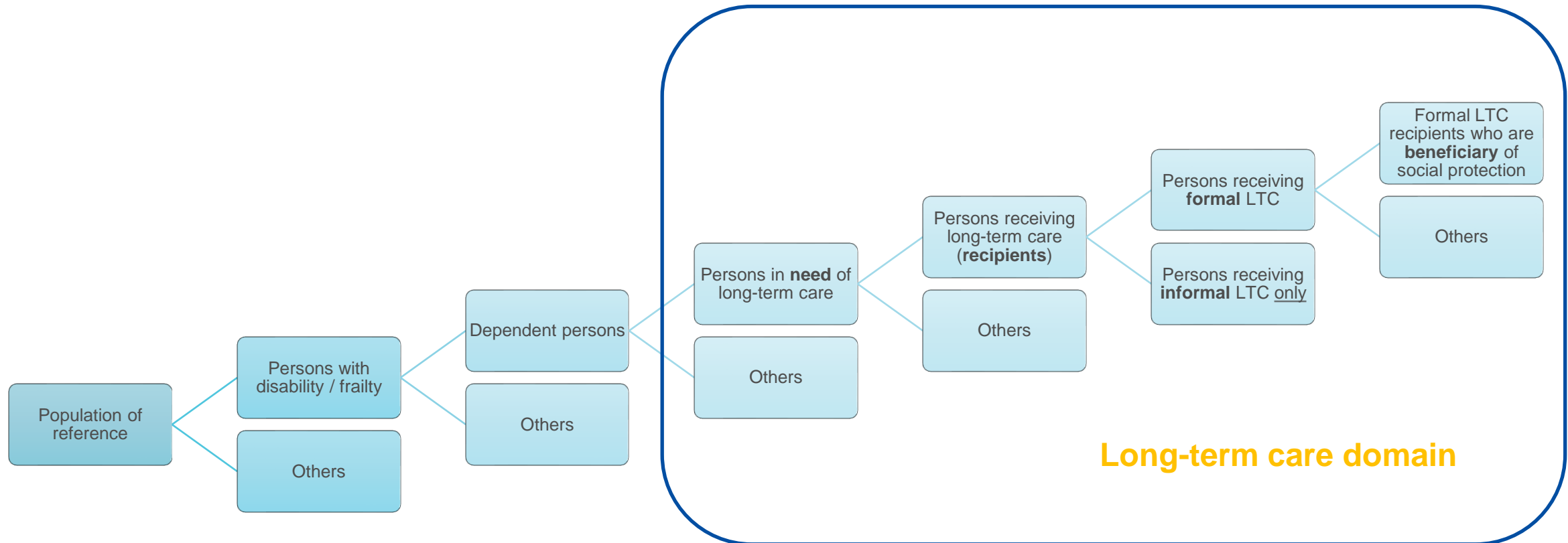
'Informal' carers

- Data source: **EHIS**

- Organization-based volunteering not (yet) covered

- Further work on estimation for non-survey years and translation into Full-Time Equivalent (FTE)
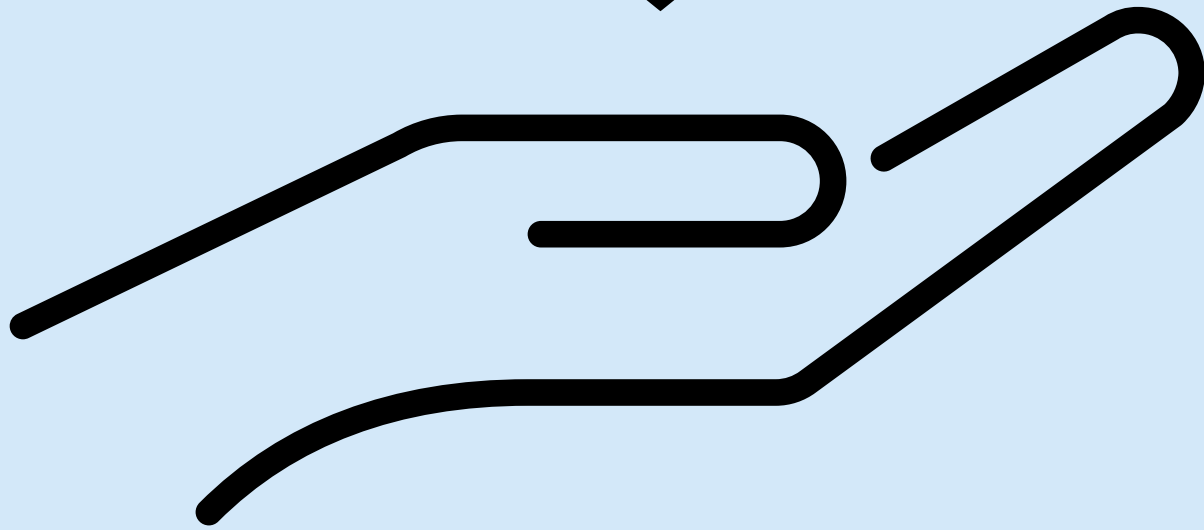
European Commission

LTC expenditure and recipients

- A main target of the TF LTC

- Improvements sought in the reporting of both the '**health**' and the '**social**' components of long-term care

- It concerns important data sources:

  - System of Health Accounts (SHA)

  - European System of integrated Social PRotection Statistics (ESSPROS)

European Commission

A tentative consistent classification

Population of reference → Persons with disability / frailty → Dependent persons → Persons in **need** of long-term care → Persons receiving long-term care (**recipients**) → Persons receiving **formal** LTC → Formal LTC recipients who are **beneficiary** of social protection / Others

Persons receiving **informal** LTC <u>only</u>
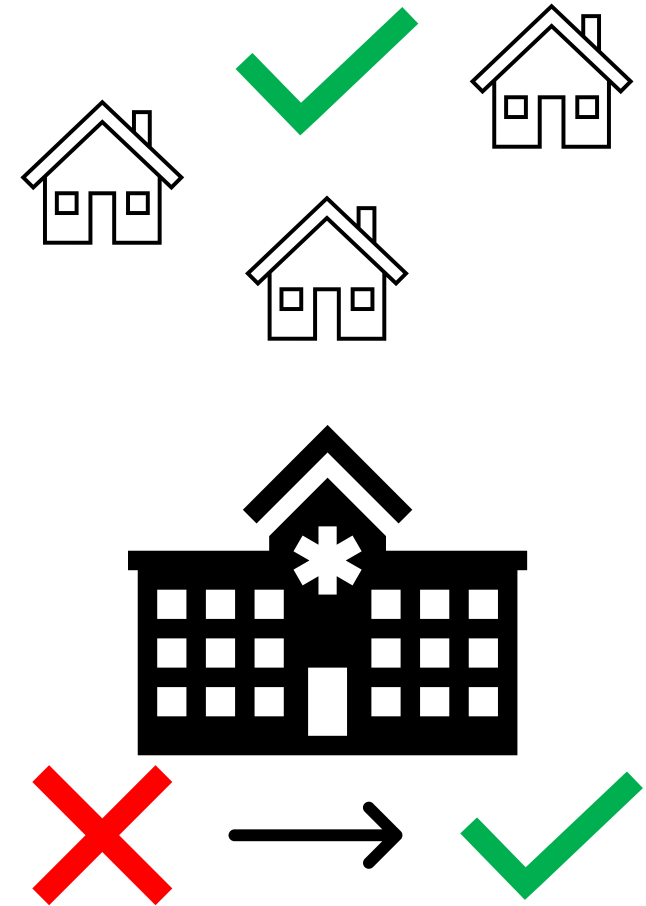
Long-term care domain

European Commission

The initiatives
in the
EU social surveys

Improving EU survey data on LTC

- Target population of current EU social surveys (EHIS, EU-SILC, EU LFS, etc.), as defined in the framework EU Regulation 2019/1700, is composed of **persons living in private households**.

- However, the Commission may launch **feasibility and pilot studies**, aiming to evaluate and develop alternative methodologies **to extend the coverage** of the data collection **to persons not living in private households** or to sub-populations that are difficult to reach.

- The **European Health Interview Survey (EHIS)** to be the survey to deal with the coverage of 'institutionalized population' using feasibility/pilot studies. In the same survey, there are variables directly related to long-term care.

European Commission

LTC in EHIS

- **What is EHIS**: sample survey covering the population aged 15+ living in private households, providing data to support **public health** policies and monitoring the effects of those policies both at national and European levels

- **Periodicity**: about every 5 years from 2008 (3 waves so far). 6 years from 2019 onwards, next wave in 2025.

- **Geographical coverage** (2019): EU Member States, Iceland, Norway, Serbia and Türkiye

- **EU sample size**: about 300k units.

LTC-related variables in EHIS:

- Difficulty in personal care (PC1) or household activities (HA1)

- Receiving help with personal care (PC2) or household activities (HA2)

- Need for (more) help with personal care (PC3) or household activities (HA3)

- Use of any home care services for personal needs during the past 12 months (AM7)

- Providing care or assistance to one or more persons suffering from some age problem, chronic health condition or infirmity, at least once a week (professional activities excluded) (IC1)

- Prevailing relationship of the person(s) suffering from any chronic condition or infirmity or due to old age being provided with care or assistance at least once a week from the respondent (IC2)

- Number of hours per week providing care or assistance to the person(s) suffering from any chronic condition or infirmity or due to old age (IC3)

European Commission
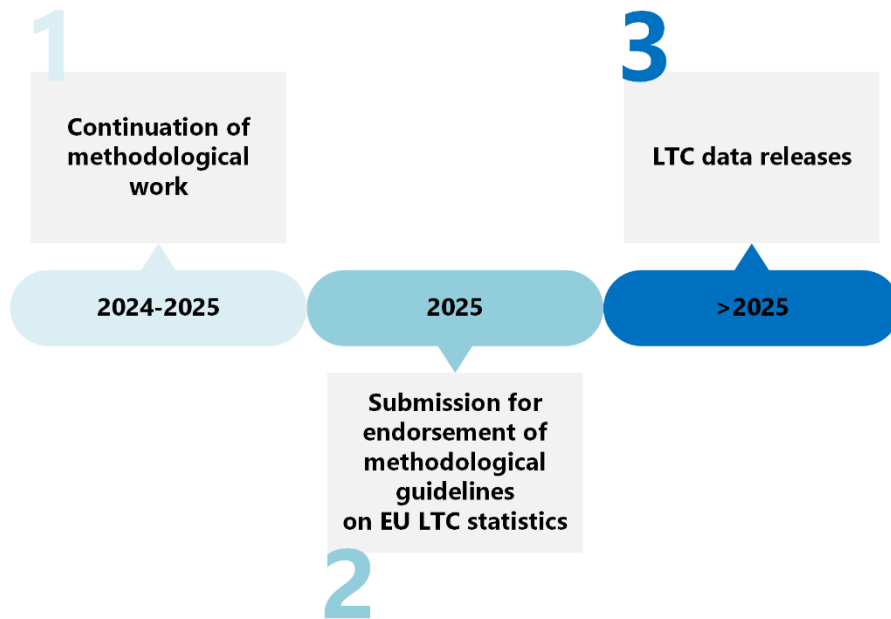
Improvements in EHIS relevant for LTC

- Additional LTC-relevant variables from 2025 onwards:

    - **Receiving** regularly (at least once a week) **informal care** or assistance due to a chronic health condition or infirmity or due to old age (LT1)

    - **Receiving** regularly (at least once a week) any **formal services** due to a chronic health condition or infirmity or due to old age (LT2) (*it replaces AM7*)

    - **Number of hours** per week regularly receiving (**formal**) **home care** services for personal needs (LT3)

    - **Barriers to participation** in specific life domains (BA1 – BA7)

- Feasibility studies on the coverage of the (health-related) institutionalized population

European Commission

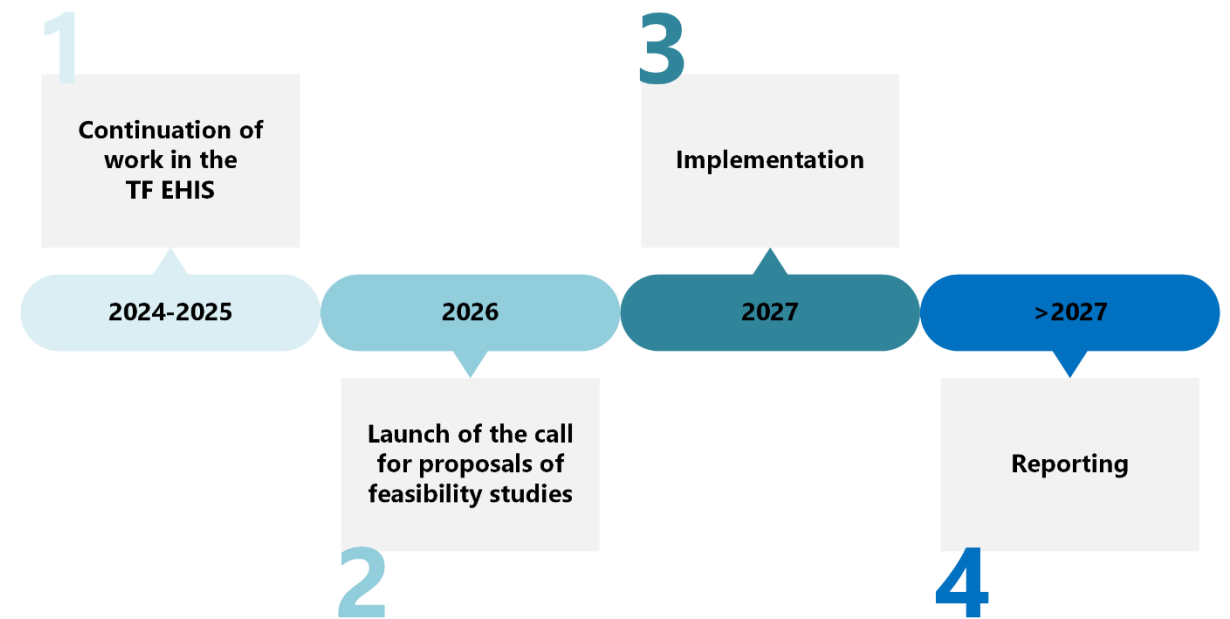# Preparatory work for the feasibility/pilot studies

- Discussions within the Task Force on the European Health Interview Survey (TF EHIS)

  - Review of past work of Eurostat (2011)

  - Collection of national experiences

  - Taking note of the UNECE Recommendations for Measuring Older Populations in Institutions (2020)

- Set up of dedicated TF EHIS sub-groups dealing with different issues such as types of institutions, questionnaire, sampling, data collection mode, etc.

European Commission

Timelines

TF LTC

Coverage of institutionalized population in EHIS (feasibility/pilot studies)

1
Continuation of methodological work

2024-2025

2
Submission for endorsement of methodological guidelines on EU LTC statistics

2025

3
LTC data releases

>2025

1
Continuation of work in the TF EHIS

2024-2025

2
Launch of the call for proposals of feasibility studies

2026

3
Implementation

2027

4
Reporting

>2027

European Commission

LTC-relevant survey modules

- As part of the EU Survey in the Income and Living Conditions (EU-SILC):

    - On health: **2022**, and then every 3 years

    - On access to services: **2024**, and then every 6 years

    - On mental health and wellbeing: **2027**, single exercise

European Commission

Further useful references

Morbidity statistics in the EU (2023)

Methodology EHIS wave 4 (2024)

European Commission

Thank you

For additional info, please contact:
Dr. Giampaolo LANZIERI
Senior Expert
Chair of the Task Force on Long-Term Care statistics
Eurostat, Unit F5 "Education, health and social protection"

giampaolo.lanzieri@ec.europa.eu
estat-tf-ltc@ec.europa.eu

European Commission