



Submission to the EU call for evidence on the European Care Strategy

March 2022

BACKGROUND

The InCARE project brings together a multi-disciplinary group of 10 project partners across 6 European countries. We work with care users, care providers and policy-makers in Spain, Austria and North Macedonia to design, implement and scale-up socially innovative care services.

Our aim is to design a coordinated approach to developing long-term care policy and services through socially innovative and participatory decision-making processes. One and a half years into the implementation of the project, we have collected evidence, data and information (summarized in the following) that allows us to formulate recommendations for long-term care policy and service design that are relevant at European level.



RECOMMENDATIONS FOR LONG-TERM CARE POLICY AND REFORM ACROSS EUROPE:

- **Promote an inclusive, person-centered, rights-based and value-driven vision for long-term care systems and service development**, which recognizes the crucial roles played by families, communities, local, regional and national stakeholders.
- **Promote participatory approaches to decision-making**, empowering local actors to take ownership and design locally customized solutions, within a supportive national policy framework
- **Invest in community-based care solutions** and empower local innovators and stakeholders to increase care service provision across Europe.
- **Invest in the development of data infrastructure in long-term care** to ensure decision-making reflects the preferences of individuals and communities, that it is informed by reliable data and that progress can be monitored on a continuous basis.
- **Match investment in design and development of innovative long-term care services with investment in scale-up and sustainability of innovative approaches**, in order to increase societal impact. This will require dedicating resources and attention to the creation of broad partnerships and ally networks that actively focus their efforts on the long-term sustainability of innovative initiatives.
- **Agree to ambitious targets at EU and national level, develop national long-term care strategies and increase financial support for the development of accessible, affordable and high-quality community-based long-term care services.**

In support of our recommendations, we present a summary of results and learnings derived from the following activities: rapid evidence review, online survey on attitudes, experiences and expectations on long-term care and multi-stakeholder Theory of Change processes in 3 project countries.

Co-funded by
the European Union



REVIEW ON SOCIAL INNOVATION IN LONG-TERM CARE

Over the past decade, the European Commission has actively and increasingly supported the development, uptake and scale-up of social innovation initiatives: according to the CORDIS database, 531 projects explicitly mentioning 'social innovation' among their objectives and tasks were funded since the year 2000 and 106 since the beginning of 2020. As a result, the body of knowledge on social innovation has been steadily increasing in Europe. Based on a rapid review of the growing grey and scientific literature and a mapping of initiatives on social innovation in long-term care, the InCARE team has attempted to define a common narrative for socially innovative change and to provide practical recommendations on how such change can be promoted and supported.

Given that both the innovativeness (i.e. the character of being different from previous initiatives in the same area) and success (i.e. effectiveness of addressing local needs) of social innovation initiatives is context dependent, we propose that for those stakeholders who wish to engage directly with implementing social innovations in their local context, **it is less productive to think about the 'best' innovation initiative, than about the 'best-fit for purpose' initiative.**



The experiences of the past decades have shown most social innovation initiatives are precarious and remain local, although they can be very valuable in their local context and generate tools and ideas with far reaching impact. **What can be easily transferred with great value to local implementers, is the process of identifying innovative ideas, adapting them to match the characteristics of local settings and advocating for a flexible policy framework that supports local implementation.**

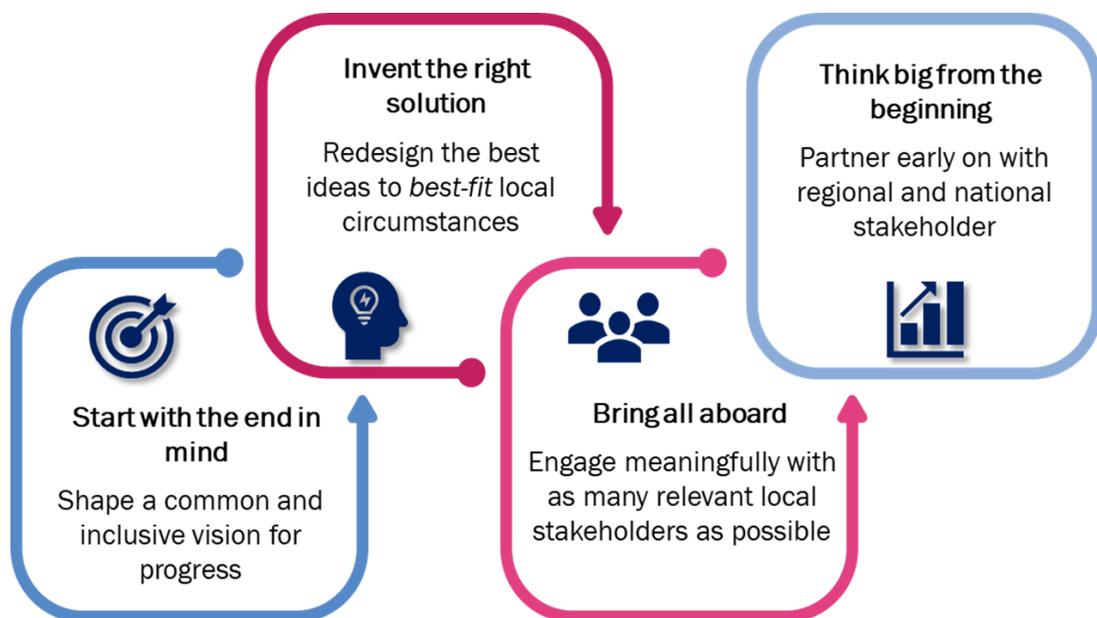
The processes of adaptation and joint learning in local innovation contexts deserves more investment and attention. Instead of taking a particular model or innovation as the point of departure, local implementers should start from their local perspective. **Building on a shared understanding of local circumstances, strengths and weaknesses, they can then identify social innovation approaches that respond to local needs** and can shape the social innovation initiative to match local circumstances.



Social innovation investment in Europe has thus far overwhelmingly focused on the development and implementation side of social innovation. Considerably less has been invested into understanding and creating the conditions necessary to achieve sustainability and scale-up of promising and successful local initiatives and pilots. This imbalance must be urgently addressed if we are to achieve maximum impact from social innovation investment.

The available evidence suggests that sustainability and scale-up of social innovation initiatives often fall outside the reach of local implementers and should be pursued in partnership by diverse stakeholders, better suited to understand and influence funding and regulatory structures at higher governance levels. We argue that **there is a need to match investment in social innovation design and development with investment in scale-up and sustainability of social innovation approaches, by supporting the creation of broad partnerships** between communities, local service providers and policy makers (at local, regional and national level).

A common narrative for change: Four principle for promoting social innovation in long-term care



You can read more about our results in:

- InCARE short report no.1 – Social Innovation in LTC in Europe: Towards a common narrative for change. Available at https://incare.euro.centre.org/wp-content/uploads/2021/07/InCARE-Short-Report-Social-innov-review_final-April2021.pdf
- InCARE Policy Brief no. 1 – Promoting social innovation in long-term care. Available at: https://incare.euro.centre.org/wp-content/uploads/2021/07/InCARE-Policy-Brief-1_Social-Innovation_April2021.pdf



THE INCARE SURVEY

Key Findings

- One quarter of respondents identify a mix of formally and informally provided care in their home as their preferred care arrangement
- Access to care services has worsened considerably since 2007 in two of its major aspects: availability and affordability of care services, especially with respect to home-based care
- Trust in the ability of long-term care systems to respond to future care needs is declining in the European population: only 1 in 10 respondents in 2021 is confident needed care will be available when needed, down from 1 in 5 in 2007
- A pronounced gender gap remains in the detrimental effects of informal caregiving on wellbeing (2 in 3 women but 1 in 2 men) and employment (1 in 3 women but 1 in 6 men)

The InCARE survey on attitudes, experiences and expectations on long-term care is modelled after the Special Eurobarometer 283/ Wave 67.3, implemented in EU countries in 2007. Our aim is to understand how views of care for older people with support needs have changed through time and how Europeans assess the long-term care systems of their countries. This data is essential in order to design better support systems for older people with care needs, for their families and communities. Unfortunately, it is also very scarce, as no comparable data collection effort has been carried out in the intervening 15 years.

While the Special Eurobarometer 283 polled a representative sample of over 28000 Europeans, the InCARE survey achieved 2314 responses from 26 EU countries. This sample of convenience, collected online, is clustered around 6 EU countries (with over 100 responses) and shows overrepresentation of women (3/4 of respondents) and underrepresentation of younger age groups. While limited in its representativeness, our preliminary analyses point to significant and highly relevant changes in the attitudes, expectations and preferences of Europeans with respect to long-term care services and systems. This highlights the need to update and expand data collection in order to reflect user and public preferences in the design of care systems.

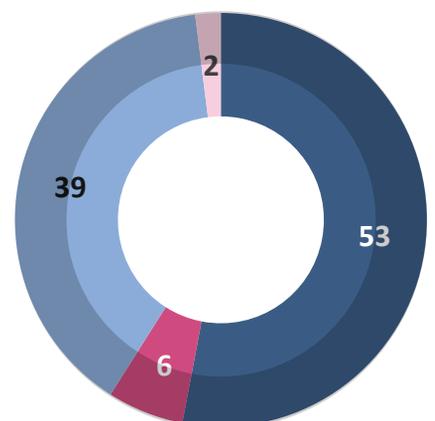
EXPERIENCES WITH CARE

Experiences with care are increasingly more common in Europe. A majority of respondents (61.5%) report they or a person close to them has been in need of regular help and support, compared to 44% in 2007. This increase partly reflects a pattern of experience increasing with age.

Of those who have direct experiences with care, **slightly more than half (53%) consider the appropriate help was available for the person who needed support, a reduction with respect to 58% in 2007.** At the same time 39% feel needed support was only partly available and 6% believe needed care was not given (compared to 10% in 2008).

Was the appropriate help and care given to the person in need? (in %)

■ Yes, totally ■ Yes, partly ■ No ■ Other



ACCESS TO CARE SERVICES

The InCARE data indicate that **access to care services has worsened considerably in two of its major aspects, in the last 15 years**. Whereas in 2007 only 25% and respectively 28% of respondents negatively rated the availability of care services in the home and in care facilities, **the share had nearly doubled in 2021 with 1 in 2 respondents reporting accessibility of care is fairly bad or very bad**. This trend likely reflects the inability of care supply to keep up with the marked increase in demand for care. Similarly, **a growing share of respondents negatively rate the affordability of care, with a large increase for care services in the home (46% in 2021 vs. 32% in 2007)**, indicating a failure of Member States to strengthen social protection for long-term care.

Share of respondents who rate the availability, quality and affordability of care as fairly bad or very bad (in %)

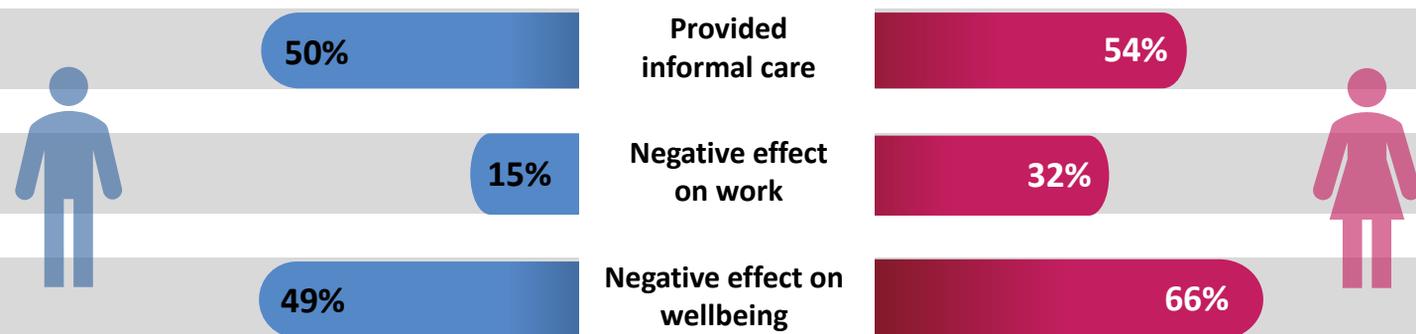


INFORMAL CAREGIVING

Experiences with informal care are both very prevalent and well-balanced between women and men in the InCARE sample, a result that likely reflects a motivational bias to participate in data collection for those with care experiences. However, there is **a very pronounced gender gap with respect to the detrimental effects of informal caregiving on wellbeing (66% of women vs. 49% of men) and socio-economic opportunities**.

One in three women report having to give up work completely or reduce working time in order to provide regular help for someone close to them, while less than one in six men experienced a similar constraint on their labor market participation. This represents a very worrisome increase with respect to data from 2007, when only 4% of respondents felt their work had been affected by care responsibilities.

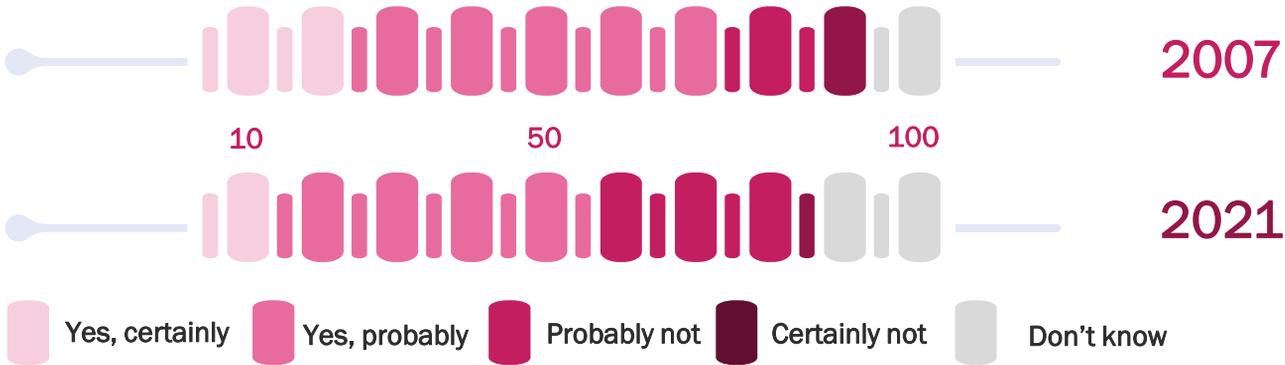
Share of respondents reporting experiences with and negative effects from informal caregiving (in %)



EXPECTATIONS AND PREFERENCES FOR LONG-TERM CARE

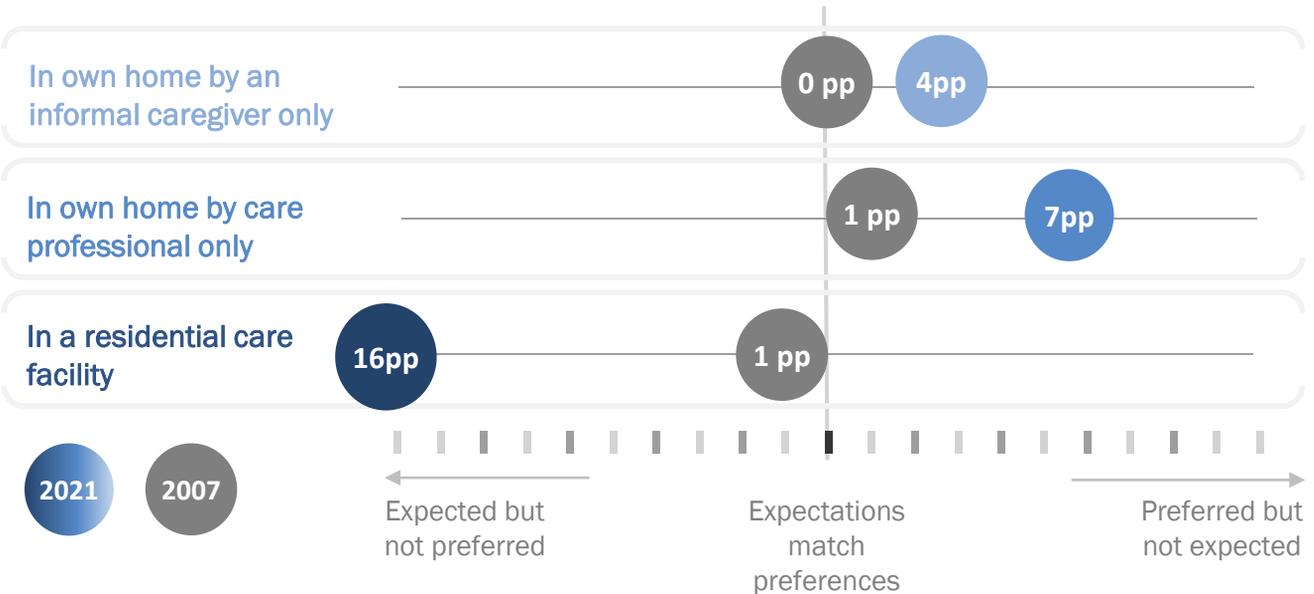
Trust in the ability of long-term care systems to respond to future care needs is declining in the European population. While a large majority of respondents (71%) in 2007 believed appropriate help and long-term care will certainly or probably be available to them when needed, the share has declined to 53% by 2021. Only 1 in 10 respondents is confident needed care will be available while 1 in 4 consider needed care will probably not be available to them, in a marked increase of negative expectations on the availability of appropriate care.

Do you think that you would be provided with the appropriate care if you were to need it? (in%)



As trust in the availability of care has progressively eroded, so has the trust in the responsiveness of care systems. Over the last 15 years, the preferences of Europeans have significantly changed, with a prominent decline in preferences for care provided by informal caregivers and an increase in preferences for professionally provided care. In 2021, 1 in 4 respondents identified as their preferred care arrangement a mix of formally and informally provided care in their home (an option not included in the 2007 Eurobarometer). At the same time, the mismatch between preferences and expectation for future care arrangements has increased to alarming levels. While in 2007 comparable shares of respondents reported expecting to receive the type of care they desired, in 2021 many Europeans who would prefer to be cared for in their own homes do not expect they will be able to access this type of care. Conversely, a 16 percentage-points gap has arisen between those who expect they will be cared for in a residential facility and those who would prefer to be care for in this way. This indicates a generalized concern on the future availability of formal and informal care in the community.

Difference between preferences and expectations of care arrangements in the home (in percentage points)

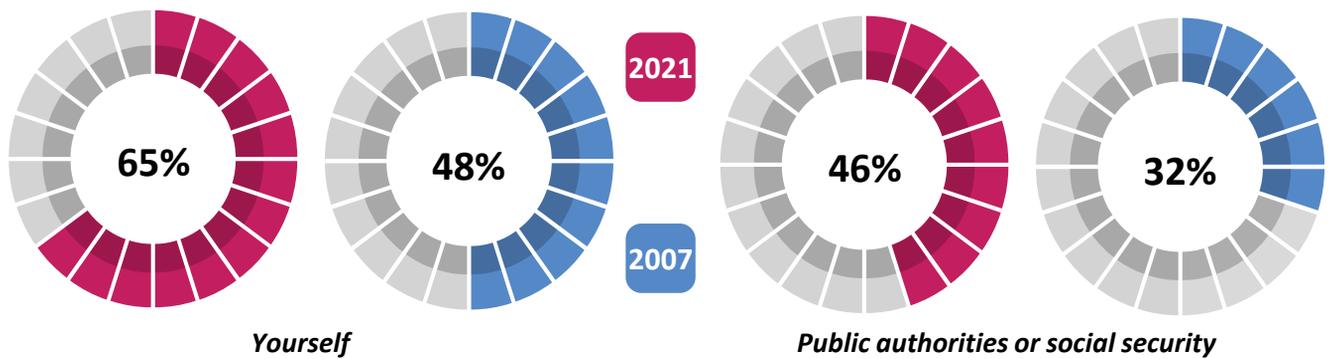


FINANCING LONG-TERM CARE

Europeans continue to overwhelmingly favor a strong role for the State in the organization and provision of long-term care (97% in 2021 and 93% in 2007), while attitudes towards inter-generational responsibility to cover care costs are changing. Opinions were equally divided in 2007 over whether children should pay for the care of their parents if their parents' income was not sufficient (48% agree and 48% disagree). In 2021, two thirds disagreed that children should bear the financial responsibility for their parents' care.

At the same time, respondents increasingly expect the costs of care will be shared between public authorities and individuals themselves, with 65% of respondents expecting to contribute to the costs of their own care while only 46% expect a public contribution to care financing.

*If you were to need regular care that would require payment, who do you think will finance this?
(multiple answers possible)*



You can read more about the **InCARE survey results** (in English and national InCARE project languages) as they become available, at: <https://incare.euro.centre.org/publications-tools/>

Testimonials and messages from our survey respondents are available at: <https://incare.euro.centre.org/testimonials/>

RECOMMENDATIONS BASED ON THE INCARE SURVEY:

- Strengthen community based-care across Europe and increase recognition, support, and access to social rights including adequate minimum income for informal caregivers
- Intensify public engagement efforts and ensure the voices of care users, their informal carers, families and communities are heard and acted upon, in order to rebuild trust in long-term care systems
- Invest in systematic, detailed and representative data collection on preferences, expectations and attitudes on long-term care in the European population, in order to capture relevant changes in a timely manner and reflect them in service and system design. An essential first step is the replication of the Special Eurobarometer on Health and Long-term care in all EU and candidate countries
- Ensure data collection efforts capture relevant group differences and can contribute to better understanding and reducing inequalities (including but not limited to those based on gender, age, education and level of urbanicity).



THEORY OF CHANGE (ToC) PROCESSES

InCARE aims to facilitate the development of multi-level partnership models in all project countries, recognizing the need to develop inclusive governance models that bring together care users, their care partners and families, local communities, civil society organizations and public entities. This is reflected in our Theory of Change (ToC) process, focused on developing a cohesive vision for LTC system development, a common set of goals, a shared understanding of the pathways towards achieving them and a blueprint for tracking progress. **One project-wide and three country-specific ToC workshops were organized by project partners, bringing together more than 100 stakeholders, with diverse backgrounds, experience and roles in their national long-term care systems. Notwithstanding the difficulties of planning and managing the workshops during the COVID-19 pandemic, both organizers and participants evaluated the experience as empowering and enriching.** Furthermore, the InCARE team has derived useful insights from all workshops, which help guide our pilot implementation and policy-advice activities.

We have summarized some of these learnings below and will soon publish further results at:

<https://incare.euro.centre.org/publications-tools/>

ToC map co-developed by participants in the Spanish national multi-stakeholder workshop



Develop a joint vision for change. Our interaction with varied stakeholders indicates that, while each group brings a different perspective to the discussion, agreement is easily reached on the ultimate goals and vision on the development of care systems. This initial agreement facilitates and underpins all following discussions, acting as an anchor point from which all stakeholders can think through a logical structure that works back from expected impact to needed actions.



Bring diverse stakeholders into the development process. Our workshops brought together local care services providers, carers' representatives, care users and informal carers, policy makers at local and regional level and health care professionals. Together they have suggested both changes to planned activities and insightful new actions that were highly valuable to the national implementation teams and enriched an already detailed, evidence-based and expert-led pilot planning process. **Diversity, experience and expertise complement each other in decision-making processes.**

Define practical pathways to implement this vision. InCARE includes 3 different pilot projects and a focus on guiding local and national policy processes. The ToC workshops allowed participants to work together through a wide range of processes and actions aimed at addressing the final desired impact through different pathways and with the involvement of different groups. They defined intermediate and final objectives, highlighted risks and opportunities and drew the boundaries of the project's ability to influence outcomes. Finding order and structure in the complexity of change was considered highly valuable by the project team, as a guide for pilot implementation work, as well as by participating policy-makers.

Create a local ally network. Innovation adoption is often hindered by mismatches between the characteristic of the innovative model proposed and the particularities of the local setting in which it is transferred, as well as, by the lack of motivation of local stakeholders to engage with the innovation. Participatory decision-making approaches and ToC processes are an excellent way to overcome these challenges. They allow for involving diverse stakeholders in the development process, creating an accessible space for interaction and co-design and a sense of shared ownership. We found exchanges between participants continued after the multi-stakeholder workshops and that most participants showed high levels of motivation and willingness to engage with and support the national project teams in dissemination and advocacy activities long after the workshops.

Keep track of progress and evaluate outcomes. The ToC process seamlessly leads to the creation of a plan for change as well as to the development of evaluations and monitoring tools. The initial workshops helped create an outcomes chain, based on explicit assumptions to be tested during project and pilot evaluation. This is co-developed by participants and summarized in the ToC map, which contains explicit statements of challenges and assumptions, the desired project outcomes and impact, and how which activity block within the project is expected to influence these. Indicators for monitoring progress can be easily developed following the structure of the ToC map, therefore generating the basis for evaluating the extent to which each intermediate and final objective was reached as well as the quality and efficiency of the processes and activities that were undertaken.

Create more spaces and opportunities for multi-stakeholder interaction and exchange. After all our national workshops the evaluation team has consistently documented feedback from participants who appreciated the opportunity to hear from and engage with other stakeholder groups. They valued direct communication, the chance to ask and answer questions and finding so much common ground and shared interests. Most participants also reported such opportunities are unfortunately rare and that they would welcome similar interactions in the future.



RECOMMENDATIONS FOR THE EU CARE STRATEGY

- Promote an **inclusive, person-centered and rights-based vision for long-term care systems** and service development, which recognizes the crucial roles played by informal carers and families, communities, local, regional and national stakeholders.
- **Reorient the public discourse towards the value of care**, rather than its cost, and invest in raising awareness of the societal contributions of formal and informal care through a European-wide public communication campaign (including a European Year of Care)
- Ensure **informal carers are granted recognition, rights, support, and adequate training as well as the possibility to make choices with regards to their care activities.**
- Recommend and support the elaboration of **national strategies for strengthening long-term care in every EU country**, coordinating and aligning with existing health, social and ageing national strategies
- **Recognize the key role played by local actors in long-term care delivery** and empower them to take ownership of care service development and design local solutions
- Increase **availability of stable financing for innovative long-term care providers** by setting ambitious funding targets at EU and national level on social innovation in long-term care, and set up yearly EaSI calls on long-term care
- Invest in the development of a **coordinated and harmonized data infrastructure for long-term care across Europe**, supporting the national level development of modern and effective surveillance, quality assurance, monitoring and evaluation systems for long-term care
- Invest into **regular data collection on attitudes, preferences and expectations on long-term care** (for example, by regularly reediting the Special Eurobarometer on health and long-term care) in order to ensure that long-term care system design and delivery are in line with the preferences of individuals
- **Earmark resources for the creation of multi-stakeholder interaction platforms** and local and national ally networks,
- Agree to **ambitious targets at EU level, the achievement of which should be supported by EU financial tools and monitored through the Semester process and increase financial support for the development of accessible, affordable and high-quality community-based long-term care services** in every European country
- **Invest in the wellbeing, satisfaction and stability of the EU care workforce** by improving working conditions, expanding training and career opportunities and diversifying recruitment efforts
- **Take an equity approach to all policy and decision-making for long-term care at EU and national level**, recognizing and working to reduce discriminatory stereotypes on age and gender, as well as deeply embedded gender and socio-economic inequalities in long-term care provision and use, as well as in representation in decision-making.