

The time to care about care: Responding to changing attitudes, expectations and preferences on long-term care in Europe

InCARE Policy brief No. 2 - April 2022

Authors Stefania Ilinca and Cassandra Simmons // Address correspondence to: ilinc@euro.centre.org

Executive summary Fifteen years after the Special Eurobarometer 283 on Health and long-term care in the European Union, the results of the cross-national InCARE survey bring to light significant changes in the attitudes, expectations and long-term care experiences of Europeans. As momentum for reform is building both at national and European level, we find the policy discourse has not kept up with dynamic preferences and attitudes towards care, especially among younger cohorts. Overwhelming support for increasing the role of the State in long-term care organization, provision and financing and shifting the burden of care away from families and individuals, is improperly reflected in current policies. What is more, a failure to do so is negatively affecting trust in care systems, as well as increasing the reliance on informal carers at the detriment of their health and wellbeing. Since 2007, the ability of care systems to adequately address evolving care needs has declined: residential care is unaffordable for many, and the supply of community-based services is falling considerably behind a rising demand. Rural communities and poorer individuals bear the brunt of growing capacity gaps, while women are disproportionately affected by the burden of frequent, intensive and undesired informal caregiving spells. A reorientation towards person-centered, participatory, equitable and accessible care models is urgently needed to rebuild declining public trust in the ability of care systems to respond to the preferences and expectations of individuals and communities.

INTRODUCTION

Notwithstanding remarkable gains in healthy life years individuals can expect to enjoy, the number of people in need of long-term care and support is projected to rise to over 38 million by 2050, as the European population ages (1). But even as the demand for long-term care increases, the availability of families and local communities to provide needed support is being eroded by rapidly evolving social, economic, cultural and population migration patterns. In order to respond to the combined effects of these trends, long-term care systems throughout Europe must strive for significant transformations, by strengthening and reorienting care models to better respond to population needs and preferences.



Slowly recovering from the devastating effects of the Covid-19 pandemic (1, 2), the challenges European long-term care systems must face and overcome are considerable. Capacity gaps in long-term care service provision are apparent in virtually all countries in the region and particularly pronounced for care provided in community-based settings. Even when available, the costs of needed care are burdensome, if not prohibitive, for a considerable share of older people, while the quality and appropriateness of services varies within a wide range (2). The sustainability of the care workforce - both formal and informal - is also a pressing concern that needs to be addressed to protect the wellbeing of those who provide care and to reduce the gender and socio-economic inequalities that are perpetuated by current care systems (3).

Awareness of these challenges and of the necessity to intervene in a decisive manner is growing both among policy-makers and the general public. This is reflected in the momentum for change and reform that is building across Europe. Fifteen EU countries have prioritized actions and interventions focused on strengthening and rebuilding their long-term care systems¹, while in many others national, regional and local initiatives to improve long-term care provision are being pursued. The foreseen launch of the European Care Strategy in the last quarter of 2022 represents another momentous step towards increasing recognition of long-term care within the social policy field and a unique opportunity to accelerate the development of long-term care provision throughout Europe.

In this dynamic policy environment, it is essential to reflect the voices of care users and the preferences of individuals and communities in all decision-making processes, in order to ensure that the care systems of the future are person-centered and responsive to care needs. Furthermore, as the strategies and reforms that are currently being planned and developed are likely to shape the long-term care landscape for decades to come, they must account for the evolving nature of attitudes and preferences to care as more recent birth cohorts progress through adulthood and towards old age. Evidence and systematically collected data is, therefore, urgently needed in order to monitor changes in attitudes, preferences and expectations on long-term care in the European population.

In this policy brief, we report results from a recent data collection effort, highlighting the most pronounced changes in preferences and attitudes towards the organization, delivery and financing of long-term care in Europe and the declining ability of care systems to respond to population needs and expectations in a satisfactory manner. Our results and recommendations can help policy-makers at national and European level to align their priorities and planned interventions with the evolving preferences of the European population.

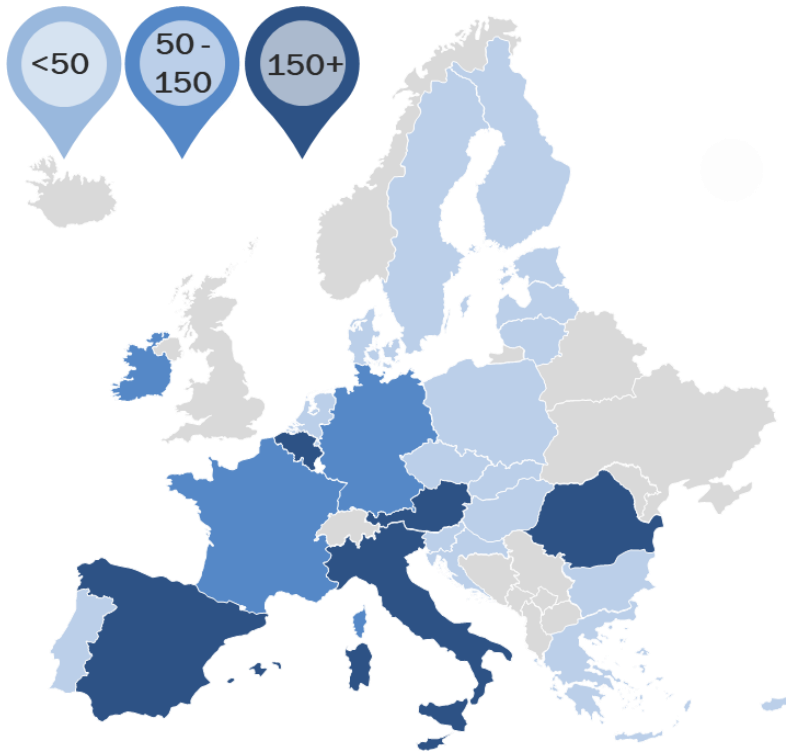
DATA COLLECTION & SAMPLE

The findings reported in this factsheet are based on data collected online from September 2021 to March 2022 as part of the InCARE survey on attitudes, experiences and expectations on long-term care. The survey instrument was modelled after the Special Eurobarometer 283/ Wave 67.3, implemented in EU countries in 2007 (4) and is, to the best of our knowledge, the first data collection effort that attempts to evaluate how the views on long-term care of Europeans have changed since. While the Special Eurobarometer of 2007 polled a representative sample of over 28,000 Europeans, the InCARE survey achieved 2,373 responses from 26 EU countries.

1. Details on reforms and investments submitted by EU countries as part of their national plan, the respective financial allocations and reports on progress, are regularly published on the [Recovery and Resilience Facility online platform](#)



Geographical coverage of the InCARE survey sample



The sample slightly overrepresents middle-aged individuals (half of sample), while underrepresenting those 18-29 years old (16%) and those aged 60 and above (33%). The sample is highly skewed towards women, who comprise 77% of the sample. Higher education is also overrepresented, with nearly 70% of participants having completed a university or postgraduate degree. Most respondents live in large towns (40%), followed by small/middle-sized towns (35%).

Throughout this factsheet, we present the results for the EU-27 region, as well as disaggregated results for the four European countries (Austria, Malta, Spain, Romania) where at least 250 observations were collected.

EXPERIENCES WITH CARE

Experiences with care are more commonly reported by respondents in 2021 than in 2007. The majority have either needed care themselves or have a loved one who needed it (62%), representing an increase of 8 percentage points (pp) since 2007. Respondents in Malta and Spain were most likely to report experiences with care (71% in each) and least likely in Romania (44%), with Austria in the middle (56%). An increase in the frequency of experiences with care is to be expected in the context of demographic ageing across the EU, given that older individuals (60+) are most likely to report experiences with care, reflecting the concentration in later life of both care needs and care use.

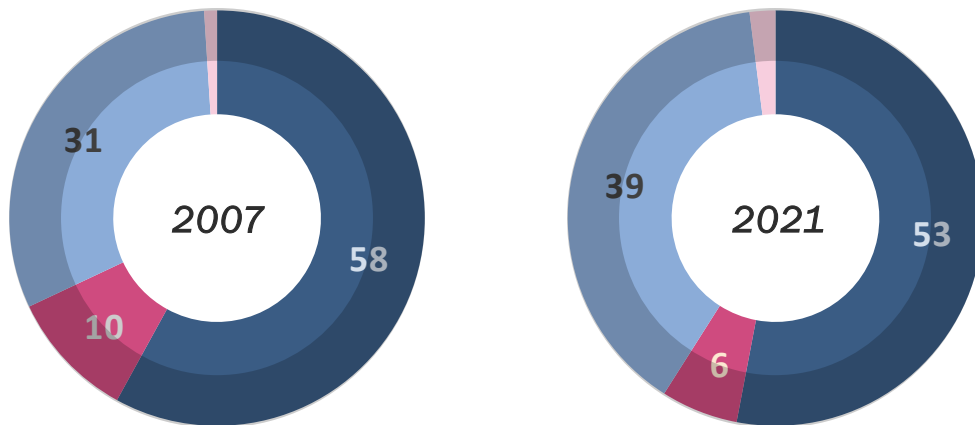
Although male respondents were collectively just as likely to report experiences with care as women at the EU level in 2021, this conceals important gender differences across countries. In each of the 4 countries (AT, ES, RO and MT), **women were more likely to report experiences with care**, with the largest gender gap seen in Malta (10 pp), followed by Austria (9 pp) and Spain (7 pp).

Even as care use and caregiving are increasingly more common for respondents across Europe, the results indicate **there has been a considerable reduction in the perceived ability of care systems to adequately address the care needs of the population since 2007.** Most European respondents believe that appropriate care was entirely received in 2021 (53%), nearly 40% report that care was only partly received and 6% that appropriate care was entirely lacking. In comparison, in 2007, appropriate care was reported to be entirely received by a higher share of respondents (58%), and partly received by 31%. This is indicative of a decline, during the intervening 15 years, in the ability of care systems to address the care needs of the population.



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

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



Male respondents were more likely to report appropriate care was available for the person who needed it (56%) as compared to women (52%) at the EU level. The largest gender gaps are registered in Romania (14 percentage points difference between women and men), Austria (10 percentage points) and in Spain (9 percentage points). This may suggest women evaluate the appropriateness of care differently than men but could also be an indication that women experience considerably more difficulties in accessing appropriate care in some countries.

AVAILABILITY, AFFORDABILITY AND COSTS OF CARE

Our results raise concern that the availability of both home care and residential care services has deteriorated since 2007. European respondents are most negative in their evaluation of home care services with respect to availability, with every 2 in 5 having faced difficulties to reach and to gain access to such care. This represents a 16 percentage point increase over the past 15 years, all the more worrisome considering numerous European countries have been actively promoting development of community-based care in during this period. Similarly, the prevalence of difficulties to reach residential care have significantly worsened during the same interval. Every 1 in 2 (54%) reported that residential care was difficult to access, a 26 percentage point increase from 2007. This may be in part due to general deinstitutionalisation efforts and emphasis on community-based care in recent years. Nearly 1 in 4 were uncertain about the availability of home-based care and 1 in 5 for residential care.

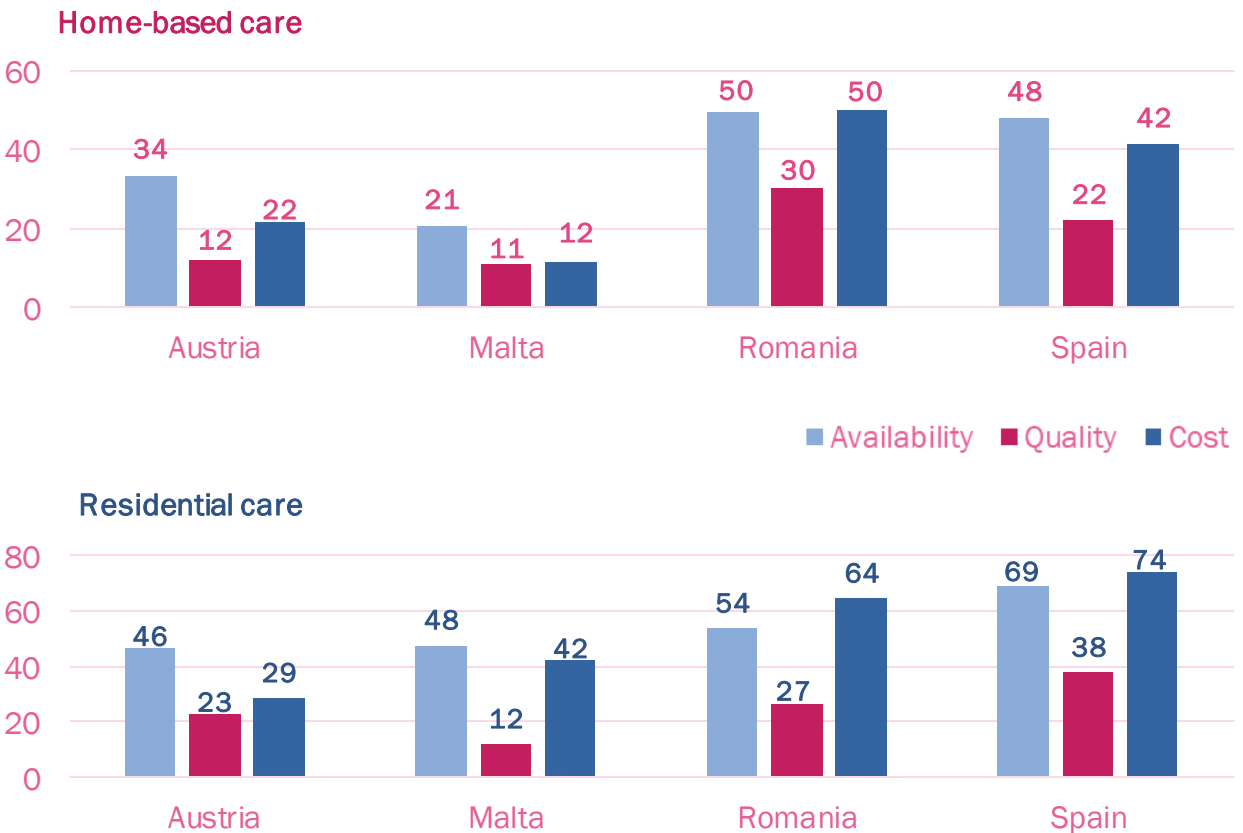
Share of European respondents rating home and residential care as difficult to access, unaffordable (cost) or of low quality in 2007 and 2021 (in %)



Residential care has become increasingly unaffordable for European respondents. Affordability is a more pronounced issue in 2021, as more than 1 in 2 reported this (56%), compared to 42% in 2007. Costly residential care services and limited accessibility of home-based care services leave individuals with limited options. In contrast, the share of respondents reporting that home-based care was unaffordable remained the same in 2021, as in 2007 (1 in 3). **Individuals with lower income were most likely to report in 2021 that care was unaffordable compared to those with higher income** for both home care (44% versus 32% respectively) and residential care (62% versus 55% respectively).

Less of a reported issue than affordability or availability, poor quality still remains a barrier for European respondents for both residential care and home care services. Although the quality of home-based care marginally improved (1.6 percentage points), the quality of residential care services has deteriorated. 28% of European respondents reported residential care to be of poor quality in 2021, a 5.1 percentage point increase from 2007. Results on care quality, however, should be interpreted with caution, as one third of respondents felt unable to assess the quality of provided services.

Share of respondents rating home and residential care as difficult to access, unaffordable (cost) or of low quality in 2021 (in %)



In line with previous results (5), challenges related to the availability, quality and affordability of care are apparent across countries but their extent varies, indicating country **differences in issues associated with the provision of care services**. Individuals in Romania and Spain were most likely to negatively evaluate the availability of both residential and home care compared to the EU average. Availability was least likely to be reported as an issue in Malta for home care (1 in 5), and in Austria for residential care (46%). Respondents in Spain and Romania also reported affordability issues more frequently: half of respondents reported home care to be unaffordable in Romania, while every 3 in 4 reported this to be the case for residential care in Spain. Poor quality was most frequently reported in Romania for home care, and in Spain for residential care.



INFORMAL CAREGIVING

More respondents in the EU reported providing informal care in 2021: 1 in 2 report providing informal care within the last 10 years (most commonly to parents and parents in law – 48%), compared to 1 in 3 in 2007. The characteristics of the 2021 sample are likely to contribute to an over-estimation of the frequency of informal care provision, considering recent estimates place the number of informal caregivers in the EU at 44 million, or 12% of the adult population (6). Nonetheless, the increasing reliance on informal care as service provision struggles to keep up with demand is corroborated by the imbalance between the informal and formal care workforce, the latter estimated to amount to 6.3 million workers (6).

Informal caregiving remains gendered, with more women providing informal care than men. The gender gap in caregiving was largest in Austria (women 60% vs. men 48%), Spain (women 66% vs. men 54%) and Malta (women 65% vs. men 53%). The smallest gender gap was reported by respondents in Romania, where approximately 38% of both women and men provided care.

Informal carers have increasingly faced negative consequences in terms of their career and women in particular bare the brunt of this burden. In 2007, 5% of carers reported they had to either quit their job completely or switch to part-time, compared to an overwhelming 29% in 2021. While women respondents were more likely than men to reduce their working hours or quit their job to provide care in both 2007 and 2021, the gender gap has substantially widened. Across the EU in 2021, 32% of women respondents either gave up paid work or reduced their work hours compared to 15% of men. In comparison, in 2007, 7% of women carers and 3% of men reported negative impacts on their paid working time.

Share of respondents in the EU who perceive pressure to provide informal care in 2021 (by gender)



Many respondents who have provided informal care report feeling obligated to do so, despite negative effects on their general wellbeing: 6 in 10 respondents at European level in 2021. The perceived pressure to provide informal care is more commonly reported by women respondents (2 in 3) as compared to men (1 in 2), suggesting gendered cultural norms that establish care as primarily a woman's responsibility remain widespread in Europe. No country specificities were apparent in the 2021 results, as similar gender gaps in perceived pressure to provide care were verified across Austria, Malta, Spain and Romania.

There is however a strong indication that attitudes are changing in Europe. Even as a majority of respondents report perceived pressure to provide care, only a small minority hold the belief that care should be provided by family members, irrespective of its negative impacts on the health and wellbeing of informal caregivers (14%) or on their careers (17%). These results suggest familialistic views with respect to care provision are being eroded, albeit at a different pace across Europe. Support for family responsibility for care is highest in Romania from all the countries in our sample, where 1 in 4 respondents believe family members should provide care despite negative impacts on health and wellbeing.



EXPECTATIONS OF LONG-TERM CARE

A large majority of European respondents expect to need care at some point in the future: nearly half felt it is likely they will require care at some point (47%), while 24% are certain they will. In stark difference, the data collected 15 years before indicates only 45% of respondents were certain or thought it was likely they will develop care needs at some point in their life. The increase in expectations to need care may indicate wider awareness and a more accurate perception of the risk to develop long term care needs, estimated in a recent US based study to 70% for the cohort currently entering old age (7). Respondents in Austria and Spain were most likely to believe they would need care at some point during their lifetime (80%), followed by Malta (77%) and Romania (50%).

Our results further indicate that **public trust in the ability of long-term care systems to respond to the care needs of the population is declining**. In 2021, 1 in 3 respondents in the EU do not believe they would be provided the appropriate help in the future if they were to need care, a significant increase from 2007 (16%). A further 1 in 7 are uncertain whether they would receive the appropriate care if needed. The lowest level of trust in 2021 is reported in Spain, where 41% of respondents were sceptical that appropriate care will be available to them, compared to Austria (34%), Romania (24%) and Malta (16%). Across all four countries for which disaggregated data is available, **the share of respondents who did not expect appropriate care will be provided, if needed, has at least doubled between 2021 and 2007.**

Share of respondents who do not expect to receive appropriate care, if needed in the future (in %)



Women respondents in 2021 are only marginally more sceptical than men (32% versus 30% respectively), while middle-aged respondents (30-59) were the most sceptical (37%) compared to younger respondents (23%) and those aged 60 or above (25%). The growing lack of trust amongst the middle-aged group points to noteworthy generational differences in the perception of the long-term care system's ability to address population care needs. Such cohort differences are likely grounded in the increasing burden of financing care, projections of increased demand for care in the future and general concerns with respect to the sustainability of current care models.

In addition to lowering levels of trust in care systems' responsiveness to needs, our results indicate a further decline in trust with respect to ability to respond to care preferences. **Fewer respondents expect they will be able to access the type of care they would prefer, compared to 2007.** In 2021, 4 in every 5 respondents in the EU do not expect the care they will receive will align with their preferences, a substantial increase from 2007 when nearly 2 in 5 believed this will be the case.

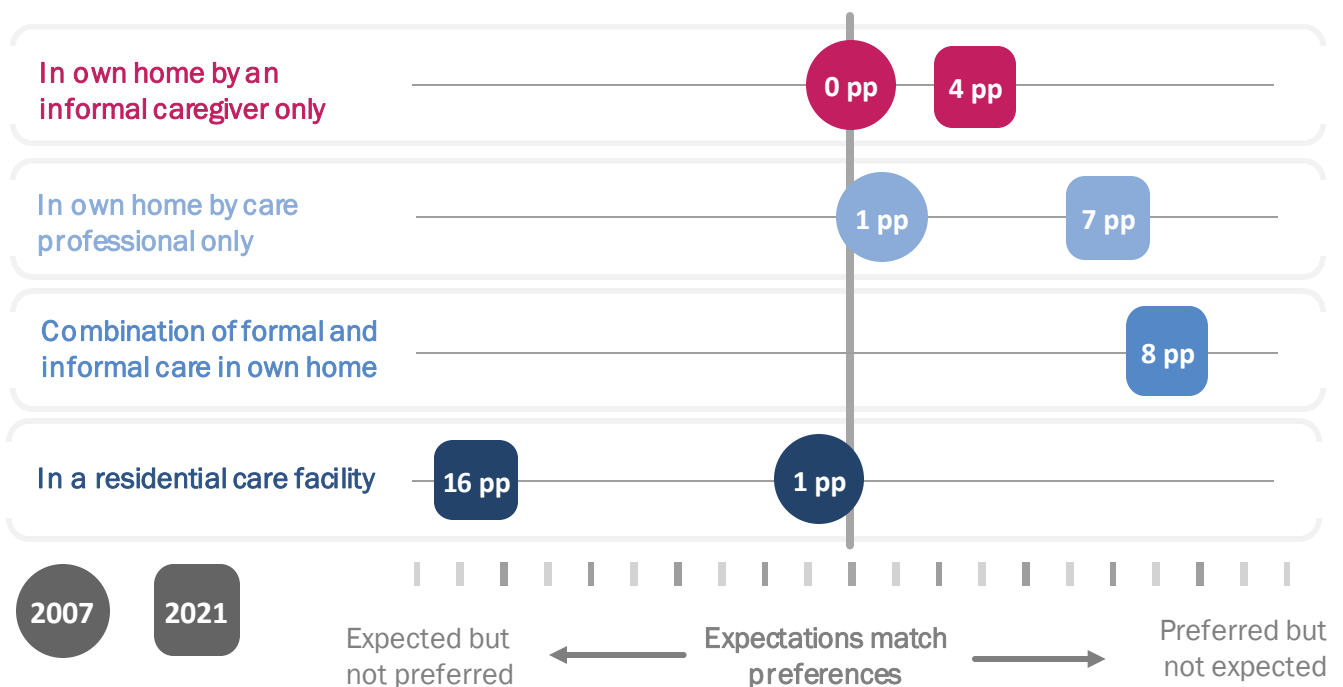


Preferences for specific care arrangements are changing rapidly, with a pronounced decline in preferences for informally provided care since 2007. While nearly 1 in 2 respondents stated informal care by a relative in their own home was their preferred type of care in 2007, only 1 in 5 respondents identify it as their top preference in 2021. Instead, there is a sizable increase in preferences for formal care provided by a professional service (29%). **Preferences for care are also highly gendered:** Informal care is more commonly identified as the preferred care type among men respondents in the EU (25%) than among women (17%), while women have a stronger preference for formal care alone, whether provided by a care service or a personal carer (42% for women versus 35% for men).

Informal care is most commonly preferred by respondents in Romania (31%) and least commonly in Spain (12%), with Austria and Malta falling in the middle (16% and 27% respectively). Conversely, preferences for care provided solely by a professional carer are highest in Austria (46%) and Spain (42%). A combination of both informal and formal care provided in one's home is the preferred care type of 31% of respondents in Spain, 30% in Malta, 23% in Austria and 12% in Romania.

Still, the strongest preference continues to be for care in the community, whether through informal care, formal care or a combination of the two (88%), and less so for residential care (10%). Nearly 1 in 4 would prefer to receive a combination of formal and informal care in their own home (24%).

Gap between preferred and expected care arrangements in the EU, by year



While preferences and expectations of European respondents were relatively well balanced in 2007, a **considerable gap is opening between what care respondents would prefer and the care they expect to receive.** This gap is particularly pronounced for residential care, as many more respondents expect to receive care in a residential facility, despite preferring a different type of care (16 percentage points difference). The largest mismatch is reported in Malta, where nearly 30% of respondents expect to use residential care, despite only 7% stating this as their preferred type of care. Conversely, there are more respondents who would prefer to receive care in their own home, than respondents who expect this will be the case. This is the case for all community-based care arrangements, with the largest gap apparent for a combination of formal and informal support in the user's home.



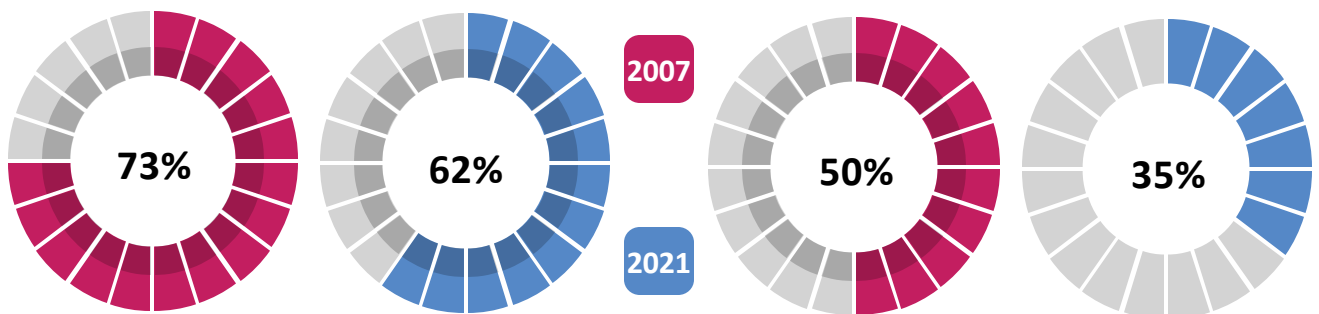
FINANCING LONG-TERM CARE

An overwhelming majority of respondents across the EU agree that public authorities should organise and provide appropriate care for older people with care needs (97%), consistent with preferences expressed in 2007 (96%). Similarly strong levels of support for placing responsibility for care with public authorities are reported in Austria, Malta, Romania and Spain. There is, however, high variability in preferences with respect to the specific financing mechanisms that should support public authorities to play a more significant role in care provision.

Support for public long-term care insurance schemes seems to be decreasing: 62% of respondents in 2021 agree that everyone should contribute to an insurance scheme that would cover care costs if needed, with respect to 73% in 2007. Support was lowest among respondents from Spain (26%) but higher than the EU average in Malta (71%), Austria (68%) and Romania (66%).

Similarly, support for placing financial responsibility for care with the family is declining. Only 35% of respondents in 2021 believe that children should be obligated to pay for their parents' care if the parents' income is insufficient to cover all costs. In comparison, 1 in 2 respondents held the same opinion in 2007. The view that children should cover the costs of their parents' care if they are unable to do so themselves, is more common among respondents from Romania (1 in 2), Malta (1 in 3) and Spain (1 in 3), but significantly less so for Austrian respondents (1 in 10).

Share of respondents in the EU who agree with the statements ...



Every individual should be obliged to contribute to an insurance scheme that will finance care, if and when it is needed

Children should pay for the care of their parents if their parents' income is not sufficient

One in two respondents believe that the State should cover all care costs or the costs of a basic, universal long-term care package, with the option of additional individual payments for higher care standards. At the same time, 1 in 3 respondents believe a means-tested cost-sharing arrangement between the State and individuals should be applied to both home and residential care use, protecting those with low assets and low income from out-of-pocket care costs. Finally, a small minority (approximately 1 in 10) of respondents consider all care use should be subject to mandatory co-payments, regardless what the care user's income and wealth are.

Despite the pressure on working age groups to cover the increasing costs of care provision in Europe, there is strong indication of support for intergenerational solidarity and redistribution of resources for financing care publicly, across generations. The strongest support for State responsibility for care costs was among younger respondents (18-29) where 72% support this, followed by those aged 30-59 (51%).



THE GENDER DIMENSION OF CARE



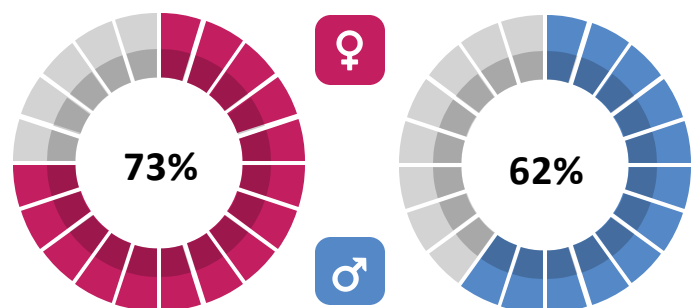
In full alignment with a growing body of evidence (8, 9), **our results point to pervasive gender differences in attitudes, expectation and experiences with long-term care.** To highlight their extent, we summarize the most pronounced here. On a country-by-country basis, women respondents were not only more likely to have experience with care, but also more likely to assess the available care was not appropriate, whether themselves or a loved one needed it. **The burden of informal caregiving also falls predominantly on women**, who provide more informal care than men and are more likely to face negative consequences on their career and well-being. More worrisome still, the comparison to 2007 reveals a widening gender gap in informal caregiving and associated impact on market labour participation.

Marked gender differences in expressed preferences for care highlight the need to adjust care models to better reflect the lived experiences and perspectives of women. Women respondents are more likely to prefer some form of formal care services in the community, while more men would prefer to receive informal care only. The stronger preference for formal care alone are likely to reflect, at least in part, women's experiences with providing informal care and a higher awareness of the negative consequences intensive or prolonged caregiving can have.

The intersection of gender with social location partly explains inequalities in experiences with care. Women tend to have lower socioeconomic status in the form of lower income and labour market participation than men which corresponds to increased cost barriers in accessing care.

Corroborating this result and accounting for the intersection of socioeconomic status (i.e. ability to make ends meet), 55% of women with lower income reported cost-related difficulties with accessing homecare versus 46% of men. Similarly, lower income status largely explains the 10 percentage points difference in reporting cost-related barriers between women and men for residential care.

Share of respondents who face barriers related to costs



Lower labour market stability and lower incomes are also likely to contribute to household decisions that lock women in caregiving roles and can explain to a considerable extent the gender gap in the negative impact of caregiving on women's career opportunities: lower income women are more likely to quit their jobs or reduce their hours than higher income women.

These findings highlight the **need for taking an equity approach in long-term care planning and provision that recognizes gender and intersecting sources of inequality.** Targeting of financial protection schemes should recognize and address gender gaps in ability to access and pay for care. A major shift towards gender-sensitive and gender-transformative policies is needed with respect to informal caregiving, ensuring access to social rights for all those who provide care and actively encouraging a gender-balanced distribution of care.



DISCUSSION & POLICY RECOMMENDATIONS

The marked changes in attitudes, preferences and experiences with care, as outlined in this policy brief, raise important concerns with respect to the alignment of current policy initiatives and the vision and expectations of Europeans. We therefore outline and discuss below, **9 key recommendations that should be considered and reflected in long-term care initiatives, policies and reforms both at national and at European level.** The list we propose is neither exhaustive nor definitive. Many other important issues which were not addressed by our study should be considered as complementary. At the same time, the dynamic nature of preferences and attitudes renders our conclusions and recommendations subject to change over time. It is therefore essential to constantly monitor and systematically update the evidence collected here.



Experiences with care have become increasingly common since 2007, reflecting population ageing and the rising portion of the population faced with health limitations requiring care. As care needs are projected to further increase over the next decades (1), care and caring will become a relevant part of daily experience for a growing share of individuals of all ages. The functioning and organisation of care systems is not only the concern of care users, rather it affects the lives and wellbeing of wide swaths of the European population. It is therefore important that **European countries recognize long-term care as a growing societal concern and accelerate care system reforms, in order to address expanding needs.**



Further highlighting the urgency of investment and reform, our results show that rising demand for care services has overwhelmed the ability of care systems to respond with sufficient and adequate supply. Fewer respondents in 2021 reported that care was adequately provided when it was needed, as compared to 2007. This indicates large capacity gaps in service provision and a paucity of care options in community settings, where the majority of respondents prefer to receive care. Our results echo previous findings that underline the marginal rise in home-care recipients across European countries, despite stated policy priorities (10). **Significant investment is needed in the planning and provision of care services in community-based settings, in order to respond to care needs through care arrangements that reflect the preferences of the population.**

Issues related to the availability of care are closely paralleled by affordability concerns, which continue to limit access to needed services for a significant share of respondents across the EU. Home care services are considered unaffordable by one third of respondents, and more than one half report cost barriers in accessing residential care services. The situation has deteriorated over the past 15 years, highlighting the need to **increase financial protection for long-term care, across care settings**, in order to ensure that individuals with care needs and their families are not exposed to financial distress.

As care service development is falling behind increases in demand, reliance on informally provided care is correspondingly increasing. As many as 44 million people are estimated to provide frequent informal care to relatives or friends in Europe, supporting our results which indicate growing frequency of experiences with informal care. While caregiving is a choice and a rewarding experience for many, it is important to acknowledge there is a large and cumulating negative impact of prolonged caregiving on paid work, wellbeing and financial resources, more acutely felt by women caregivers. Echoing the recommendation of the EU Parliament (11), our results point to widespread support of measures that recognize the contributions of informal caregiving and mitigate its detrimental effects. **This includes strengthening financial and social protection for carers (through direct financial support and recognition of social insurance rights) and increasing access to respite care, training, advice and support services.**

Support for caregivers should and must be complemented by investment in expanding **care service provision, in order to alleviate the burden on informal carers and afford every individual the possibility to make choices with regards to their care activities.** In the absence of adequate formal care alternatives, many individuals feel obligated to provide informal care despite negative impacts on their wellbeing and careers. As gendered attitudes toward care persist across Europe, women are particularly vulnerable to being locked in caregiving roles that cannot be reconciled with their professional and personal aspirations. Shifting the bulk of caregiving away from informal arrangement and towards formalized care provision, not only responds to the necessity to address persistent gender inequalities, but also reflects evolving preferences for mixed or professional care only to the detriment of care provided by family members.

Trust in the ability of care systems to adequately respond to future care needs has declined in Europe, especially among middle-aged individuals. This indicates increased awareness of the momentous effects of demographic change on social protection systems, but also reflects declining trust in the ability of national governments to drive meaningful change, in line with care demand and user preferences. A precondition to the development of inclusive and user-centered care systems, is the development of **processes that systematically elicit and monitor preferences and attitudes towards care in all European countries.** Similarly, a public debate on what a good life in older age means to citizens, should be promoted and its results reflected in all long-term care policies.



In the key conclusions of the 2021 Long-term Care report, endorsed by the EU Council², the Social Protection Committee and the European Commission commit to supporting regular analyses of long-term care developments at the EU level, as an essential step towards strengthening the evidence base for policy-making. Relevant developments that should be monitored include changes in individuals' attitudes, expectations and experiences with long-term care (for example through regular and harmonized EU level collection of information through a rotating Eurobarometer) as well as the scope and depths of mechanisms which allow civil society to play a role in public policy processes.

Our results further point to consistently strong support for increasing the role of the State in the financing and provision of long-term care and expanding long-term care insurance schemes. A majority of respondents (particularly among younger age groups) believe either all care costs or a basic package of care services should be publicly covered, in a consistent show of support for intra and intergenerational solidarity in Europe. **This should be reflected in the explicit recognition of long-term care as an essential branch of social policy across European countries and an increase in public investment and expenditure for long-term care.** The predominant emphasis on controlling rising costs in European long-term care policies and the consequent increase in the stringency of eligibility criteria lead to conditions in which unmet care needs escalate. In order to reverse this trend, increases in public financing should be complemented by initiatives to ensure stable financing sources at national level that can reduce regional inequalities, as well as innovative funding mechanisms that promote integrated delivery of care and equitable provider payments (12).

Similarly, **diversification and innovation of prevailing care models must be encouraged and pursued**, emphasizing person-centredness and a rights-based approach to care. The Covid-19 pandemic laid bare the pitfalls of segregating care users in densely populated residential care facilities. It brought to the fore a long-lasting debate about the need to reimagine care provision and expand intermediate care arrangements, assisted living models and community-based communal living (13).

Cross-cutting through all areas highlighted for intervention is the need to **adopt an equity-oriented approach to long-term care system development.** Our results add to a large literature documenting pervasive inequalities in care needs, access, care use and care provision. Above all, inequalities in experiences with care and caregiving are highly gendered and intersect with socio-economic status. Spatial inequalities are also profound, with systematic under-development of care services in rural areas and wide gaps in availability, affordability and quality of care within and between European countries. In order to fulfil the vision of a universal right to affordable long-term care services of good quality for all Europeans (Principle 18 – European Pillar of Social Rights), **long-term care policy must pursue transformative actions to combat gender, socio-economic, ethnic and geographical inequalities.**

The issues we outline in our recommendations are common challenges faced by all European countries in their efforts to strengthen long-term care systems, improve access to care and respond to users' needs and preferences. European level processes can and should support efforts at the national level in achieving these goals by setting ambitious EU-level targets, creating a common vision for long-term care development and encouraging the development of national strategies for long-term care throughout Europe. At the same time, wide variability across regional and local contexts calls for the development of more inclusive, participatory decision-making processes, which can empower local actors and communities to actively engage in the transformation of European long-term care systems. In the balanced engagement and meaningful partnership between all these stakeholders lies the pathway towards more sustainable, more equitable and more inclusive care systems.

2. <https://data.consilium.europa.eu/doc/document/ST-9144-2021-INIT/en/pdf>



REFERENCES

1. European Commission, Directorate-General for Employment, Social Affairs and Inclusion and the Social Protection Committee (2021). Long-term care report: trends, challenges and opportunities in an ageing society. Volume I, Luxembourg: Publications Office: <https://data.europa.eu/doi/10.2767/183997>
2. OECD (2021). Rising from the COVID 19 crisis: Policy responses in the long-term care sector. OECD Policy Responses to Coronavirus (COVID-19). Paris: OECD Publishing.
3. OECD (2020). Who Cares? Attracting and Retaining Care Workers for the Elderly. Paris: OECD Publishing (OECD Health Policy Studies), <https://doi.org/10.1787/92c0ef68-en>
4. Special Eurobarometer (2007). Health and long-term care in the European Union. Special Eurobarometer 283 Report
5. Spasova, S., Baeten, R. & Vanhercke, B. (2018). Challenges in long-term care in Europe. Eurohealth, 24(4), 7-12.
6. Eurofound (2020). Long-term care workforce: Employment and working conditions. Luxembourg: Publications Office of the European Union.
7. Johnson, R. W. (2019). What is the lifetime risk of needing and receiving long-term services and supports. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation.
8. European Institute for Gender Equality (2020). Gender Equality and Long-term Care at Home. Luxembourg: Publications Office of the European Union, doi:10.2839/007919
9. European Institute for Gender Equality (2020). Gender Equality Index 2019 – Work-life balance. Luxembourg: Publications Office of the European Union. doi:10.2839/319154
10. OECD (2021). Health at a Glance 2021: OECD Indicators, Paris: OECD Publishing, <https://doi.org/10.1787/ae3016b9-en>
11. Barslund, M., De Wispelaere, F., Lenaerts, K., Schepers, W., Fries-Tersch, E. (2021). Policies for long-term carers, Publication for the committee on Employment and Social Affairs, Policy Department for Economic, Scientific and Quality of Life Policies. Luxembourg: European Parliament,.
12. WHO Centre for Health Development, OECD, Barber, S., van Gool, K., Wise, S. et al. (2021). Pricing long-term care for older persons. Geneva: WHO. <https://apps.who.int/iris/handle/10665/344505>
13. Zimmerman, S., Cesari, M., Gaugler, J.E., Gleckman, H., Grabowski, D.C., Katz, P. R., ... & Werner, R.M. (2022). The Inevitability of Reimagining Long-Term Care. Journal of the American Medical Directors Association, 23(2), 187-189.

Recommended citation: Ilinca, S. & Simmons C. (2022) *The time to care about care: Responding to changing attitudes, expectations and preferences on long-term care in Europe*. InCARE Policy Brief No.2.

The InCARE survey on attitudes, experiences and expectations on long-term care was carried out with the support of funding from the European Commission's EaSI Programme (VS/2020/0258) and a network of project collaborators throughout Europe (from September 2021 to February 2022).

It contributes to the evidence-base building activities of the [InCARE project](#), which aims to design a coordinated approach to developing long-term care policy and services through socially innovative and participatory decision-making processes. 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.

For updates on our progress and publications please visit <https://incare.euro.centre.org/> or subscribe to our newsletter [here](#) or by sending an email to cc@eurocarers.org.

 **Bundesministerium**
Soziales, Gesundheit, Pflege
und Konsumentenschutz

Gefördert aus den Mitteln des Fonds Gesundes Österreich
Gesundheit Österreich
GmbH

Geschäftsbereich
 **Fonds Gesundes Österreich**


EUROPEAN CENTRE FOR
SOCIAL WELFARE POLICY
AND RESEARCH


LSE CPEC
CARE POLICY AND EVALUATION CENTRE


Vilans


EURO
CARERS

**CHANCE B
GRUPPE**


Republic of North Macedonia
Ministry of Labor
and Social Policy

 **Red Cross of the Republic of North Macedonia**

 **IMSERSO**

MATIA
INSTITUTO GERONTOLÓGICO