



Attitudes, experiences and expectations on long-term care in North Macedonia

November 2022



Co-funded by the
European Union



Republic of North Macedonia
Ministry of Labor
and Social Policy



Црвен крст на Република Северна Македонија
Red Cross of The Republic of North Macedonia



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Federal Ministry
Republic of Austria
Social Affairs, Health, Care
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Key Findings

- Availability and affordability remain major barriers in accessing formal care services, particularly for low income earners and rural-living individuals
- Many feel obligated to provide care for their loved ones, despite negative impacts on their career and health, warranting increased financial protection and recognition of social rights for informal carers, as well as expanded formal care options
- Strong preferences for formal care options and less responsibility for families demonstrate a need for expansion of community care services and an increased role of the state in providing and financing care

BACKGROUND

The North Macedonian long-term care system is characterized by a strong reliance on informal care, supported by cash benefits for persons with disabilities and their families and a care part-time work allowance, organized and financed by the central government. Benefits in kind, which fall under the combined responsibility of the central and local governments, remain a more marginal aspect of the system as the result of limited infrastructure, particularly in rural areas. Private ownership comprises a majority of formal care services provided: approximately 35 private homes currently operate in the country, compared to 4-5 public homes. Governed partly by the social protection and pension insurance system alongside the healthcare system, long-term care is primarily financed through state taxes and out-of-pocket payments. Recent years have witnessed the start of many reforms in the sector, sparked by a new 2019 law on social protection that established the responsibility and obligation of municipalities to develop local plans for social protection and establish social services at the local level. These reforms have led to initiatives to improve the quality of services, as well as a comprehensive deinstitutionalisation process where services have shifted away from traditional large-scale care homes towards the development of alternative community-based services, including mobile care services.

The findings reported in this factsheet are based on unweighted data collected through an online survey between September 2021 – February 2022, consisting of 331 responses from North Macedonia and 2042 responses from across EU countries. The sample underrepresents younger individuals under 30 (18% vs. 35% in the population) and older adults aged 60+ (13% vs. 24%), as well as men (34%). The sample is also skewed towards individuals with a university degree (65%) or secondary education (31%) and urban-dwelling individuals (53%).



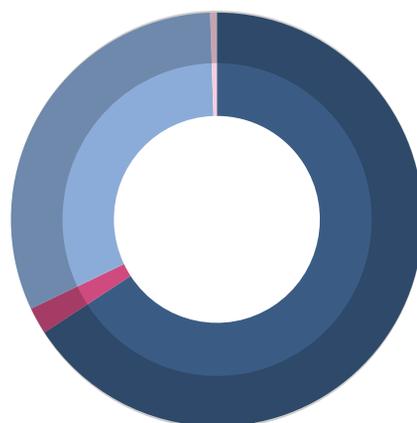
EXPERIENCES WITH CARE

The majority of respondents (57%) report having experience with care, whether themselves or a loved one, with limited gender differences. Residents in urban areas were more likely to report experience with care (58%) than those in rural areas (48%). Reflecting that care needs are distributed in later life, 71% of respondents aged 65 and older reported experiences with care compared to 41% of those 18-29 years old.

In nearly all cases, the person in need of care received some form of assistance. Around 2 in 3 felt appropriate care was provided entirely while nearly 1 in 3 felt it was only partly provided. In only a small minority of cases (2%), no care was received at all. A strong reliance on care by family and friends likely ensures that individuals receive informal care as a safety net if needed in absence of formal care.

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

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

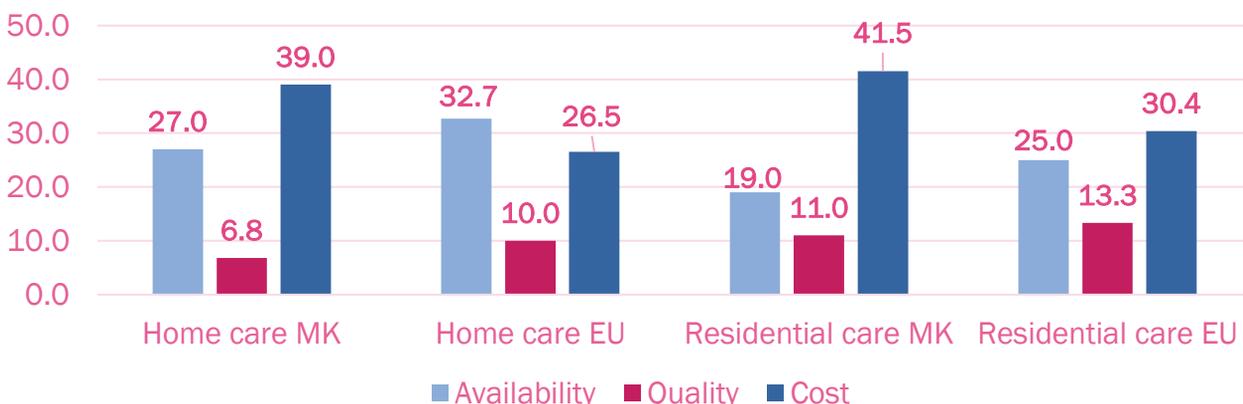


BARRIERS TO ACCESSING CARE SYSTEMS

Affordability of home- and residential care services remains a major challenge in North Macedonia. Every 2 in 5 respondents stated cost as a barrier to care in the country, surpassing that reported at the EU-level and that reported for health care (21%), indicating the need for stronger financial support. Lower income groups (45% vs. 30% for higher income) are particularly vulnerable to unaffordable care costs, as well as those living in rural areas for residential care costs (67% vs. 42%). These findings align with previous research that indicates cost to be a preventative factor for many in using residential care¹.

Availability of care services is also an issue, although less so than for healthcare: nearly 1 in 4 for home care and 1 in 5 for residential care reported availability barriers, compared to 1 in 2 for family doctors. Rural-dwelling individuals particularly face availability barriers for both home- (60% vs. 20% urban) and residential care (27% vs. 18% urban), emphasizing the need for increased investment in long-term care infrastructure outside of cities. Quality remains a less reported barrier to care than cost or availability, likely the result of limited experience with care amongst respondents and general lack of information on services.

Share of respondents reporting barriers to accessing care services (in %)



¹Previous market research carried out by the Red Cross of the Republic of North Macedonia for Skopje and Southeastern region of the country.



INFORMAL CAREGIVING

Informal care is a prominent aspect of the North Macedonian long-term care system with personal experience with providing informal care most frequently reported by women (every 1 in 2 compared to 2 in 5 men) and by urban-living individuals (48% vs. 42% in rural areas).

There's a strong obligation among respondents to provide informal care in spite of negative impacts to one's health or career. More men reduced their working hours as the result of caring (33%) than women (25%), whereas an equal share quit their job completely (1 in 10). This is likely the result of lower labour force participation among women in general due to care obligations. Similarly, slightly more men felt obligated to provide care despite detrimental effects to their health (81% vs. 77%). This is at odds with the EU-level results, where more women reported pressure to provide care than men (66% vs. 50% for men), alongside consistent findings from academic literature that women bear a larger burden of informal caregiving. This could reflect a sample bias in the survey towards men with care experience, but may also indicate difficulties among men to reconcile their role in care against traditional internalized gender roles.

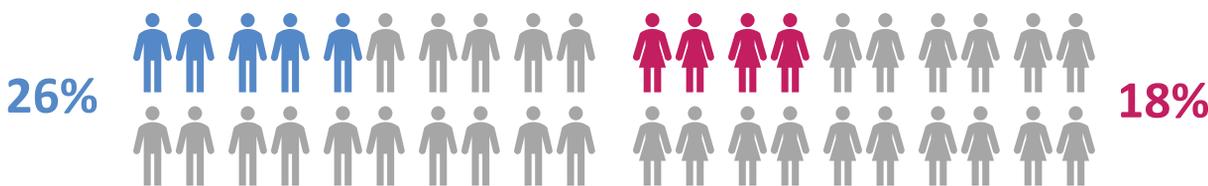
Despite the higher share of informal caregiving reported in urban areas, people in rural areas were more likely to reduce their work (47% vs. 25%) or quit their jobs completely (13% vs. 11%) due to informal care giving, highlighting the lack of formal support systems in rural areas.

Share of respondents who perceive pressure to provide informal care (by gender, in %)



While informal care continues to be a crucial aspect of the North Macedonia long-term care system, **there is an overall preference for a system that places less burden on families.** Many do not feel individuals should have to sacrifice their career (81%) or health (77%) in order to provide informal care for a loved one. Those under 30 (31% vs. 15% for 65+) and men (26% vs. 18% women) were most willing to sacrifice their career to provide care. When care is provided within a family, 7 in 10 would prefer an equal division of responsibility among family members. This sentiment is equally shared among men and women and most strongly supported by younger respondents (84%).

Share of respondents who agree that "Care should be provided by close relatives of the older person with care needs, even if that means that they have to sacrifice their career to some extent"



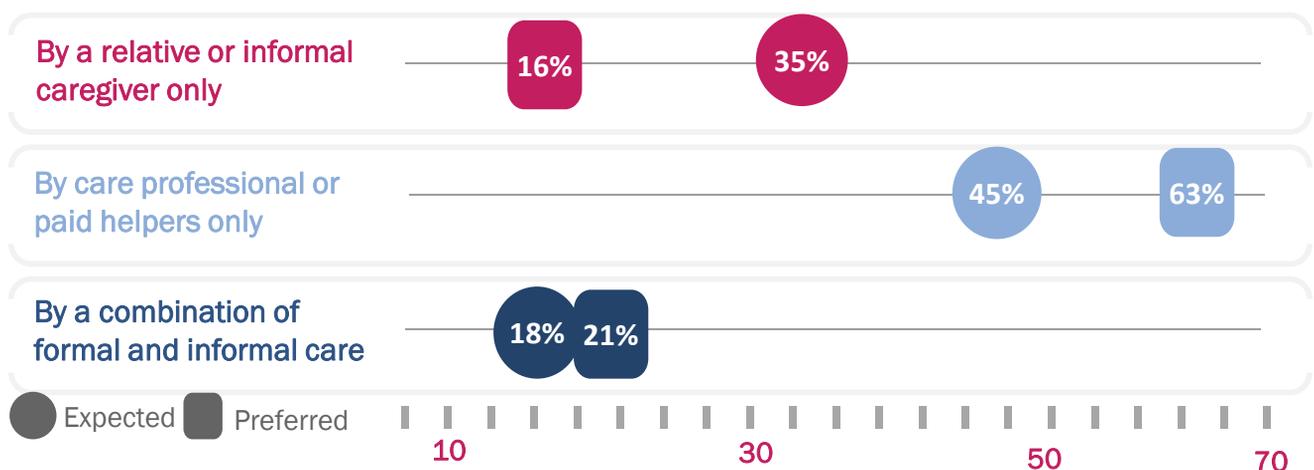
PREFERENCES & EXPECTATIONS OF LONG-TERM CARE

Against the background of high expectations of receiving informal care and general distrust in social services, there is a moderate level of trust that individuals will receive the appropriate long-term care they need in future (61%), marginally higher than at the EU-level (54%). While 17% have full confidence in receiving appropriate care, a large share of respondents (44%) believe that their care needs will only be partially met. Trust in the system is highly gendered, with men expressing a higher level of confidence than women (73% vs. 59%). Many express uncertainty in assessing the ability of the long-term care system: about 18% of respondents are unable to judge if they'll receive the appropriate care, with women more uncertain than men (20% vs. 11%).

Despite the current reliance on informal care, there is a strong preference for formal care arrangements alone (63%) and substantially less so for mixed care arrangements (21%) and for informal care (16%). Within formal care services, many express a preference for care in one's own home (39%), followed by in an institutional setting (24%). Gender differences in preferences are also evident: Men express a stronger preference for informal care (18% vs. 11%) and mixed care arrangements (26% vs. 21%), while formal care arrangements in the community are more popular among female respondents (43% vs. 30%).

Although individuals are somewhat confident they will receive the appropriate long-term care needed, there is a severe gap between how respondents prefer and expect to be cared for: **4 in 5 do not expect to receive their preferred type of care in older age**. This is entirely explained by the high proportion of people preferring formal care arrangements, but expecting to be cared for informally by relatives alone. A much higher share of citizens of North Macedonia expect to receive informal care by family/relatives than would prefer this type of arrangement (19 percentage point gap). These discrepancies highlight a lack of formal care infrastructure, both in the community and in institutional settings, alongside a strong reliance on informal caregiving as a fallback option.

Preferred and expected care arrangements (share of respondents, in %)



ATTITUDES TOWARDS CARE PROVISION

According to respondents, formal care arrangements are the best care arrangement for a person who can no longer live without regular help/support. Nearly one-third of respondents rate visits by public and private sector providers as the best option, followed by 27% that think an individual should move to a residential care facility. **The strong role of the family in providing care is particularly evident in rural settings where care services are less developed:** Respondents from rural areas are most likely to identify moving in with one's children as the most preferable option for older adults requiring regular help (43% vs. 12% urban).

There is widespread support for providing sufficient financial and social protection for informal carers: 9 in 10 agree that informal care should be recognized as formal employment, entailing social insurance and a stable income, and that the state should financially support informal carers who must reduce or quit their work to provide care. The perception of gender roles and women as natural carers was also prevalent: One-third of respondents (only marginally higher than at the EU-level) believed that care giving roles come more naturally to women than to men.

Share of respondents who agree that "Caregiving roles are more natural for women than for men"



FINANCING LONG-TERM CARE

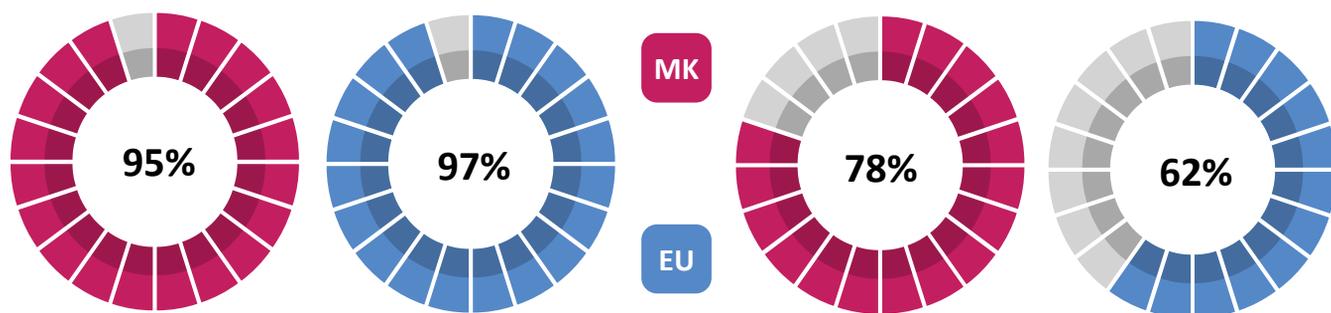
The vast majority of respondents (95%) believe that public authorities should organize and provide appropriate care for older people in need, on par with the EU-average (97%). In terms of mechanisms for financing long-term care, 78% agree that every individual should contribute to an insurance scheme that would cover their care costs if needed, considerably higher than at the EU-level (62%). Despite widespread support for publicly financed care services, a majority (56%) still place financial responsibility on children to cover their parents' care costs if needed. Younger respondents were most likely to believe that children should finance the care of their parents if needed (69%), followed by older individuals aged 60+ (56%) and middle-aged adults (53%). Few supported the use of assets to cover care costs when income is insufficient (14%).

The strongest preference concerning financing care is for the state to cover either full or basic costs of home and residential care services (75% vs ~50% EU-level). Fewer individuals support means-tested cost-sharing arrangements, where individuals would pay for care services based on their wealth and income (21% vs. 33% EU-level).

While there are limited gender differences in opinions towards the state's responsibility in financing care services, generational differences exist. Older adults (aged 65+) were most likely to support full coverage by the state, while younger individuals (30 and younger) were most likely to support basic coverage with the option of buying better care for those who can afford it.



Share of respondents who agree with the statements ...



Public authorities should organise and provide appropriate home care and/or institutional care for older people in need

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

DISCUSSION

Availability and affordability of formal care services continue to be barriers for many, especially for those with low income and living in rural areas. This suggests a need for further investment in high quality formal services targeted to the needs of the population and increased financial assistance that shelters individuals from high costs. Incentivizing the entry and licensing of new service providers, expanding eligibility criteria for services, reducing care users' out-of-pocket payments and increasing the availability of publicly provided services are all initiatives that can serve to improve the availability and affordability of care.

Across Europe, the quality of care services provided has been a key issue. Although less of a reported-barrier by respondents in North Macedonia, it is crucial that the quality of formal care services continues to be improved. The Ministry of Labour and Social Policy in North Macedonia has already initiated projects to improve the quality of care in the country, including in care homes for older adults, day care centers for persons with disabilities, etc. In addition to improving care infrastructure, the provision of sufficient qualified staff needed for various has been one focus area of improvement.

Informal care continues to comprise a large portion of long-term care in North Macedonia and is still seen by many as the role of women. This is at the detriment of families, particularly those in rural areas with limited care infrastructure, with many feeling pressured to provide care despite a negative impact on their career and health/well-being. Alongside investment in support services for carers, the social rights and financial support for carers should be strengthened to ensure that informal care is a willing decision made without the risk of financial vulnerability.

Finally, there is a disconnect between the preferences and expectations of respondents, with many expecting to resort to informal care provided by family despite preferring formal care options. Preferences for formal care services and less responsibility on the family to provide care suggest that attitudes and preferences for care are changing within the country, likely influenced in part by the mass migration of the younger generation which renders traditional care patterns implausible. These attitudes also stand in contrast with the current legislation which outlines the legal obligation of families to provide care. As well as highlighting the need for investment in care services in a way that aligns with the attitudes and preferences of the public, these findings also emphasize the necessity of regular collection of representative data to ensure the design of the long-term care system aligns with public attitudes moving forward.



COMMUNITY VOICES



“The older population is in a very bad situation because home health care is hard to come by, people are experiencing financial problem when it comes to being placed in private homes for elderly, and the public homes for elderly do not have enough space nor provide the adequate conditions. Everything is based on the informal care of the family relatives/children, and we all need to manage this, although we must work full-time alongside this because of the seniority for retirement and salary.” – Woman, 56

“I hope that caregivers will get protected or priority status - I mean at work and as workers, everyone needs us, our attention, and we somehow feel like "omnipotent" care for others”. - Man, no age provided

“Most of these issues depend on the ability and organization of state institutions and the private sector dealing with that issue.” - Man, 57

“Only a small percentage of the population in North Macedonia is able to financially afford to have quality in [older age].” – Woman, no age provided



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.

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Gefördert aus den Mitteln des Fonds Gesundes Österreich

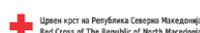
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