

***Impact of the
Covid-19
outbreak on***

***informal carers
across Europe***

Final report

May 2021



**EURO
CARERS**

European Association **Working for Carers**



Istituto
di Ricovero
e Cura
a Carattere
Scientifico

HEALTH
AND SCIENCE
ON AGING

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Introduction

This report presents the findings of an online survey targeted at the informal/family/unpaid carers of older, frail or disabled people across Europe regarding their experience during the COVID-19 crisis.

The aim of this study, promoted by [Eurocarers](#) in collaboration with the Centre for Socio-Economic Research on Ageing at [IRCCS-INRCA](#) (National Institute of Health and Science on Ageing, Italy), and with the support of the European Commission, was twofold. Its objective was indeed to:

1. Document and analyse how the COVID-19 outbreak impacted on informal/family/unpaid carers' health, caregiving situation, support networks, access to health and social services, working status, work-life balance and finances – among other aspects; and
2. Collect the views and recommendations of carers on how to better support them in times of a pandemic.

The online survey specifically targeted European informal/family/unpaid carers providing regular care and/or support (i.e. not occasional or temporary) to one or more people with their daily activities, personal care or in any other way due to their physical or mental illness, disability or old age.

The cross-national activities carried out to disseminate the survey were coordinated by Eurocarers, through its broad network of [member organisations](#) across Europe. Besides this core EU-wide recruitment channel, country-specific dissemination activities and strategies were put in place by both Eurocarers member organisations as well as partner organisations engaged in research and/or advocacy work regarding carers in order to respond to national/local specificities. Respondents were mainly recruited from among the membership of carer/patient organisations, or via them, by means of mailing lists, websites, newsletters, or through social media channels (e.g. Facebook groups or pages targeting informal carers and cared-for persons as well as Twitter). Local governments

and their social departments, local charities, welfare or voluntary organisations also contributed to the dissemination exercise at national, regional or local level. Moreover, whenever possible, the organisations involved were requested to share the survey on their website and social networks.

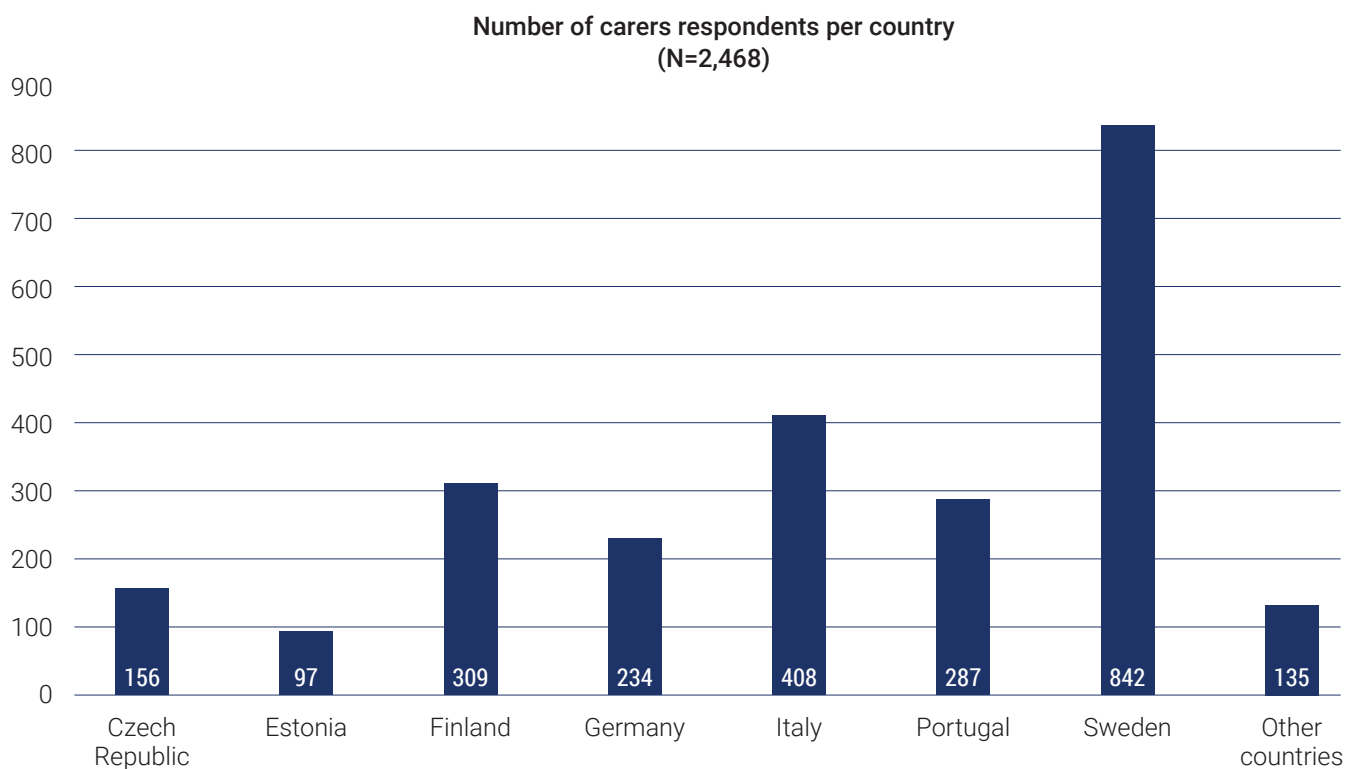
The questionnaire focused on the overall care situation of the informal carer providing care to a person due to his/her physical or mental illness, disability or old age. In some questions, however, should the carer provide support to more than one care recipient, reference was made to the person to whom the carer provided "the majority of his/her care" (also referred to as being the "primary carer").

In the data analysis, continuous variables were reported as mean, while categorical variables were expressed either as absolute number or as percentage. The analysis was conducted for the whole sample and, separately, stratified by: country, carer's gender, carer's age band and age band of the cared-for person.

Electronic Consent was requested from respondents who confirmed: 1) having read the background information to the study; 2) voluntarily agreeing to participate; 3) being at least 18 years old. All responses to the survey were collected anonymously, in compliance with the EU Regulation no. 679 of the European Parliament and of the Council, of 27 April 2016 and the Helsinki Declaration (2013).

The results presented in this report refer to the data collected between the 24th November 2020 and 8th March 2021 via the online survey available in 10 European languages (i.e. Czech, English, Estonian, Finnish, Finnish/Swedish, French, German, Italian, Portuguese, and Swedish). This report therefore builds on 2,468 questionnaires submitted by European carers from Czechia, Estonia, Finland, Germany, Italy, Portugal and Sweden as well as 'other countries' grouped together (i.e. Austria, Belgium, France, Ireland, Luxembourg, Slovenia, Spain, Switzerland, the United Kingdom)¹. The distribution of respondents is as follows: 842 in Sweden, 408 in Italy, 309 in Finland, 287 in Portugal, 234 in Germany, 156 in Czech Republic, 97 in Estonia and 135 in 'other countries' (Figure 1).

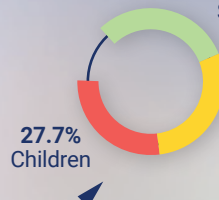
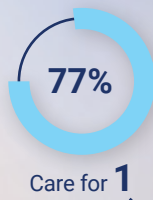
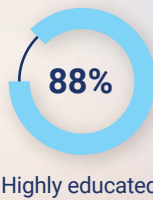
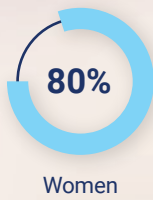
¹ This report includes only some of the tables and figures related to the collected data. The tables or figures not included here but discussed in this document can nevertheless be requested from the authors at m.socci@inrca.it. In some cases, the number of questionnaires completed by carers living in 'other countries' was not fully comparable to the seven other countries and it was therefore deemed unnecessary to present separate data for these countries.

Figure 1

The percentages reported in the document are calculated on the basis of the total number of respondents to each question (i.e. considering valid responses and excluding missing answers). The main characteristics of the sample are shown in the first section of the report, the main findings of the study are illustrated in the following sections, while the policy suggestions/implications emerging from the survey are presented in the last section. Moreover, the Annex section presents some key data for each country.

SOCIO-DEMOGRAPHIC AND PERSONAL INFORMATION ON SURVEY RESPONDENT(S) AND CARE RECIPIENT(S)

Out of respondents



30.3% Spouse/partner

29.4% Parents

11.8% - 18 years old

59.5% aged 65+

28.7% 18 - 64

Age distribution



60.8% feel that their health status has been negatively affected by their caregiving

63.4% of care recipients live with the carer

23.7% of care recipients live alone

Independence



Sources of care needs

Duration of caregiving

27.2% 5 - 10 years

32.4% 1 - 4 years

35.2% 10 years +

5.2% - 1 years

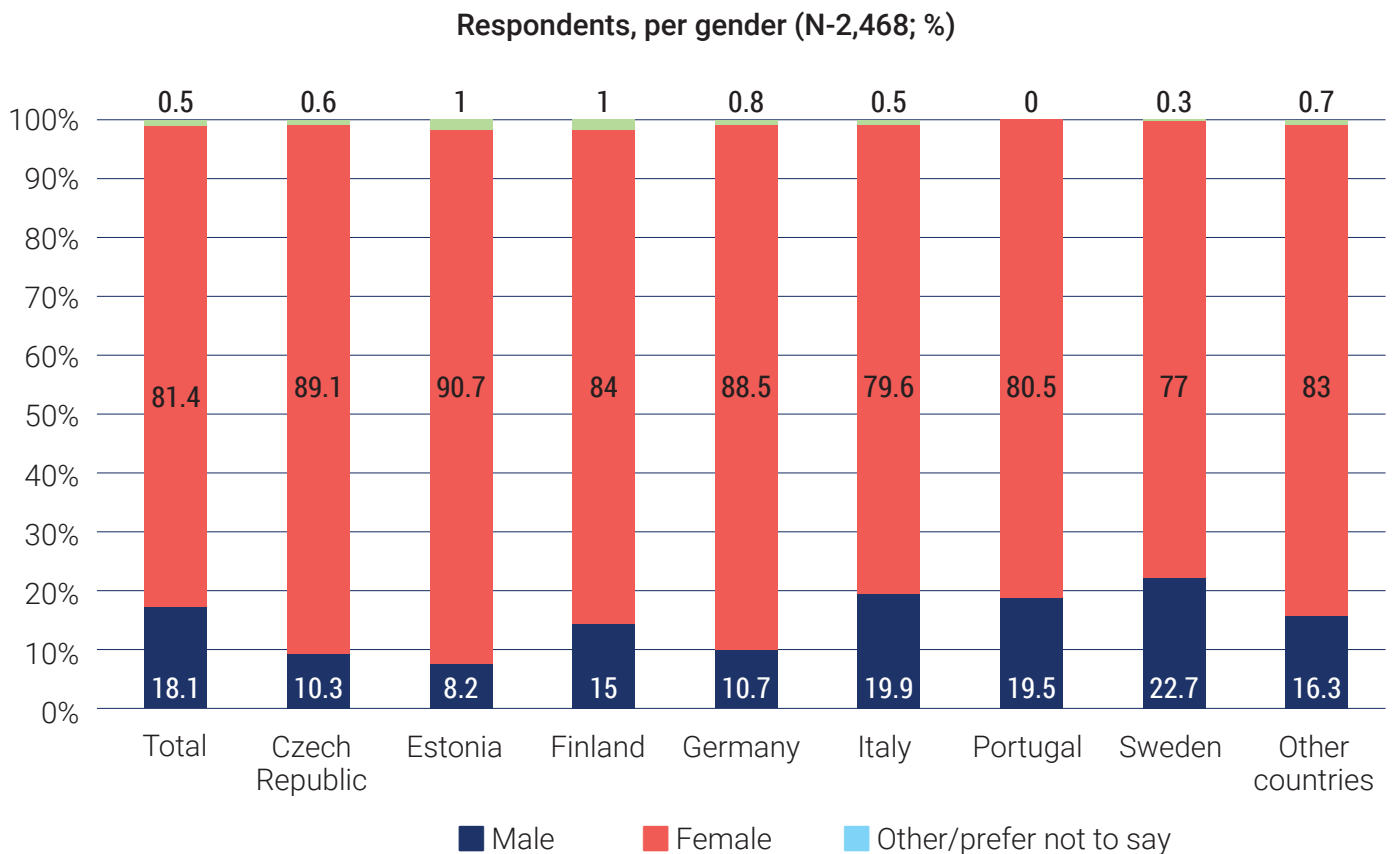
SUMMARY OF KEY POINTS

- Almost 80% of respondent are women; mean age: 57.3 years;
- Respondents are highly educated: 87.7% have at least 9 years of schooling (upper secondary education or university);
- Most respondents care for one person (77.5%), usually their spouse/partner (30.3%), parents (29.4%) or children (27.7%) including in-laws;
- Care recipients are equally distributed between genders; 11.8% are under 18 years old, 28.7% between 18 and 64 years of age, and 59.5% aged 65 or more; mean age: 60.5 years old
- Source of care needs: physical (64.8%), cognitive (46.5%), neurological (45.9%) or psychological conditions (45.9%), multi-morbidity is common among care recipients;
- 63.4% of care recipients live with the carer while 23.7% of them live alone;
- The average duration of caregiving is pretty long, with 35.2% providing assistance for more than 10 years, 27.2% between 5 and 10 years, 32.4% between 1 and 4 years, and 5,2% for less than 1 year;
- 3 out of 5 carers (60.8%) assert that their health status has been negatively affected by their caregiving.

Characteristics of Informal Carers

In our sample, **four out of five carers were women** (81.4%), with the highest percentages in Estonia (90.7%) and Czechia (89.1%) and the lowest ones in Sweden (77%) and Italy (79.6%). Men represented 18.1% of responding carers (highest value in Sweden, 22.7%) while 0.5% of respondents ticked the “other” or “prefer not to say” box when asked about their gender (Figure 2).

Figure 2



The mean age of carers was 57.3 years. Swedish carers were on average older (62.8 years) whereas Portuguese carers were younger (51.8 years).

Most carers were married or cohabitant (73.8%). That was especially the case in Sweden (82.7%) and less so in Portugal (57%), where the highest number of both single/unmarried (24.5%) and divorced/separated (16.8%) carers were observed. The latter attribute concerned a similar proportion of respondents in Czechia (16.7%) and Estonia (16.5%). The highest number of widow(er)s was recorded in Czechia (5.1%).

As regards the educational level of respondents, **half of them (50.2%) had a university degree**, Sweden and Portugal were the countries with the largest share of highly educated informal carers (57.7% and 57.3% respectively) while the Czech Republic and Germany presented

the lowest share (38.5% and 38%). **A large majority of respondents (87.7%) had at least nine years of schooling (upper secondary education or university)** with the highest values in Estonia and the Czech Republic (almost all respondents to this question in both countries) and the lowest share in Germany (67.1%).

Most carers live in the same household as their care recipient (63.4%), with a range spanning from 56.1% (Sweden) to 85.3% (Finland). This is partly related to the relationship between them, mostly as partners or parents/children. The second most common category relates to people living “not within walking distance, but less than 30 minutes one-way travel” (14.2%), with the highest percentage in Estonia (19.6%) and lowest in Finland (3.6%). This means that, when carers and care recipients do not live together, a relatively high geographical proximity exists between them.

Carers and care recipients “living in different households but in the same building” is a characteristic that was more commonly reported in Germany (10.7%) but was also notable in Czechia (9.6%), while this category was negligible in Finland and Sweden. It is interesting to note that 5.8% of Swedish respondents live at “over 1-hour one-way travel” from their care recipient, which can partly be related to the high number of care recipients living in a nursing home/residential home, group home, health facility, a group that amounts to 18.3% of the Swedish sample.

countries’ report a positive impact of their caregiving on their health status.

43.9% of respondents had links with or was a member of one or more carer/patient organisations, with higher percentages in Finland and Sweden (63.7%; 53.9%) and much lower rates in Portugal and Estonia (17%; 19.8%).

Those providing care to only one person represent 77.5% of the total sample (with a higher number in Finland, 88.9%, and lower in Germany, 70.5%), followed by **17.7% of respondents caring for two persons** (24.4% both in Czech Republic and in Germany and 9.5% in Finland). Overall, about one in five carers (22.6%) provides care to more than one person, and this is more frequent among female respondents (19.5%), compared to males (14.9%).

Carers who started providing care more than 10 years ago formed the largest group of respondents (35.2% overall; with higher percentages in Italy, 47.4%, and Estonia, 40.2%), while those who started 1-4 years ago amounted to 32.4% (higher percentages in Czech Republic, 36.8%, and in Portugal, 35.8%) and between 5-10 years ago to 27.2% (more in Finland, 31.6%). **The share of respondents who took on caregiving less than a year ago (thus during the pandemic) totals 5.2%**. All in all, female respondents and Italian carers have been caring for longer, while Portuguese carers got involved in caregiving more recently.

Almost half of respondents (49.4%) in the overall sample consider their own health status as “good or very good”, 32.4% as “neither poor nor good” and 18.2% as “poor or very poor”. National differences are manifest: a majority of carers in the Czech Republic (64.7%) consider their health status as “good or very good”, compared to only 21.4% of German carers. Thus, the poorest health status is reported by German carers (28.6%) who also more frequently express uncertainty about their health (50%).

Male respondents reported a better health status than females (57.9% of men assessed their health status as “good or very good” vs 47.5% of women).

Three out of five carers (60.8%) in the overall sample assert that their health status has been negatively affected by their caregiving; the percentage is much higher in Germany (76.4%), lower in Portugal (55.4%), and **much higher among female respondents (63.8%) compared to men (47.8%)**. It is worth mentioning that 16.3% of carers in the ‘other

Characteristics of care recipients

The gender of the person receiving the majority of the carer's care was almost equally distributed between males (50.4%), and females (48.5%) (1.1% answered other or preferred not to disclose their gender); in Finland though the share of men was substantially higher (64.8%) while, in Portugal, women formed the majority of the group (62.4%).

The mean age of care recipients was 60.5 years. Portuguese care recipients were older (72.6 years), while Italians were younger (52 years). As regards age brackets, three out of five care recipients (59.5%) were aged 65 or older (an age group that was over-represented in Portugal, 79.1%, and the Czech Republic, 71.6%, but was less present in Italy, 42.1%), 28.7% were adults (18-64) and 11.8% were under 18 years of age. In Finland, the proportion of young people was higher than in all other countries (22.8%), while it was the lowest in Portugal and Estonia (5.2%; 6.2%). In Italy, the shares of older and adult care recipients were similar (42.1% and 41.9% respectively), while the proportion of young care recipients amounted to 16%.

Spouses and partners were the main categories of people to whom informal care is provided (30.3% overall; with higher values in Finland and in Sweden, 47.7% and 46.4%, respectively), followed by parents (29.4% overall; twice as much in Portugal, 58.7%) and by children including in-laws (27.7% overall; lowest value in Portugal, 13.6%) (Figure 3). In Italy, the situation was quite the opposite, with care recipients consisting of children (including in-laws) (40.7%), parents (31.4%) and spouses/partners (13.7%).

The most frequent chronic diseases/health conditions underlying caregiving duties were: physical disabilities (70% overall; higher value in Estonia, 82.6%, and Germany, 82.1%), cognitive impairments such as Alzheimer's and dementia (51.2% overall; higher percentage in Germany, 70.1%), neurological disabilities or learning difficulties (50.6% overall; higher value in Finland, 65.2%), other chronic illnesses (e.g. diabetes, heart disease; 49.8%), psychological/mental health issues (47.9%) and other health problems due to old age (45.3%). Lower proportions of respondents reported other kinds of health conditions (Figure 4).

Relationship between carer and cared for person (N=2.458; %)

Figure 3

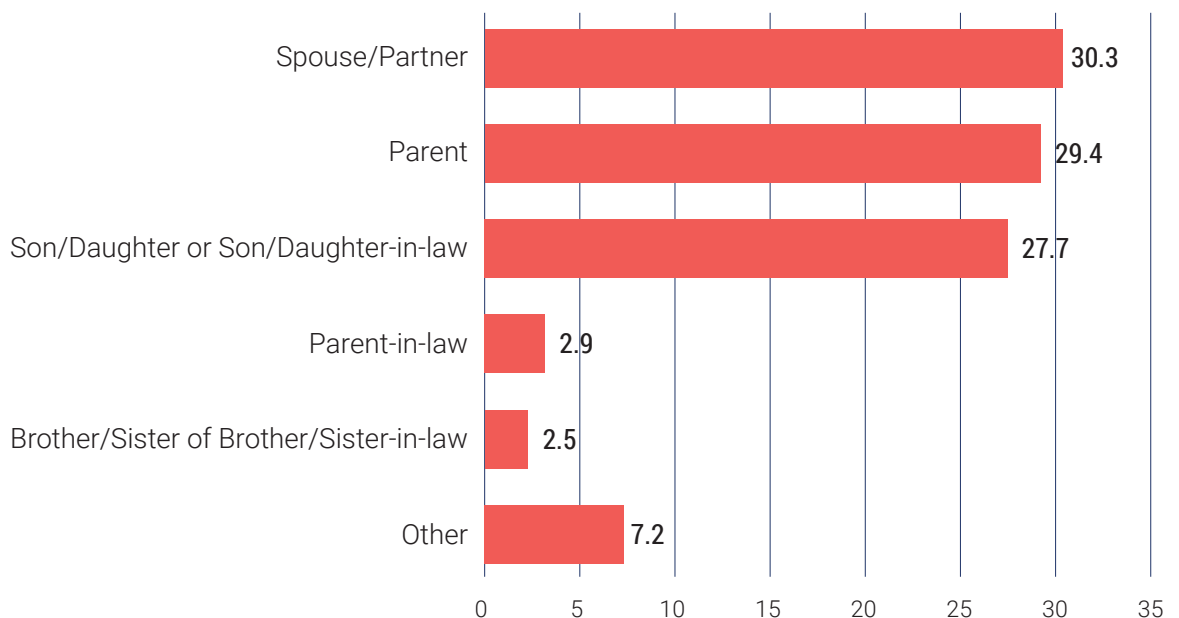
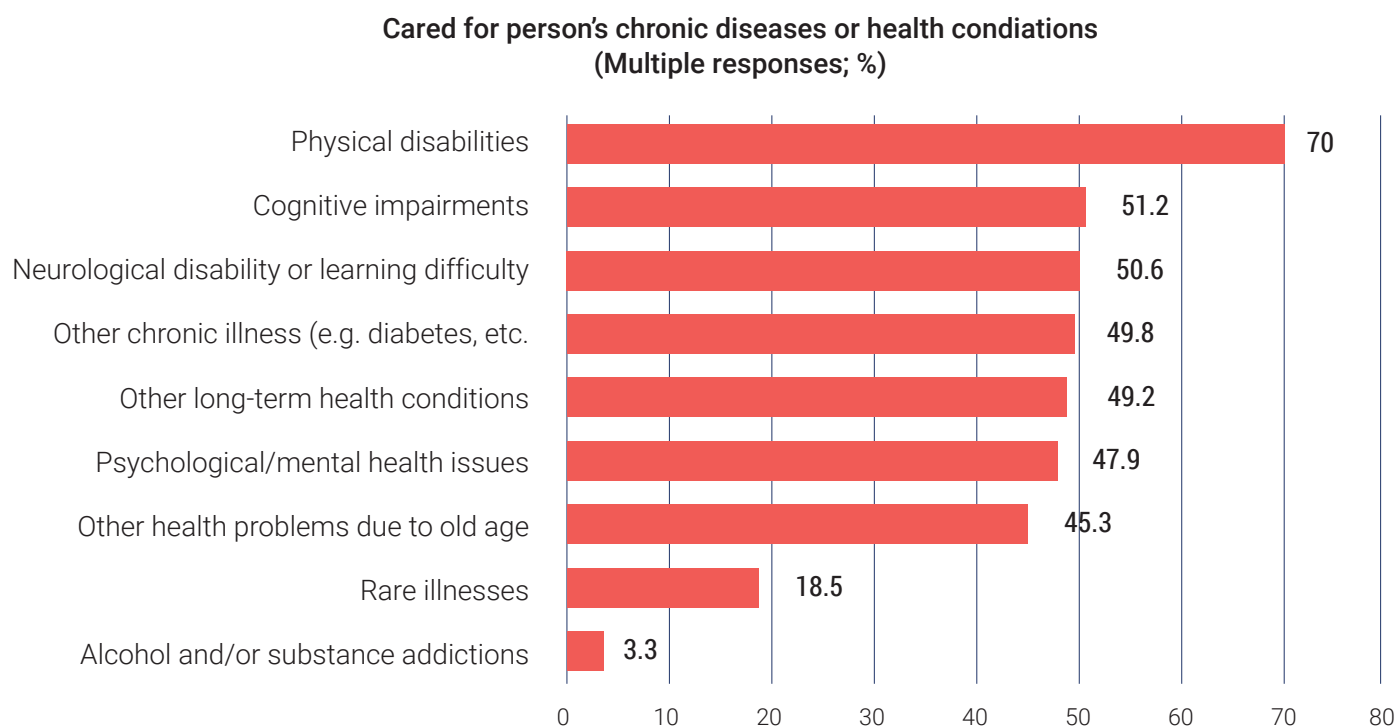


Figure 4



In contrast with the general trend, whereby **older people were more frequently affected by physical disabilities (75.7%) and cognitive impairments (64.5%)**, the **adult age cohort (18-64 years)** was most commonly affected by **neurological disabilities or learning difficulties (66.9%)**, **physical disabilities (65.3%)** and **psychological/mental health issues** (e.g. depression, anxiety, etc.) (51.8%). **Younger care recipients scored high in neurological disabilities or learning difficulties (83.3%)**. The pervasiveness of almost all **chronic diseases/health conditions** affecting care recipients was **higher in Germany** than in other countries, except for neurological disabilities and physical disabilities, which were more common in the Finnish and Estonian subsamples respectively.

Almost half of the care recipients live in their own home (49.2%), with high proportions in Portugal (71.2%) and Italy (64.6%) and lower ones in Sweden (39.1%). Almost one out of three care recipients (28.3%) lives in the carer's home, with higher percentages in the Czech Republic (47.4%) and Estonia (38.5%). 9.2% of care recipients live in someone else's house/apartment (mainly in Germany, 13.9%) while 7.9% live in a nursing home/residential home, group home, health facility.

According to the overall sample, **almost one in four care recipients (23.7%) lives alone**, with a more frequent occurrence in Estonia and Germany (38.1% and 31.3% of cases, respectively).

IMPACT OF THE COVID-19 OUTBREAK ON PERSONAL AND CARING CIRCUMSTANCES



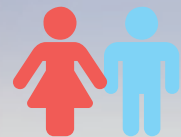
More than 10% of respondents started to provide care as a result of the pandemic



14.5%
of carers

14%
of carers recipients

have been infected by the COVID-19 coronavirus



The impact of the pandemic was more severe for women than for men



Average number of weekly hours of informal care provided



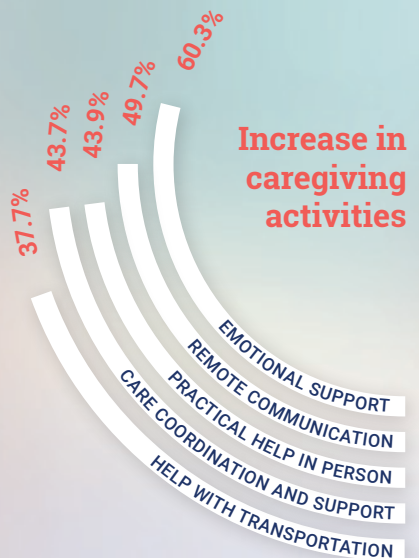
Carers concerned by the consequences of COVID-19 on their caring role



Only 17.5% of informal carers feel that their caregiving during the COVID-19 crisis has been well valued by society



61.7%
Carers feel overwhelmed



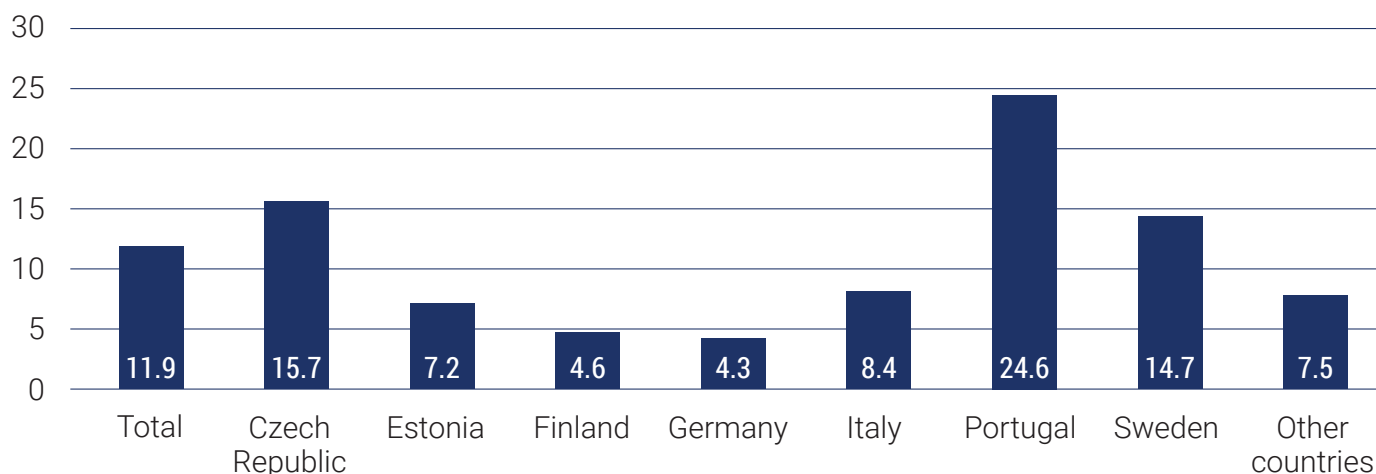
SUMMARY OF KEY POINTS

- More than 10% of respondents started to provide care as a result of the pandemic;
- 14.5% of carers and 14% of care recipients have been infected by the COVID-19 coronavirus;
- COVID-19 negatively impacted on the following aspects of the carer's life: social network/participation (78.7%); quality of life (76.8%); mental health/psychological state of mind (66.5%); access to health/social services for the care recipient (59.8%); and care recipient's health status (54%); the impact of the pandemic was more severe for women than for men;
- The average number of weekly hours of informal care provided has increased from 46.6 before the pandemic to 54.5 (+17%), with women experiencing a higher increase than men;
- During the pandemic, informal carers, and especially women, have had to intensify their caregiving activities, in particular their emotional support (60.3%), remote communication (49.7%), practical help in person (43.9%), care coordination and support (43.7%) and help with transportation (37.7%). This took place in the context of reduced support from health and social services and the challenges posed by the COVID-19 outbreak (e.g. social isolation, containment measures, etc.);
- A huge majority of carers (90.6%) are concerned by the consequences of COVID-19 on their caring role and on their personal and caring circumstances (e.g. what would happen to the care recipient should they have to self-isolate or be infected by COVID-19?);
- Most carers (61.7%) feel overwhelmed as a result of the pandemic and just about half of them (51.5%) feel "able to look after their own health and wellbeing";
- Only 17.5% of informal carers feel that their caregiving during the COVID-19 crisis has been well valued by society, just like the one of healthcare workers;
- About 30% of carers providing care to an older person report witnessing occasional or regular instances of ageism towards the care recipient by social and/or health care providers.

More than one out of ten (11.9%) informal carers report that they started providing care as a result of the COVID-19 outbreak in the total sample (the proportion reaches 24.6% in Portugal). This underlines an increase in the number of informal carers across Europe as a result of the pandemic (Figure 5).

Figure 5

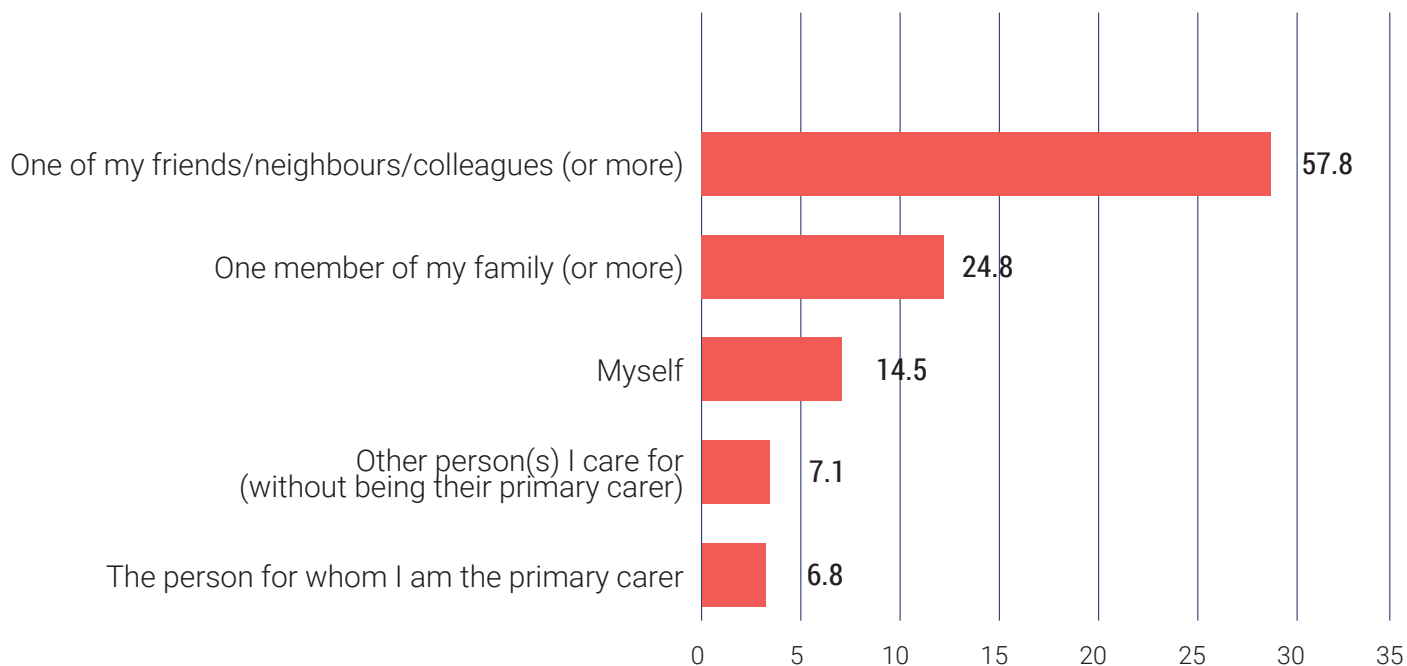
Carers who started providing care due to COVID-19 outbreak, per country (N=2,451; %)



14.5% of responding carers have been infected by COVID-19 in the overall sample (with peaks of 29.4% in Czechia and lows of 2.7% in Finland), which has not only caused personal health problems to them but negatively affected the caring conditions and quality of care that they provide to their loved one(s). A lower number of **care recipients for whom the carer is the primary carer were infected overall (6.8%)**, even though almost three times that amount was observed in Czechia (21.6%). **Other people receiving care from the same carer were infected in 7.1% of cases** (15.4% in Czechia). In cases when care recipients were infected, it is likely that the burden of care increased markedly. Almost one out of four carers (24.8%) state that other members of their family were infected, in particular in Czechia (55.2%) and Portugal (43.5%), while more than half of carers (57.8%) on average report that one of their friends, neighbours or colleagues was infected (89.3% in the Czech Republic and 71.8% in Portugal). It should be noted that Finland was the country with the lowest number of infected persons reported in the study. This seems to indicate that the measures put in place by families to prevent contagion (in addition to the containment policies implemented by the government), may have acted as a protective factor against the consequences of the pandemic (Figure 6).

Figure 6

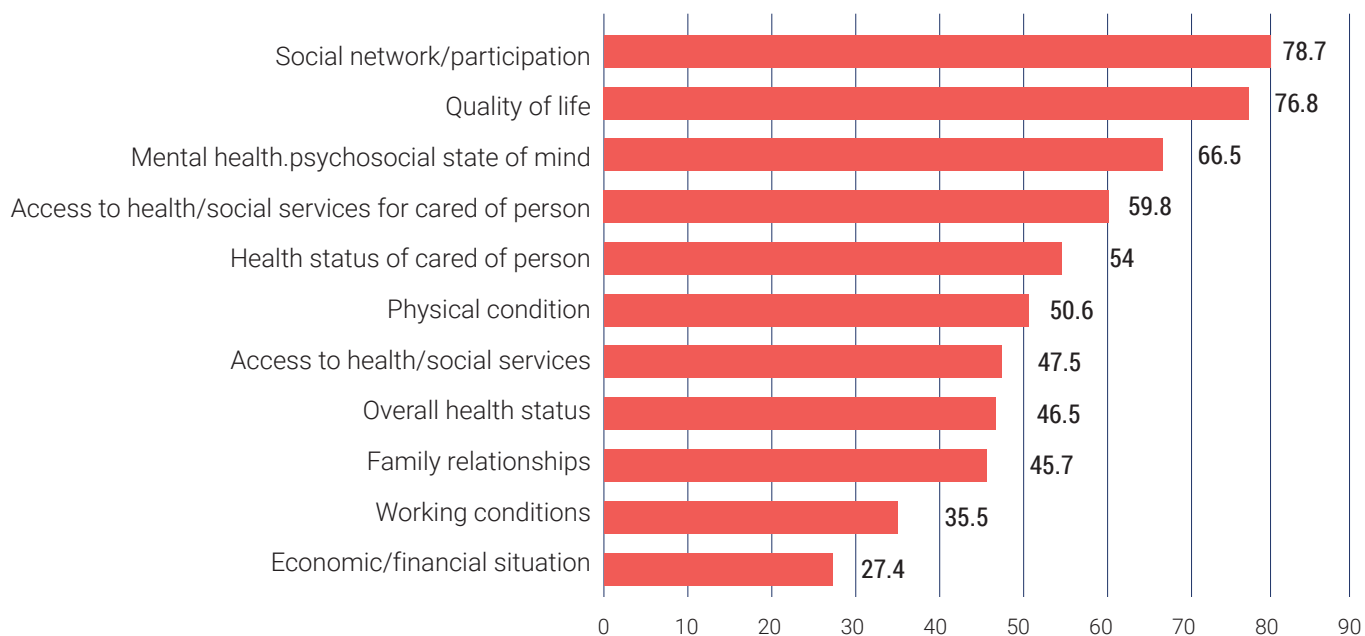
**Have you or somebody you know been infected by the COVID-19 virus?
(Multiple answers; %)**



The COVID-19 outbreak mostly had a negative impact on the following aspects of the carer’s life (Figure 7): **“social network/participation”** (78.7% overall; higher in Finland, 83.7%); **“quality of life”**, and **“mental health/psychological state of mind”** (76.8% and 66.5% overall, respectively; higher values in Germany); **“access to health/social services for the care recipient”** (59.8% overall; higher in Italy, 75.6%) and the care recipient’s **“health status”** (54% overall; higher in Germany, 59.9%).

Figure 7

The impact of the COVID-19 outbreak on informal carers’ and care recipients’ life realms (% of respondents)



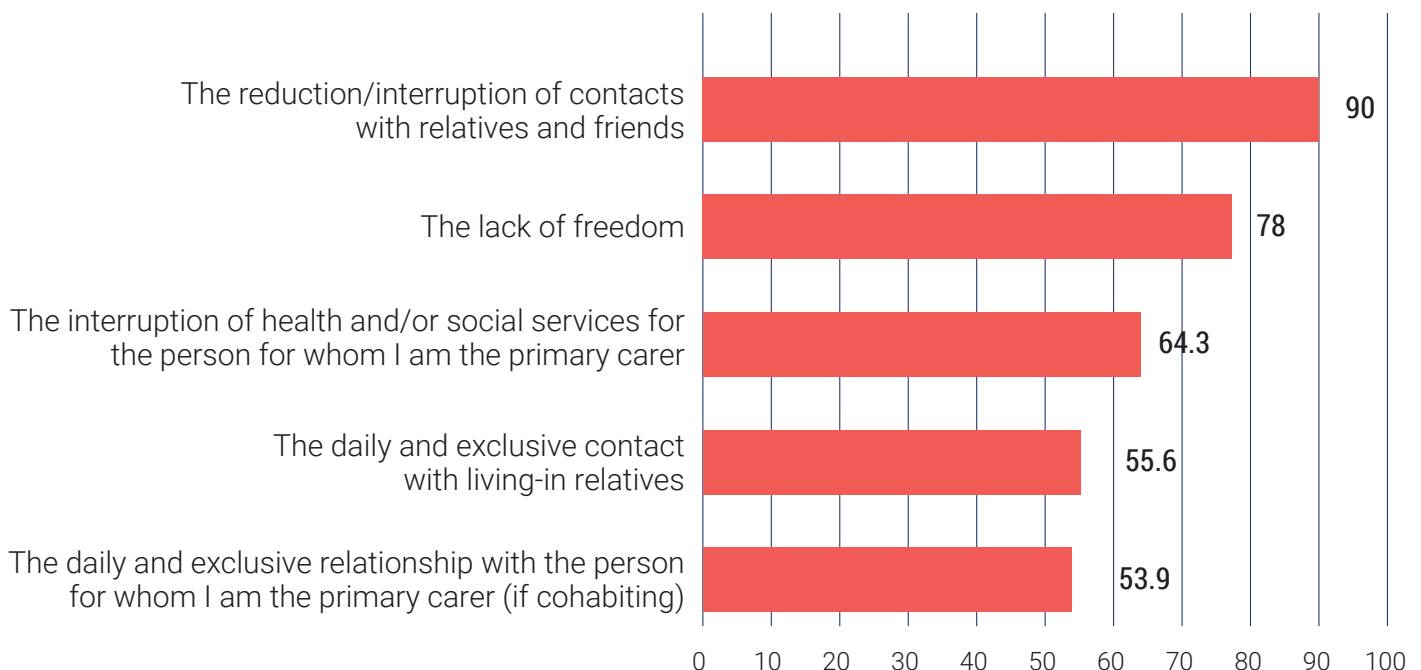
Consistent with what was observed with carers' self-reported health status, German carers show the worst rating in various aspects explored by the survey, while Portuguese carers report the most negative impact of COVID-19 on their "access to health/social services for themselves", "family relationships" and "working conditions". Estonian carers score very high (more than twice the overall percentages) vis-à-vis the impact on their "economic/financial situation" and "education/training conditions". Italian carers were the group most affected in their "access to health/social services for the person for whom they are the primary carers" (75.6%).

It is important to note that **the impact of the pandemic was more severe for female carers in all aspects of the caregiving experience than for their male counterparts** (e.g. 68.7% of women reported a worsening of their mental health/psychological state of mind compared to 56.7% of men, this being the item where the difference between genders was higher, +12%, followed by "overall health status" +11.4% and "physical conditions" +9.3%).

The elements that most affected the caring situation and carer's quality of life at the peak of the first wave of the pandemic (Spring 2020), following the introduction of strict containment measures, were: "the reduction/interruption of contacts with relatives and friends" (90% overall; 93.8% in Sweden); "the lack of freedom or feeling of being trapped at home" (78% overall; 82.1% in Portugal); "the interruption of health and/or social services for the care recipient" (64.3% overall; 78.1% in Estonia); "the daily and exclusive contact with relatives or with the cared for person (if cohabiting)" affecting more than half carers (Figure 8).

Figure 8

What do you think impacted more on your caring situation and your quality of life during the first peak of the COVID-19 outbreak (in Spring 2020)?
(Multiple responses; %)



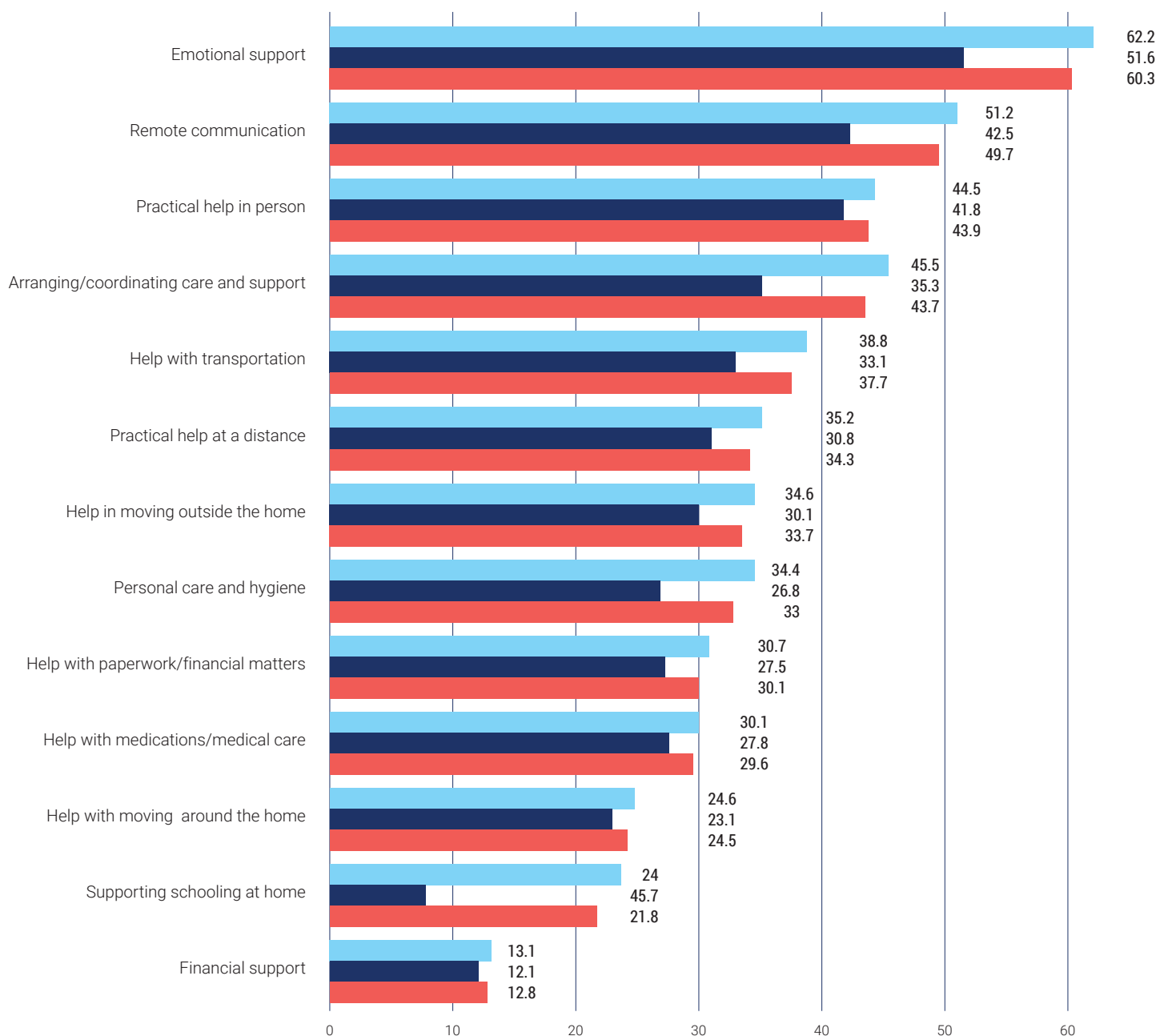
The number of weekly hours of care has increased in all countries following the COVID-19 outbreak. **Considering all care recipients (if more than one), the average number of weekly hours of informal care provided has increased from 46.6 before the COVID-19 outbreak to 54.5 by the time of the survey**, with significant differences among countries. The highest values were recorded in Finland (70.1 before and 75.1 after the outbreak, a 5% increase) while the lowest were reported in Sweden (31.4 before and 34.9 after the outbreak, a 3.6% increase). The highest increase was observed in Portugal (+15.5%) and in Germany

(+13.9%). **Women experienced a higher increase in the average number of weekly hours of care compared to men** (from 47.9 to 56.5 and from 39.2 to 45.2, respectively).

Since the beginning of the COVID-19 pandemic, informal carers have experienced important increases in the intensity of care provided to their care recipients, especially for some activities (see Figure 9).

Figure 9

Increased intensity in care activities provided by the carer since the start of the COVID-19 outbreak (% on total and per gender)



The care activities where informal carers report increased intensity since the start of the pandemic include “emotional support” (60.3%), **“remote communication”** (e.g. by telephone, mobile phone, PC, etc., 49.7%), **“practical help in person”** (e.g. preparing meals, shopping, laundry, housework, etc., 43.9%) and **“arranging/coordinating care and support”** (43.7%). The provision of greater “emotional support” was especially reported by carers from Germany and ‘other countries’ (76.5% and 71.9%, respectively), compared to those from Italy (65.3%), Portugal (63.4%) and especially Estonia, Sweden and Finland (54.6%, 54.5% and 50.5%, where values are below average). “Remote communication” was also listed as an intensified care activity by carers from Germany, ‘other countries’ and Italy (59.7%, 55.3% and 53%, respectively) compared to Scandinavian respondents, for whom the increase was below the European average (i.e. 46.5% in Sweden and 41% in Finland). Aside from “emotional support” and “remote communication”, the majority of carers report that the intensity of the care they provide has remained the same - on average - since the start of the outbreak. However, as mentioned already, “practical help in person” and “arranging/coordinating care and support” are tasks where a significant intensification was also recorded

compared to pre-pandemic times (43.9% and 43.7%, respectively), especially, in the samples from Germany, Portugal and ‘other countries’ when it comes to the former task, and German, Italian and ‘other countries’ respondents, concerning the latter one. Other types of care activities that have been reported as more intense by about one third or more of the total sample of respondents are: “help with transportation” (e.g. for shopping, going to the GP, etc., 37.7%), “practical help at a distance” (e.g. arranging for food and medication/drugs deliveries, etc., 34.3%), “help in moving outside the home” (e.g. walking, etc., 33.7%), “personal care and hygiene” (33%), “helping with paperwork/financial matters” (30.1%). For all the above-mentioned care activities, the intensification was systematically higher among female than male respondents (e.g. the increase of emotional support was reported by 62.2% of women and by 51.6% of men).

Carers were also asked to indicate to what extent they agreed (“strongly/quite agree”) or disagreed (“strongly/quite disagree”) with some statements regarding their feelings on how the COVID-19 outbreak impacted on their caring role and personal and caring circumstances (Table 1).

Table 1. To what extent do you agree or disagree with the following sentences?

	Strongly/Quite agree	Undecided	Strongly/Quite disagree
I am worried about what would happen to the person(s) for whom I care should I have to self-isolate or become ill due to COVID-19	90.6	5.6	3.8
I am worried about my ability to care safely due to a lack of knowledge, information or equipment about COVID-19	41.8	20	38.2
I feel able to manage my caring role at the moment	69.6	17.3	13.1
I feel able to look after my own health and wellbeing	51.5	20.4	28.1
I am worried about my financial situation due to COVID-19	30.4	23.7	46
The COVID-19 outbreak made me feel alone, socially isolated or lonely	64.5	16.4	19.1
I feel overwhelmed due to the COVID-19 outbreak	61.7	20.3	18
I am satisfied with my social life	15.6	17.1	67.3
I am worried about a possible decline in the physical and mental health of my care recipient(s) due to the COVID-19 outbreak	78.2	12.7	9.1
I feel that during the COVID-19 crisis my work as an informal carer has been well valued by society, just like that of healthcare workers	17.5	23.7	58.8

Results show that **90.6% of respondents agree with the statement “I am worried about what would happen to the person(s) for whom I care should I have to self-isolate or become ill due to COVID-19”** (highest percentage in the Italian sample, 96%; lowest in the Swedish one, 84.9%). This may be connected to the fact that **about four out of five carers (78.2%) are “worried about a possible decline in the physical and mental health of their care recipient(s) due to the COVID-19 outbreak”** (higher values observed in Estonia and Portugal, 90.7% and 87%, respectively; lowest in Czechia, 59.4%).

About four out of ten carers (41.8%) are “worried about their ability to care safely due to a lack of knowledge, information or equipment about COVID-19” (highest value in Estonia, 66%, lowest in the Czech Republic, 25.3%), while 38.3% of respondents disagree with this aspect and 20% are undecided. Only in Czechia, Germany and Sweden did the majority of carers disagree with this perception.

Interestingly, at the time of the survey completion, **about seven out of ten (69.6%) carers felt that they were “able to manage their caring role”**. This feeling was confirmed in all country samples, with higher percentages in Finland (81.3%) and the Czech Republic (80.7%), and the lowest share in Germany (56.6%). **In spite of this, 61.7% of carers “felt overwhelmed due to the COVID-19 outbreak”** (highest values reported in Sweden and Portugal, 73.6% and 69.1%, respectively; lowest in Finland and Germany, 44.1% and 43.7%). **Perhaps related to this, only just half of respondents (51.5%) felt “able to look after their own health and wellbeing”** (higher values in Portugal and Italy, 61.3% and 59.5%) while 28.2% disagreed (mainly in Estonia, 37.1%, and Germany, 37.8%) and 20.4% were undecided. Germany is the only country where the majority of respondents felt unable to take care of their health and wellbeing (the highest share of undecided carers about this aspect was also observed there).

Nearly two out of three carers (64.5%) state that “the COVID-19 outbreak made them feel alone, socially isolated and lonely” (higher percentages were observed in Italy, 75.4%, and Finland, 69.2%; lower in Estonia and the ‘other countries’ group, 56.3% for both). **This echoes with the high proportion of respondents (67.3%) who do not feel “satisfied with their social life”** (mainly in Portugal and Czechia, 73.7% and 71.2%, less so in Estonia and Germany, 60.4% and 58.7%, respectively).

30.4% of carers stated that they feel “worried about their financial situation due to pandemic”. This was especially the case in Estonia (57.8%), Italy (47.7%) and Portugal (47%), the countries where, together with the Czech Republic (39.6%), a majority of respondents support this statement. Overall, 46% of respondents refuted feeling that way (with a peak in Sweden, 62.6%) while 23.1% of respondents were undecided in relation to this aspect.

Even though carers have played a key role in providing assistance to their frail loved ones during the pandemic, while having to deal with an even more adverse context (e.g. difficulties in accessing and receiving public or private health and/or social services - see chapter 3 - physical distancing imposed by governmental containment measures for

facing the consequences of the outbreak, etc.), **only 17.5% of respondents “feel that their work as informal carers has been well valued by society, just like the one of healthcare workers, during the COVID-19 crisis”** (lowest value among the German sample, 7.3%; highest in Italy, 28.1%).

During the COVID-19 pandemic, **ageism**, while not widespread, was reported by the sub-sample of carers who provide care to an older person (N=1,419). Indeed, **9.9%** of respondents state that they have witnessed **regular** examples of discrimination towards people on the ground of age by social and/or health care providers and **18.3%** report having noticed **occasional** occurrences. Ageism was more frequently reported in Germany (15.3% “often”; 19.4% “sometimes”), Italy (11.8% “often”; 24.9% “sometimes”) and the Czech Republic (14.5% “often”), but was least apparent in Estonia (1.8% “often”; 12.5% “sometimes”).

IMPACT OF THE COVID-19 OUTBREAK ON HEALTH AND SOCIAL SERVICES FOR CARERS AND CARE RECIPIENTS



48%
carers benefited from the support of public or private health and/or social services

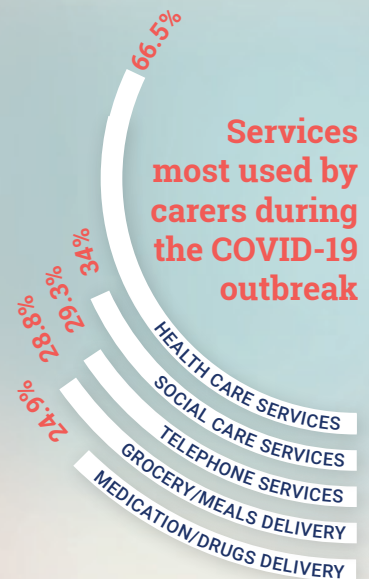


Difficulties in accessing public or private care services **for themselves**



Difficulties in accessing services **for the care recipient**

Most effective sources of support to carers during the pandemic



58.5%
carers not sufficiently supported in their caregiving



SUMMARY OF KEY POINTS

- Almost half (47.6%) of responding carers benefited from the support of public or private health and/or social services, while 31.9% reported that this service provision decreased after the outbreak;
- 29% of carers report that they experienced difficulties in accessing public or private care services for themselves while 37.1% faced difficulties in accessing services for the care recipient;
- The (public or private) services most used by carers to support them in their caring role during the COVID-19 outbreak include: health care services (66.5%); social care services (34%); counselling/information via helplines and telephone services (29.3%); grocery/meals delivery at home (28.8%); medication/drugs delivery at home (24.9%);
- In their daily caring routine (i.e. before the pandemic), 60.3% of informal carers reported being mainly supported by other informal carers (e.g. family members, friends and neighbours), 44.3% by public or private health and/or social care services professionals, and 13.4% by the paid personal assistant(s) of the care recipient(s);
- More than half (58.5%) of carers feel that they are not sufficiently supported in their caregiving;
- The five most effective sources of support to carers during the pandemic were: family members (42.2%); pharmacists (40.1%); friends and neighbours (21.7%); general practitioners (20.8%); and public health services/professionals (17.9%).

Nearly half of respondents (47.6%) across the countries captured by the study benefited from the support of public or private health and/or social services in their caring role. The highest percentage was observed in Finland (77.6%), followed by Germany (49.8%), Italy (47.3%) and Sweden (44.2%). Portugal is the country where the smallest share of respondents benefitting from public or private support in their caring role was observed (26.9%).

Considering those who - at the time of the survey - benefitted from the support of health and/or social services (1,159 people overall; almost half of the sample), 50.8% state that services have remained the same since the peak of the COVID-19 outbreak in the Spring 2020, while 31.9% declare instead that the level of service has decreased. The cut in services was especially reported by respondents from Italy (44%), 'other countries' (43.5%), and Portugal (33.8%). In Finland, one out of five carers reported an increase in the services received.

More than two out of five respondents (45.2%) say that they have "never" or "seldom" experienced difficulties **in accessing and receiving public or private health and/or social services for themselves** during the COVID-19 outbreak. However, almost one in four (25.8%) has experienced difficulties "sometimes", while **29% have encountered difficulties "often" or "almost always"**. The highest percentage of informal

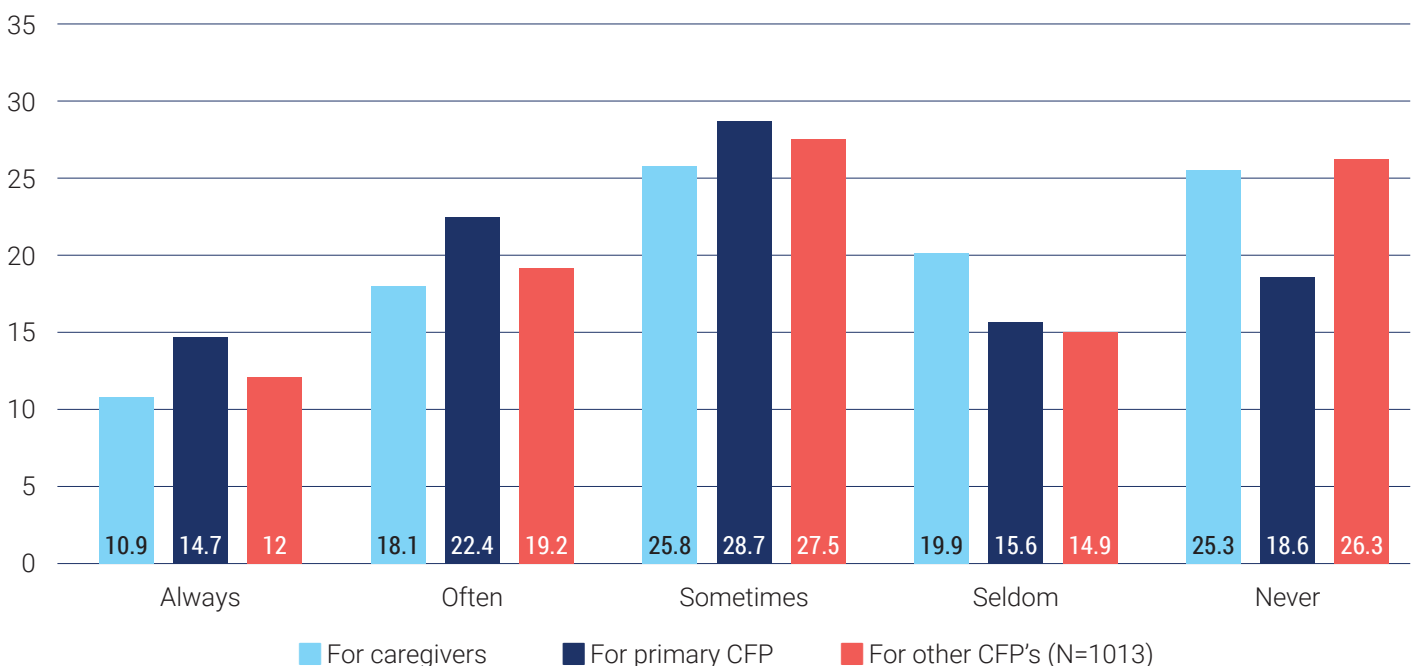
carers facing difficulty in accessing services for themselves "almost always" was found in Italy (21.3%, or more than 10 points above the total sample's average of 10.9%), while the largest share of informal carers reporting that they have never experienced problems in accessing services for themselves during the pandemic was observed in Sweden (38.9%).

When asked about difficulties related accessing and receiving public or private health and/or social services for the **primary care recipient, 37.1% of respondents report facing problems "almost always" (14.7%) or "often" (22.4%)**, 28.7% "sometimes", 34.2% "seldom" (15.6%) or "never" (18.6%) (Figure 10). Remarkably, more than half of the Italian sample (55.5%) and 45.7% of Estonian respondents experienced problems with receiving and/or accessing services for their primary care recipients "almost always" or "often", compared to 27.7% and 25.6% of their Swedish and Finnish counterparts respectively

When more than one care recipient is present, the percentage of carers reporting problems in accessing and receiving public or private health and/or social services for non-primary care recipients "almost always" or "often" amounted to 31.2%, with more frequent difficulties in Estonia (53.7%) and Italy (48.2%), compared to Finland and Sweden (20.2% and 20%, respectively).

Figure 10

Frequency of difficulty experienced by Informal Carers when accessing services for themselves and the care recipient(s) (% of respondents)



Note: CFP=cared for person

The five public or private services most used by all respondents to support them in their caring role during the pandemic were: **health care services (66.5%); social care services (34%); counselling/information via helplines and telephone services (29.3%); grocery/meals delivery at home (28.8%); medication/drugs delivery at home (24.9%).**

This ranking is mirrored at country level, only with diverging percentages. The percentage of use of health-care services is indeed higher than the European average (66.5%) in Finland (90.2%), Estonia (82.3%), Sweden (73%) and Czechia (70.9%), while it is lower in Portugal (61.5%), Germany (53.5%), and Italy (37.6%), the country with the lowest percentage of healthcare service users among informal carers. These national discrepancies tend to decrease when focusing on the use of social services, although Germany, Italy and Portugal remain below the European average (34%) with 29.6%, 22.8% and 18.6% respectively, while Czechia (44.6%), Sweden (42.3%) and Finland (41.8%) surpass it.

Informal carers from Finland (48%), the Czech Republic (34.7%) and Germany (31.1%) report using counselling/information via helplines and telephone services more actively than other European respondents such as informal carers in Sweden (26.8%), Portugal (24.3%) and Italy (22%).

During the COVID-19 outbreak, grocery/meals delivery at home was quite common in the Czech Republic (39.7%), Sweden (33.8%), Germany (34.5%) and Finland (29.2%), and much less so in Italy (11.6%). Finally, medication/drugs delivery at home was a service used by 43% of informal carers in Germany, 33.2% of carers in Sweden, and just 14.7% and 14.4% of respondents in Finland and Italy.

In the cross-national sample, 59% of informal carers report that **service provision** for themselves or the people for whom they provide care has been **postponed** (principally in Finland, 66.3%; Portugal, 67.5%, and Italy, 79.3%). 55.2% state that they have **decreased**, 50.4% that they have been **cancelled**, and 50.2% of respondents consider that services have been **adapted** to the physical restrictions imposed by the pandemic (more than one answer was possible). Only 33.5% of respondents report that services have **increased or remained as they were before the crisis**. At country level, the Czech Republic, Italy and Finland show the highest share of informal carers reporting that services have been adapted (66.2%, 58.5% and 57%, respectively).

60.3% of all informal carers report being mainly supported by other informal carers in their daily care routine, e.g. family members, friends and

neighbours (most in Sweden and in Italy, about 60%). **44.3% of respondents report receiving support from public or private health and/or social care services professionals**, especially in Sweden (51.3%) and Finland (48.4%) and less so in Germany (32.5%) and Italy (31.6%). **Informal carers also receive support from the paid personal assistants** of the care recipient(s): 6.8% report to be supported by care workers with a migrant background, with a particularly high proportion of respondents being in that case in Italy (21.6%) in comparison to 0.4% of Czech, 2.1% of Finnish, 2.5% of Swedish and 3.3% of German respondents. When considering the amount of help provided by paid personal assistants to informal carers, 13.4% of respondents declare being supported by part-time paid assistants (mainly in Italy, 22.5%; Portugal, 17.4% and Finland, 17%), 6.7% of respondents receive support from full-time paid assistants (higher percentages in Italy and in Sweden, 8.9% and 8.8%, respectively), and 5.9% from paid personal assistants who live with the care recipient (higher percentages in Portugal, 11.9%; and Italy, 8.9%). Finally, just **6.1% of respondents benefit from the support of volunteers** (highest value in Germany, 12.6%; lowest in Estonia, 3.3%).

More than half of carers (58.5%) feel that they are not sufficiently supported by the above-mentioned actors (with the highest values in Estonia, 69.9%; Portugal, 65.3% and Italy, 62.7%). In contrast, 18% feel that they are well supported (more so in the Czech Republic, 22.9% and in Sweden, 21.3%).

However, the most effective support received by informal carers during the COVID-19 outbreak only partly matches the above-mentioned list of help providers. Indeed, **the five most effective sources of support during the pandemic** (i.e. deemed “very” and “extremely effective”) **include: family members (42.2%); pharmacists (40.1%); friends and neighbours (21.7%); general practitioners (20.8%); and public health services/professionals (17.9%)**. Interestingly, the latter group has slipped from the second to the fifth position in the ranking of the most effective services in support of carers during the extraordinary times of the pandemic, while pharmacists became a key and effective source of help.

Nevertheless, peculiarities were observed at country level.

In Finland, carers’ most effective help suppliers were pharmacists (57.3%), the family network (50%), and public health services/professionals (35.5%).

For German informal carers, the most effective support came from the family network (44.8%), pharmacies (42.6%) as well as friends and neighbours (25%).

Informal carers from Estonia also reported family members as the most effective source of support (44.5%), while pharmacies (23.7%) and friends/neighbours (16%) came second and third.

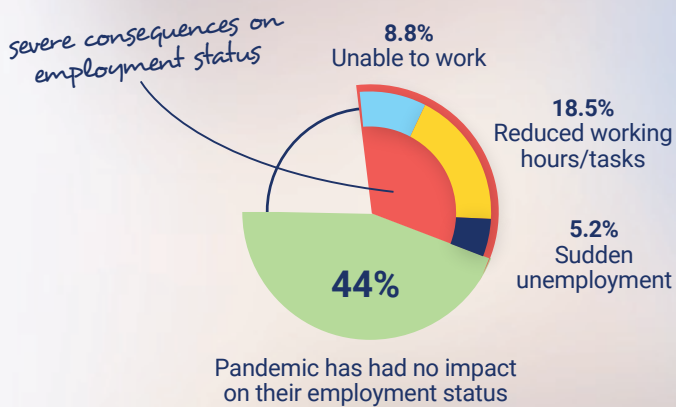
In Czechia, a very low number of respondents report using services in general. For example, only 47.6% are in contact with a carer organisation, 35.9% with a voluntary organisation and just 25% receive support from private care services/providers. As a result, the assessment of the effectiveness of available support by Czech respondents is quite low. Yet, family members and pharmacies come first on the list of effective sources of support, with a percentage of 15.5% and 6.2%, respectively.

The same applies to Portugal, where access to private and public services and support sources is low and family members (14.5%) as well as pharmacies (10%) are thus listed as the most effective support.

In Italy, family members (32%) and migrant/private care workers (21.6%) are reported as the most effective sources of support. The latter response is most frequently selected in Italy compared with other countries with a score 11.2 points above the cross-country average of 10.4%. This faithfully mirrors the percentage of Italian informal carers receiving routine support from migrant care workers.

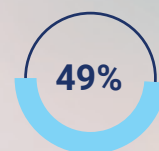
Finally, Swedish informal carers list family members (44.1%), pharmacists (39.1%), as well as friends and neighbours (22.6%) as their most useful sources of support.

IMPACT OF THE COVID-19 OUTBREAK ON WORKING STATUS AND FINANCES



Not able to reconcile paid work and caring responsibilities during the pandemic

Reconcile paid work and caring duties during the COVID-19 outbreak



Flexible working arrangements



Flexible working hours



Paid/unpaid leaves

SUMMARY OF KEY POINTS

- A minority of carers (44.1%) report that the pandemic has had no impact on their employment status;
- 32.5% of respondents state that the crisis has had severe consequences on their employment status: 5.2% became unemployed, 18.5% had to reduce their working hours/tasks, and 8.8% have been unable to work due to COVID or other illness; women have been more markedly affected than men;
- The most common measures available to carers to reconcile paid work and caring duties during the COVID-19 outbreak were: flexible working arrangements (49%), flexible working hours (30.9%) and paid/unpaid leaves (21.8%);
- Nearly 1 out of 5 carers (18.7%) has not been able to reconcile paid work and caring responsibilities during the pandemic;
- 20.1% of carers have seen their income decrease as a consequence of the COVID-19 outbreak.

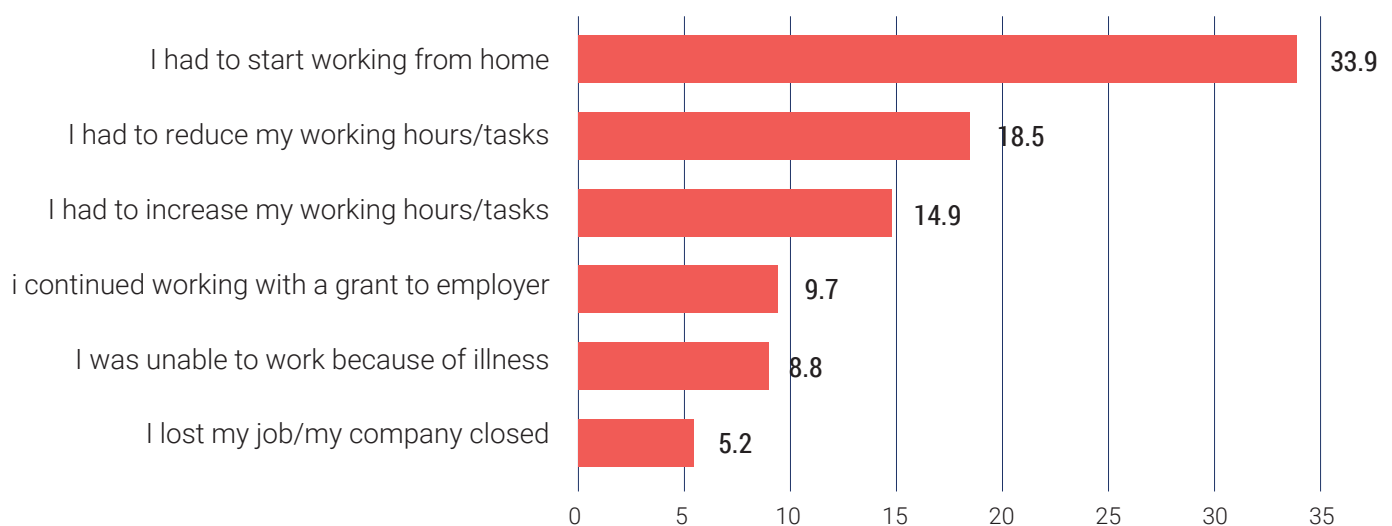
As regards their employment status before the COVID-19 crisis, more than half of respondents were employed (55.6%, out of which 35.5% worked full-time, 14.1% part-time and 6.2% were self-employed/entrepreneurs) while unemployed carers were retired (30.4%), housewife/husband (8.4%), seeking a job (4.5%), or studying (1.1%). Estonian (76.3%) and Portuguese respondents (75.2%) were most frequently in employment, especially full-time (55.7% and 63.2%, respectively). Italian carers were most frequently employed as entrepreneurs/self-employed (11.4%). The highest shares of retired carers were present in Sweden (46.6%) and Finland (45.8%), while the lowest were located in Portugal (9.5%) and Estonia (8.2%). The highest share of housewife/husband was found in Czechia (17.5%) while the highest proportion of unemployed carers before the pandemic was present in Italy (7.4%). Female respondents were more often employed than their male counterparts (57.3% and 48.7%, respectively).

44.1% of respondents report that the COVID-19 outbreak has had no impact on their employment status, and this was observed especially in Germany (54.8%) and the Czech Republic (50.4%) while, Italian, Swedish and Estonian carers presented the lowest percentages (38.5%, 40.7% and 43%, respectively) in this aspect. Among carers stressing the consequences of the pandemic on their employment situation, **5.2% report having lost their job or facing the closure of their company as a result of the pandemic** (highest

shares in Estonia, 11.5%, Germany and Italy, 7.1% in both countries), **and 18.5% have had to reduce their working hours/tasks**. The latter type of restriction was mainly reported by carers from Germany (29.5%) Estonia (26.9%) and the Czech Republic (23.6%), and was less apparent among Swedish carers (10.3%). **These adverse consequences of the pandemic on the employment status of informal carers have mainly affected female respondents** (24% become unemployed or had to reduce working hours/tasks; men: 22.4%), and primarily Estonian and German carers (38.4% and 36.6%, respectively) when comparing with their Finnish and Swedish counterparts (19.7% and 13.9%). **8.8% of respondents** (8.7% of women and 8.5% of men) **have been unable to work due to COVID-19 or other illnesses** (higher percentages in Estonia, 12.8%, and the Czech Republic, 11.8%; lower in Italy, 6.7% and in Finland, 6.6%). **One in three respondents (33.9%) - more often women (34.6%) than men (30.6%) - have had to start working from home** (e.g. teleworking, etc.) **as a result of the pandemic**, mainly in Portugal (51%) and Estonia (44.2%), compared to Sweden (29%) and especially Finland (23.6%). Out of the whole sample of informal carers, 14.9% have had to increase their working hours/tasks (higher percentage in Portugal, 24%; lower in Germany, 8.4%) and 9.7% have continued working with a COVID-19 government support grant to their employers (higher value in Portugal, 18.9%; lower in the Czech Republic, 4.8%). Only 1.7% of respondents were unemployed and have found a job after the COVID-19 outbreak (higher percentages in the Czech Republic and Estonia, 4.8% and 3.9%, respectively) (Figure 11).

Figure 11

Impact of the COVID-19 outbreak on carer's employment status
(% of respondents)



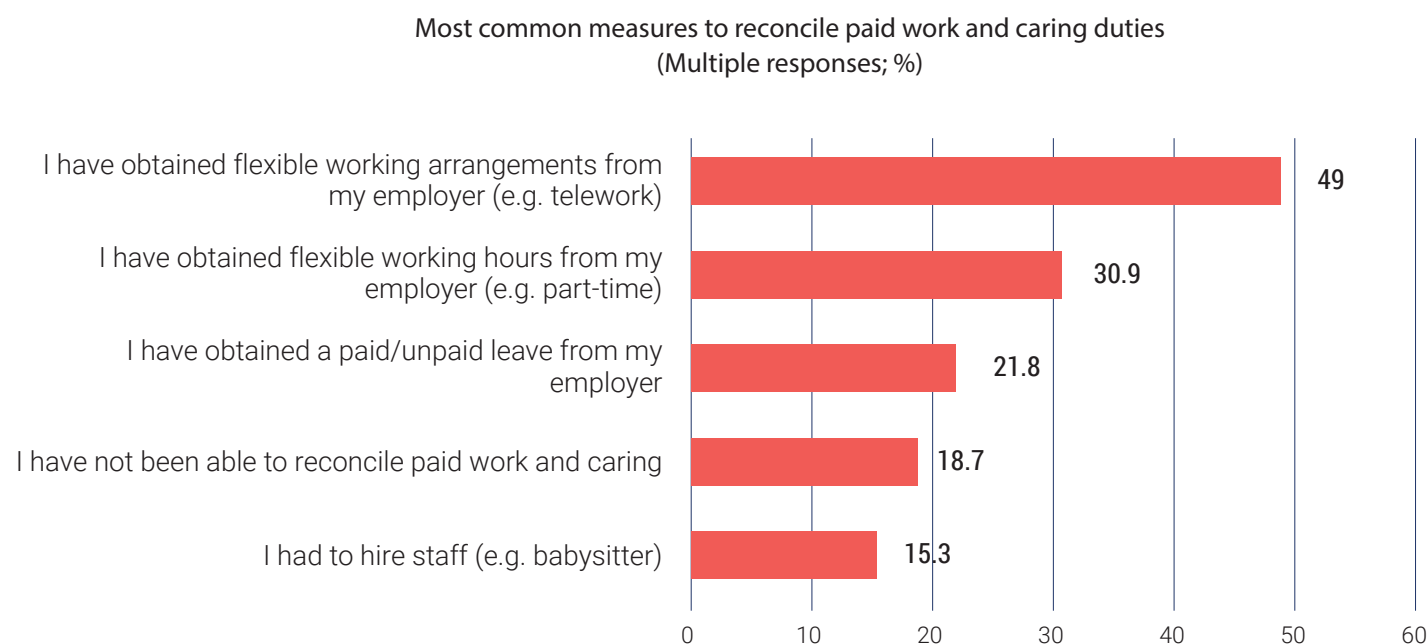
At the time of the survey compilation, about half of respondents were employed (50.7%), with a higher proportion among women (52.1%) compared to men (44.9%). The highest shares of employed informal carers were found in Estonia (68.8%) and Portugal (67.8%) while the lowest was found in Finland (35.1%).

According to employed informal carers, **the most common measures at their disposal to help them reconcile their paid work and caring duties during the COVID-19 outbreak** (Figure 12) **were: flexible working arrangements** (e.g. telework; 49%), **flexible working hours** (e.g. part-time; 30.9%) **and paid/unpaid leaves** (21.8%). The latter measure has been more commonly accessed/used by Italian carers (51.3%), while it has remained virtually inaccessible/unused by Portuguese (3%) and Czech carers (1.2%). German and Estonian respondents present the highest share of working carers who have benefitted from flexible working hours (55.6% and 49.2%, respectively)

compared to Portuguese (23.2%) and Italian (22%) carers. Portuguese (62.7%) and Estonian (58.7%) respondents have most commonly been using/benefitting from flexible working arrangements, while this type of measure has less often been obtained by Italian and Swedish working carers (42.7% and 42.3%, respectively). 15.3% of the sample has had to hire staff (e.g. babysitter) and this phenomenon has been more common in Italy (27.8%) and Czechia (24.4%), while it has proven practically absent in Sweden (1.4%).

Despite all of the above, it is essential to emphasise that **18.7% of employed respondents (23.2% of males and 18% females) report that they have been unable to reconcile paid work and caring responsibilities during the pandemic**, and this issue has been more common in Portugal (25.3%), 'other countries' (22.6%) and Sweden (22.3%), compared to Germany (10.5%) and, especially, Estonia (5.5%).

Figure 12



When it comes to the impact of the COVID-19 crisis on carers' income, in the cross-national sample, when disregarding the 13.3% of respondents who do not have any income, 63.3% report that their income has remained the same, while only 3.3% have seen their income increase. However, **20.1% informal carers experienced a decrease in their income as a result of the pandemic**, and this negative effect has mainly been reported by women (20.2%; men: 19.5%) as well as by Italian and Estonian respondents (31.9% and 28.9%, respectively), compared to the samples in other countries, with the lowest observable percentages related to this aspect in Germany (13.4%) and in Sweden (13%).

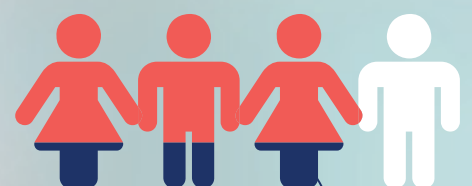
Among respondents facing a decrease in their income, **45.3% report that the pandemic has had a highly negative impact on their income** (highest percentage in Estonia, 70.4%; lowest in Sweden, 28.2%), 37.8% report an intermediate negative impact (highest percentage in Finland, 46.4%; lowest in Estonia, 25.9%) and 16.9% a low negative impact (highest percentage in Sweden, 34%, and Germany, 33.3%; lowest in Portugal, 4.3%, and Estonia, 3.7%).

THE USE OF TECHNOLOGY TO FACE THE CONSEQUENCES OF THE COVID-19 OUTBREAK

Widespread use of tools and technologies during the pandemic

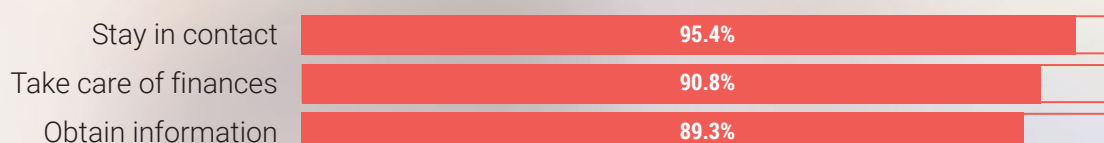


78% of carers never used care-related technologies



only 27% would be interested

Main reasons for using technologies



SUMMARY OF KEY POINTS

- Carers report a high and widespread use of tools and technologies during the pandemic, mainly smartphones, personal computers, social media;
- The main reasons for using these technologies were to: keep in contact with family members, relatives and friends (95.4%); take care of finances (90.8%); obtain information on current events and on the pandemic (89.3%); about half of carers have used technologies to keep in touch with carer/patient organisations;
- More than three out of four carers (77.8%) have never used care-related technologies; among them, 27% would be interested in accessing them.

The devices most commonly used by carers to access online services during the pandemic **include smartphones** (93.7%) and **personal computers** (89.2%), without any significant variations between countries. Conversely, differences were observed regarding the reasons why digital tools have been used. In Finland and Germany, carers have indeed mainly used them to access the **social media** (84.3% and 91.7%, respectively) while in Italy, despite a widespread use of social networks (90.3%), 74.7% of carers have used their devices for videoconferencing, above the cross-country average of 72.8%. With 63.1% and 55.8% respectively, Germany and Czechia are the only two countries where the share of carers who have used new technologies for videoconferencing is below the cross-country average.

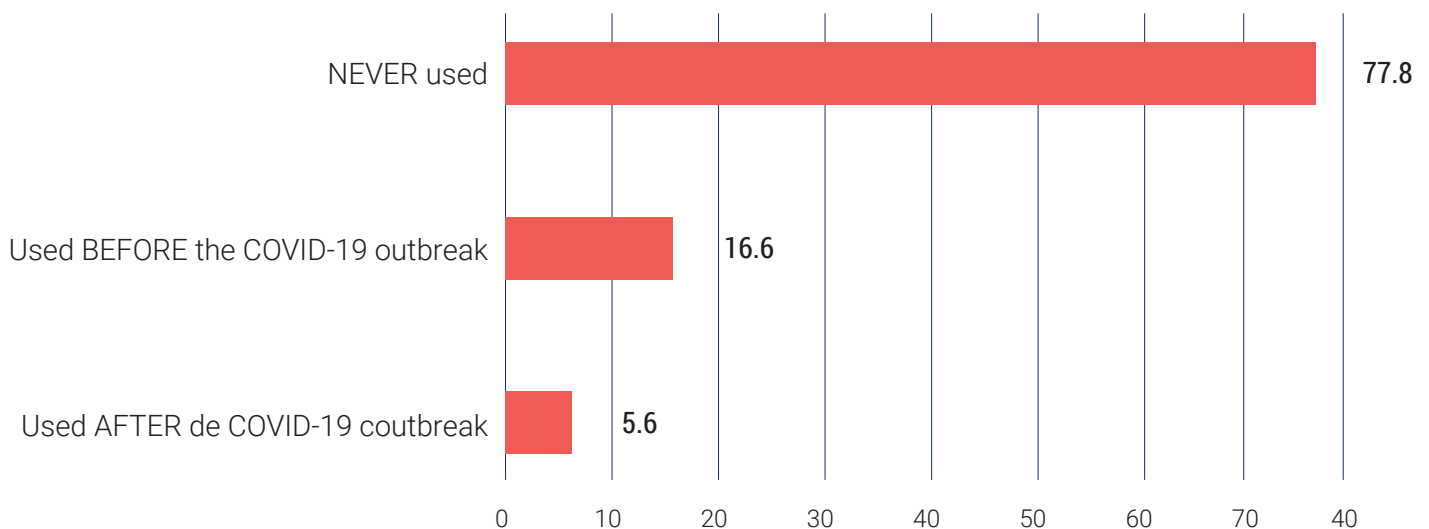
According to respondents, **these are the three main reasons why technologies have been used during the pandemic: to keep in contact with family members, relatives and friends** (95.4%); **to take care of finances** (e.g. pay bills, check bank accounts, 90.8%); **to obtain information on current events and the COVID-19 outbreak** (89.3%). Moreover, respondents have also used technologies to contact health and social care services (80.5%) while 75.3% of them have

shopped online. On average, **49.8% of respondents have used technologies to keep in touch with carer/patient organisations**, with a peak in Germany (with 59.8%, i.e. 14 points above Italy, where only 45.8% of carers have had digital contacts with carer/patient organisations). Apart from the latter aspect, no particular discrepancies can be identified between countries when it comes to the use of technologies by responding carers.

More than three out of four respondents (77.8%) have never used care-related technologies (e.g. telecare systems, personal alarms, environmental monitors, mobility-related devices for fall detection, videophones, GPS positioning/tracking systems) as part of their caregiving activities (Figure 13). The highest percentage of non-users - regardless of the COVID-19 crisis - was observed in Estonia (90.6%), the Czech Republic (84.2%) and Italy (80.5%), while Swedish (76.1%) and Finnish non-users were less numerous (76.4%). The proportion of carers who had come across care-related technologies before the pandemic amounted to 16.6% on average, with higher percentages in Portugal (20.2%), Finland and Germany (both 18.4%).

Figure 13

Use of new care-related technologies for supporting caring activities
(% of respondents)

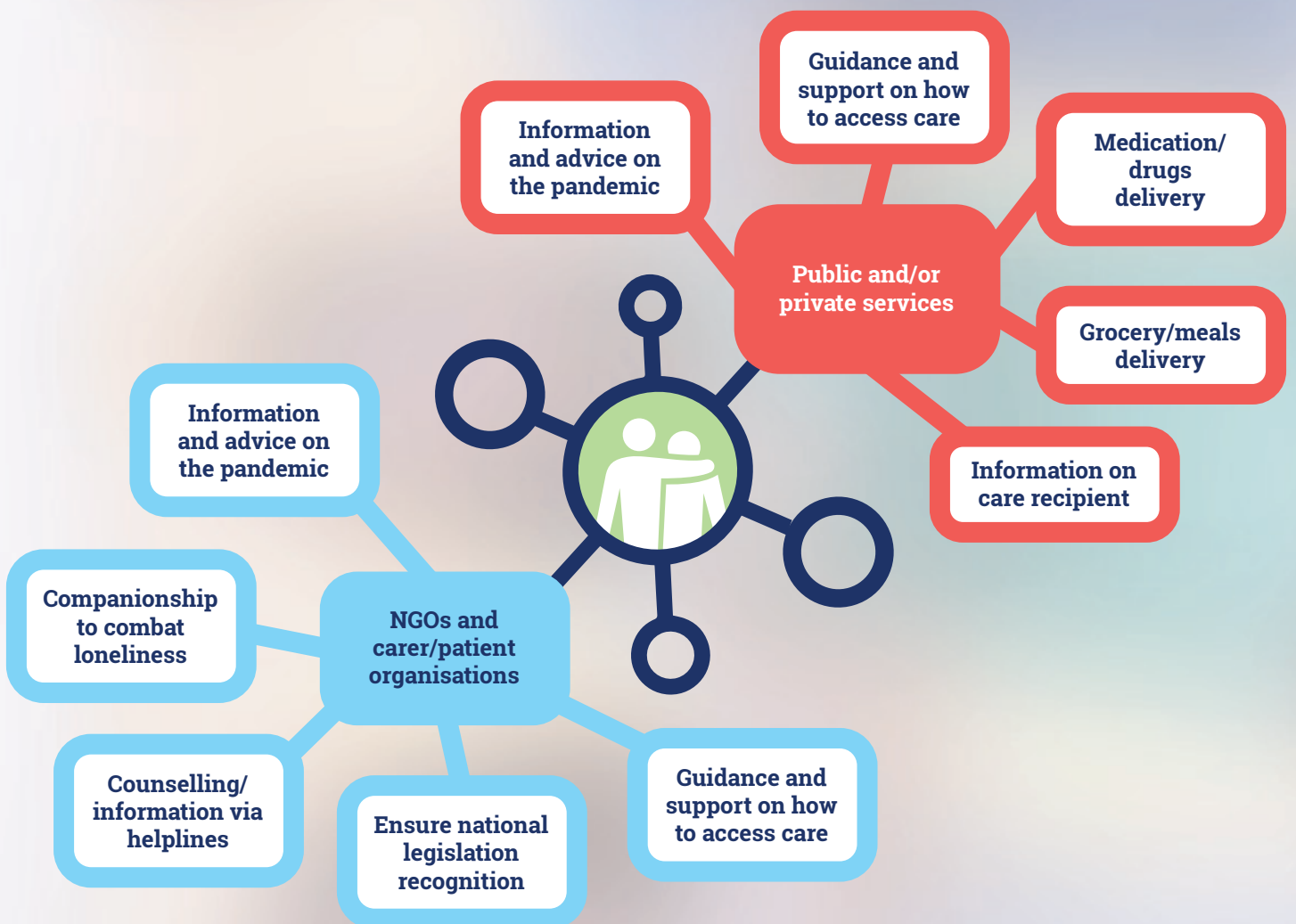


A meagre 5.6% of respondents have started using care-related technologies following the COVID-19 outbreak and the greatest effort towards digital literacy is recorded among informal carers from Italy (6%) and the Czech Republic (5.9%), compared to a smaller share of new technology users in Germany (3%). It should be noted that the use of this kind of technology has not only been dependent on carers' willingness to adopt them, but also on their acceptability by care recipients who - at times - still seem to consider them as overly intrusive in their life environment.

Among those who have used care-related technologies either before or during the pandemic and responded to the question "how helpful have they been to you as a carer?" (N=476 overall), **68.9% have found them useful**; with the most satisfied respondents in Estonia (all respondents to this question, i.e. 9), Czechia (86.4%), and Germany (73.8%). Only 6.3% of respondents rated care-related technologies as unhelpful, with a particularly high proportion in Finland (12.1%) and a smaller share in Germany and 'other countries' (respectively, 2.4% and 2.9%).

Among informal carers who have never used new care-related technologies and responded to the question "would you be interested in accessing them to help you with your care duties?", **27% replied that they would be interested in accessing them**, thereby demonstrating their curiosity and keenness towards new technologies aiming to support carers. The greatest interest is observed among respondents from Estonia (43.4%), Portugal (39.3%) and Italy (35.7%) while the smallest was found among Scandinavian and German informal carers whose percentages were below the countries' average, i.e. 21.6% in Finland, 21% in Sweden and 20.7% in Germany. Carers who are not interested in care-related technologies represent 24.2% of the whole sample and are particularly numerous in Sweden (28.9%). The rest of carers, nearly half in each country barring Italy and Portugal (41.9% and 42.7%, respectively), are uncertain about their interest in the use of technologies potentially helpful for their caregiving, in particular when they are not in direct contact with their loved ones. This might be related in part to the stage we are in with regard to the development of new technologies targeted at carers in Europe, although the sector is undergoing a fast transformation and expansion due to the COVID-19 pandemic. However, as mentioned already, acceptability by care recipients and investment in carers' training on new technologies are also important elements.

HOW TO BETTER SUPPORT CARERS IN TIMES OF A PANDEMIC? OPINIONS AND RECOMMENDATION



SUMMARY OF KEY POINTS

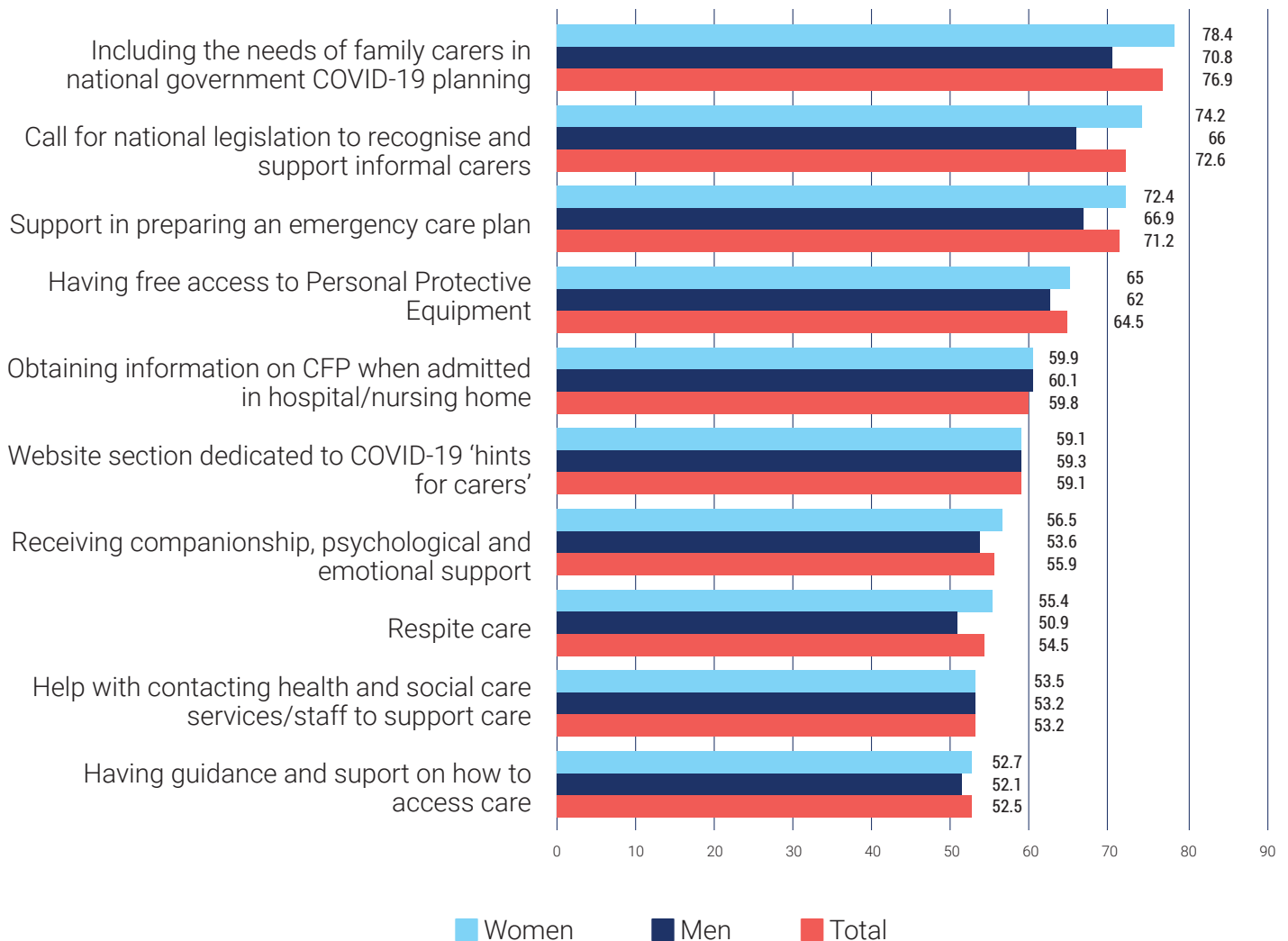
- Public and/or private services, NGOs and carer/patient organisations are providing a range of helpful support services/measures (including through innovative solutions) to respond to the needs of carers arising from the pandemic;
- Helpful support measures/services provided by public or private care services to meet carers' needs arising from the COVID-19 pandemic include: Information and advice on how to deal with the pandemic in daily life (36.4%), Guidance and support on how to access care should the carer and/or care recipient be infected by COVID-19 (32.2%), Medication/drugs delivery at home (25.5%), Grocery/meals delivery at home (24.9%), and Information on care recipient if hospitalised/admitted in nursing home/health care facility (21%).
- Helpful support measures/services provided by NGOs or carer/patient organisations to meet carers' needs arising from the COVID-19 pandemic include: Information and advice on how to deal with the pandemic in daily life (10.3%), Companionship to combat loneliness, psychological and emotional support (7.5%), Counselling/information via helplines, telephone services and websites (6.9%), Campaigning to ensure that the national legislation recognises and supports informal carers and carer/patient organisations (6.8%), and Guidance and support on how to access care should the carer and/or care recipient be infected with the COVID-19 virus (6.4%);
- In spite of this, informal carers pointed out that a great amount and variety of support measures and initiatives are yet to be received and/or implemented in order to better support them in fulfilling their caring role in times of a pandemic (e.g. considering their needs in national COVID-19 planning; developing national legislation to recognise and support informal carers and carer/patient organisations; support in the preparation of emergency care plans, etc.)

The questionnaire included a section aimed at collecting the opinion and recommendations of carers on how to better support them in times of a pandemic. Carers were asked to provide their views on available and prospective support measures aiming to meet their needs arising from the COVID-19 outbreak, and on the extent to which these were/would be considered useful by respondents (i.e. 1. helpful but not received / 2. helpful and received via public or private services / 3. helpful and received via NGOs or carer/patient organisations). In its responses, the overall sample of carers, irrespective of the gender of respondents, highlights the following **support initiatives/measures/services**

as helpful but not yet received/implemented (Figure 14): **considering the needs of informal carers in national governments' COVID-19 planning** (76.9%; women, 78.4%; men, 70.8%); **national legislation to recognise and support informal carers and carer/patient organisations** (72.6%; women, 74.2%; men, 66%); **support in preparing an emergency care plan** should the carer become unavailable to care (71.2%; females, 72.4%; males, 66.9%); having free access to Personal Protective Equipment (64.5%; females, 65%; males, 62.7%); obtaining information on the care recipient if/when hospitalised/admitted in nursing homes/health care facilities (59.8%; females, 59.4%; males, 60.1%).

Figure 14

Informal carers' opinion on support that would have been helpful during the COVID-19 outbreak (first 10 items only) (% of respondents)



Interestingly, **for almost all of the “useful but not received/implemented” support measures and services mentioned above, the highest proportions were mainly observed among female respondents, and in both the Italian and Portuguese samples, while the lowest shares were found in the Finnish and Czech samples.** About half or more of the respondents (highest percentages in Portugal and Italy, lowest in Czechia) further underlined the following **support measures** as **“helpful but not yet received”**: [access to] **websites’ sections dedicated to COVID 19 ‘hints for carers’** (e.g. services available for carers, etc., 59.1%); **companionship, psychological and emotional support** (55.9%); **respite care** (54.5%); **support with contacting health and social care services/staff** (53.2%); **guidance and support on how to access care should the carer and/or care recipient be infected by COVID-19** (52.2%); **economic and financial support** (51.3%); **more online (ICT based) support services** (50.3%).

In relation to **helpful support measures/services received from public or private providers**, respondents report the following as **most important**: **information and advice on how to deal with the pandemic in daily life (36.4%)**; **guidance and support on how to access care should the carer and/or care recipient be infected with the COVID-19 virus (32.2%)**; **medication/drugs delivery at home (25.5%)**; **grocery/meals delivery at home (24.9%)**; obtaining information on care recipient if/when hospitalised/admitted in nursing homes/health care facilities (21%). Other types of helpful measures obtained from public or private services concerned the support received/sought from paid care workers (19.5%) and counselling/information via helplines and telephone services (19%). Overall, these types of support were mainly reported as helpful and received from public or private services by informal carers living in Finland (as well as, but to a lesser extent, Portugal, Czechia and ‘other countries’) and less often by Italian, German and Estonian carers. With the exception of grocery/meals delivery at home and guidance and support on how to access care should the carer and/or care recipient be infected with the COVID-19 virus, the aforementioned support measures/services from public or private services recorded higher percentages among female respondents.

The sample of informal carers regarded the following **support measures received/implemented by NGOs or carer/patient organisations as helpful**: **information and advice on how to deal with the pandemic in daily life (10.3%)**; **companionship, psychological and emotional support (7.5%)**; **counselling/information via helplines and telephone services**; **websites sections dedicated to COVID-19 ‘hints for carers’ (6.9% in both cases)**; **call for national legislation to recognise and support informal carers and carer/patient organisations (6.8%)**; **guidance and support on how to access care should the carer and/or care recipient be infected with the COVID-19 virus (6.4%)**. Respondents who indicated receiving helpful support from NGOs or carer/patient organisations were mainly living in the Czech Republic and Finland, while the lowest shares were found in the Estonian, Portuguese and Swedish samples, as well as in the ‘other countries’ group.

When disaggregated by gender, the data shows that **male carers report higher percentages vis-à-vis the helpfulness**

of the following support measures received/implemented by NGOs or carer/patient organisations: guidance and support on how to access care should the carer and/or the care recipient be infected with the COVID-19 virus (7.9%; 6% females), call for national legislation to recognise and support informal carers and carer/patient organisations (7.4%; 6,6% females). Conversely, **female respondents show higher values as regards information and advice on how to deal with the pandemic in daily life (10.3%; males, 10.2%), companionship, psychological and emotional support (8%; males, 4.4%), counselling/information via helplines and telephone services (7.3%; males, 4.6%), and websites’ sections dedicated to COVID-19 (7.2%; males, 5.1%).** Moreover, male carers highlight more often than their female counterparts that NGOs or carer/patient organisations put in place initiatives to include the needs of informal carers in national government COVID-19 planning (total, 5.2%; males, 6%; females, 5%), while women (6%) report a higher percentage than men (4.2%) concerning online (ICT-based) support services obtained thanks to NGOs or carer/patient organisations (5.6%).

CONCLUSIONS AND POLICY IMPLICATIONS

The findings presented above demonstrate that the COVID-19 pandemic has exacerbated aspects and issues facing carers that pre-existed the outbreak, and generated a new set of challenges. For example, the fact that women represent about 80% of respondents to the survey is in line with the well-documented and unequal distribution of caring responsibilities and roles between men and women. The findings of this study allow to identify a series of policies which, if implemented, would improve support available to carers in times of a pandemic and beyond, as highlighted below.

FILLING THE GENDER GAP: EQUAL ACCESS TO THE LABOUR MARKET AND VALIDATION OF SKILLS

Women have faced even more serious consequences than men when it comes to the negative impact of the pandemic on various aspects of the carer's experience (e.g. lower quality of life, worse physical and mental/psychological health status, social network/participation, income, working status). In light of this, and in accordance with the principles of the EU Pillar of Social Rights, more effective gender-oriented policies are recommended to ensure equal opportunities for female informal carers and to protect their access to the labour market, especially by means of education, training and lifelong learning. Validating the skills acquired by both women and men while caring is crucial as it may allow them to find employment in the formal social and health care sector.

STRENGTHENING WORK-LIFE BALANCE POLICIES: REMOTE WORK AS AN OPTION

The findings of this study suggest that a better recognition of the caring role is needed in the workplace and that adequate measures should be put in place to help carers (and especially women) employed in the private and public sectors strike a suitable work-life balance. Our findings highlight the rapid spread of tele- and smart working solutions during the pandemic, especially in countries where such flexible

work measures were previously uncommon (e.g. Italy). This suggests that policies aiming to support the adoption of this kind of approaches is urgently needed, while leaving it up to informal carers to choose whether and to what extent they want to work from home. This question of choice between in-person and remote work is essential for carers since employment can represent a break from caregiving, a means of socialisation and self-determination. Moreover, the fact that about 20% of employed respondents report not having been able to reconcile paid work and caring responsibilities during the COVID-19 outbreak, calls for comprehensive policies and measures at company level to better support work-life balance for carers across Europe.

ENSURING SOCIAL PROTECTION AND INCLUSION: PENSION CREDITS

Considering the impact of the COVID-19 pandemic on informal carers' working conditions, it is more urgent than ever to recognise carers' central role in saving public health systems' economic and human resources, through the introduction and/or reinforcement of pension credits that take into account the time and effort dedicated to caregiving tasks.

BOOSTING THE PROVISION OF SOCIAL (IN ADDITION TO HEALTH) SERVICES AND RELIABLE INFORMATION

The survey highlights that many carers urgently need social services, e.g. in order to address their relational, psychological, counselling and/or emotional needs. This is especially clear for female respondents. The need for reliable (i.e. not alarmist) information was especially apparent among male respondents.

INVOLVING INFORMAL CARERS IN THE CO-DESIGN OF SUPPORT MEASURES AND POLICIES

Gendered preferences for services are only one illustration of the need for increased and improved opportunities for consultation with informal carers and organisations that represent them, in order to co-design and co-produce services that effectively respond to their specific needs.

DESIGNING CROSS-SECTORAL POLICIES FOR FAIR, EQUAL AND INTEGRATED LONG-TERM CARE SYSTEMS

Personal (migrant) care assistants represent one of the most common and effective sources of support for informal carers both in ordinary and pandemic times, especially (but not only) in Italy. This - mainly out-of-pocket - service, together with the contribution of other family members and neighbours, allows to fill existing gaps in the provision of long-term care by public health and social services, which have been further challenged by the pandemic and thus end up further impoverishing informal carers. During the pandemic, many privately-paid migrant care assistants were infected by COVID-19 via the care recipient (or vice versa), while others were dismissed, out of their employer's fear of contracting the virus. In both cases, many informal carers remained without support when they needed it most. As such, the pandemic demonstrates the fragility and inequality of those LTC systems depending on migrant care arrangements. This finding calls for cross-sectoral governance at European level in order to promote policies that meet the needs of health systems, health labour markets as well as the rights of (migrant) care workers, therefore ensuring better coordination between hospital, residential and home-based care services.

ADDRESSING THE DIGITAL DIVIDE AND PROMOTING RESEARCH AND INNOVATION

Although many informal carers regularly use their smartphone, personal computer and tablet to access social networks and keep in touch with relatives and friends, 77.8% of them have never used telecare systems, tele-monitoring or other care-related ICT devices, and just 5.6% of respondents have started using them following the pandemic. This sheds light on informal carers' digital illiteracy with regard to telecare systems, just when they would be most useful. The lack of access to telecare technologies indeed hinders the principle of equal access to health and social services, and puts care recipients at risk of not receiving appropriate care if/when needed. The non-users of care-related technologies might benefit from dedicated training programmes/courses, possibly online and including on basic aspects, in order to bridge the digital gap and give them the opportunity to access online resources and tips. Interestingly, those who have never used - and are not willing to use - care related technologies form a subgroup that is particularly at risk. Ad hoc strategies should be developed to overcome their reluctance towards technology. This finding confirms the need for policies focusing on education and training in the use of technology-based systems. Public funding for the development of innovative ICT solutions is also needed.

RECOGNISING INFORMAL CARERS THROUGH NATIONAL LAW IN EVERY EUROPEAN COUNTRY

Our data shows the disparity of health and social services targeted at informal carers across Europe. In some countries, carers are more vulnerable than in others (German carers seem more fragile in terms of health status, quality of life, increase in weekly hours of caregiving etc. than Scandinavian carers, who seem more protected by their service provision systems, for example). This finding calls for national laws recognising informal carers' role, rights and needs in every European country, as a first step towards equal access to health and social services and specific social protection measures for carers. This could also be considered at European level, where awareness raising activities regarding carers' needs, their recognition and the development of support mechanisms targeted at them and carer/patient organisations could be orchestrated.

STRENGTHENING INVESTMENT IN RESEARCH ON INFORMAL CARERS

Last but not least, the need for broad, comparative pan-European research on informal carers, which is at the core of any policy and measure aiming to support them, especially following the current pandemic, remains crucial. Existing data sources are indeed either incomplete or partially reliable. Yet, the availability of a full and comprehensive overview of the situation of informal carers in Europe would allow to have more precise estimations of their number, needs for support and services, and contribution to EU LTC budgets and economies. More investment in applied research in this field is highly recommended.

DEVELOPING COMPREHENSIVE AND COORDINATED POLICY ACTIONS AND SUPPORT MEASURES

The findings of this survey call for the development of holistic and coordinated policy actions and support measures by public and private services, NGOs and carer/patient organisations (including through innovative solutions and models of support co-designed with networks of stakeholders and on the basis of good practices emerging from the pandemic). Specific attention should be paid to interventions and policies that consider national specificities (e.g. in terms of services and supports available) and carers' characteristics (e.g. gender, age, etc.). The results of this survey could be used to design better support policies and services targeted at informal carers as well as European guidelines aimed at policy makers and service providers on how to cope with the COVID-19 outbreak and future pandemics. Moreover, the study findings also call for the development of appropriate and coordinated policies to support the active ageing of informal carers in Europe.

ACKNOWLEDGEMENTS

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ANNEX:

KEY DATA PER COUNTRY



CZECH REPUBLIC

Item	%
GENDER	
<i>Female</i>	89.1
<i>Male</i>	10.3
MEAN AGE OF CARERS	53.2
MAIN CARE RECIPIENT	
<i>Parent</i>	39.7
<i>Son/Daughter or Son/Daughter-in-law</i>	21.8
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	27.6
GENDER OF THE MAIN CARE RECIPIENT	
<i>Female</i>	51.6
<i>Male</i>	45.8
MEAN AGE OF THE MAIN CARE RECIPIENT	65.1
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	15.7
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
<i>Quality of life</i>	71.9
<i>Mental health/psychological state of mind</i>	57.5
<i>Access to health/social services for the care recipient</i>	57
THREE MOST INCREASED CARING ACTIVITIES	
<i>Emotional support</i>	60
<i>Remote communication (e.g. by telephone, mobile phone, PC, etc.)</i>	51.3
<i>Practical help in person (e.g. preparing meals, shopping, laundry, housework, etc.)</i>	42.9
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
<i>What would happen to the care recipient(s) should the carer have to self-isolate or become ill</i>	70.1
<i>Physical and cognitive decline of the care recipient(s)</i>	31
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	32
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
<i>Health care</i>	70.9

<i>Social care</i>	44.6
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
<i>Other informal carer(s) (e.g. family members, friends, neighbours, etc.)</i>	82.5
<i>Public or private health and/or social care services professionals</i>	45.3
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
<i>Including the needs of family carers in national government COVID-19 planning</i>	43.1
<i>Call for national legislation to recognise and support informal carers</i>	43
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
<i>Reduction of working hours/tasks</i>	23.6
<i>Job lost/Closure of carer company</i>	5.6
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	22.7
TWO MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Flexible working arrangements</i>	45.1
<i>Flexible working hours</i>	28
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	15
CAREGIVERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	22.9


ESTONIA

Item	%
GENDER	
<i>Female</i>	90.7
<i>Male</i>	8.2
MEAN AGE OF CARERS	54.1
MAIN CARE RECIPIENT	
<i>Parent</i>	40.2
<i>Son/Daughter or Son/Daughter-in-law</i>	32
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	21.9
GENDER OF THE MAIN CARE RECIPIENT	
<i>Female</i>	56.7
<i>Male</i>	41.2
MEAN AGE OF THE MAIN CARE RECIPIENT	61.5
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	7.2
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
<i>Social network/participation</i>	80.4
<i>Access to health/social services for the care recipient</i>	74.2
<i>Access to health/social services for the carer</i>	62.9
THREE MOST INCREASED CARING ACTIVITIES	
<i>Emotional support</i>	54.6
<i>Remote communication (e.g. by telephone, mobile phone, PC, etc.)</i>	52.6
<i>Arranging/coordinating care and support</i>	44.3
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
<i>What would happen to the care recipient(s) should the carer have to self-isolate or become ill</i>	82.5
<i>Physical and cognitive decline of the care recipient(s)</i>	56.3
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	35
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
<i>Health care</i>	82.3
<i>Transportation (e.g. to go to the General Practitioner, etc.)</i>	35.5
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
<i>Other informal carer(s) (e.g. family members, friends, neighbours, etc.)</i>	62.9
<i>Public or private health and/or social care services professionals</i>	27.5
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
<i>Including the needs of family carers in national government COVID-19 planning</i>	82.2
<i>Call for national legislation to recognise and support informal carers</i>	79.8
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
<i>Reduction of working hours/tasks</i>	26.9

<i>Job lost/Closure of carer company</i>	11.5
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	28.9
TWO MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Flexible working arrangements</i>	58.7
<i>Flexible working hours</i>	49.2
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	5.5
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	43.4

 **FINLAND**

Item	%
GENDER	
Female	84
Male	15
MEAN AGE OF CARERS	59.6
MAIN CARE RECIPIENT	
Spouse/Partner	47.7
Son/Daughter or Son/Daughter-in-law	33.3
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	11.1
GENDER OF THE MAIN CARE RECIPIENT	
Female	33.9
Male	64.8
MEAN AGE OF THE MAIN CARE RECIPIENT	54.7
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	4.6
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
Quality of life	69.5
Mental health/psychological state of mind	59.2
Access to health/social services for the care recipient	49
THREE MOST INCREASED CARING ACTIVITIES	
Emotional support	50.5
Practical help in person (e.g. preparing meals, shopping, laundry, housework)	43.1
Arranging/coordinating care and support	42.7
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
What would happen to the care recipient(s) should the carer have to self-isolate or become ill	73.8
Physical and cognitive decline of the care recipient(s)	38
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	29.3
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
Health care	90.2
Counselling/information via helplines and telephone services	48
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
Other informal carer(s) (e.g. family members, friends, neighbours, etc.)	54.3
Public or private health and/or social care services professionals	49
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
Including the needs of family carers in national government COVID-19 planning	65
Call for national legislation to recognise and support informal carers	57.7
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
Reduction of working hours/tasks	17

<i>Job lost/Closure of carer company</i>	2.7
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	18.5
TWO MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Paid/unpaid leaves</i>	30
<i>Flexible working arrangements</i>	37
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	12
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	21.6


GERMANY

Item	%
GENDER	
Female	88.5
Male	10.7
MEAN AGE OF CARERS	53.2
MAIN CARE RECIPIENT	
Parent	33.3
Spouse/partner	23.9
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	29.5
GENDER OF THE MAIN CARE RECIPIENT	
Female	50.4
Male	48.3
MEAN AGE OF THE MAIN CARE RECIPIENT	61.5
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	4.3
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
Quality of life	82.5
Mental health/psychological state of mind	80.3
Access to health/social services for the care recipient	68.7
THREE MOST INCREASED CARING ACTIVITIES	
Emotional support	76.5
Arranging/coordinating care and support	63.6
Personal care and hygiene	62.1
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
What would happen to the care recipient(s) should the carer have to self-isolate or become ill	81.5
Physical and cognitive decline of the care recipient(s)	48.9
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	28.7
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
Health care	53.5
Medication/drugs delivery at home	43
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
Other informal carer(s) (e.g. family members, friends, neighbours, etc.)	64.2
Public or private health and/or social care services professionals	44.5
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
Including the needs of family carers in national government COVID-19 planning	82.7
Support in preparing an emergency care plan	81
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
Reduction of working hours/tasks	29.5

<i>Job lost/Closure of carer company</i>	7.1
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	13.4
TWO MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Flexible working hours</i>	55.6
<i>Flexible working arrangements</i>	53.8
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	10.5
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	20.7



Item	%
GENDER	
<i>Female</i>	79.6
<i>Male</i>	19.9
MEAN AGE OF CARERS	53.6
MAIN CARE RECIPIENT	
<i>Son/daughter</i>	40.7
<i>Parent-in-law</i>	34.1
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	23.6
GENDER OF THE MAIN CARE RECIPIENT	
<i>Female</i>	51.7
<i>Male</i>	47.8
MEAN AGE OF THE MAIN CARE RECIPIENT	52
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	8.4
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
<i>Social network/participation</i>	82.4
<i>Access to health/social services for the care recipient</i>	75.6
<i>Access to health/social services for the carer</i>	64.1
THREE MOST INCREASED CARING ACTIVITIES	
<i>Emotional support</i>	65.3
<i>Remote communication (e.g. by telephone, mobile phone, PC, etc.)</i>	53
<i>Home schooling</i>	58.3
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
<i>What would happen to the care recipient(s) should the carer have to self-isolate or become ill</i>	82.5
<i>Physical and cognitive decline of the care recipient(s)</i>	51.2
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	44
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
<i>Health care</i>	37.6
<i>Social care</i>	22.8
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
<i>Other informal carer(s) (e.g. family members, friends, neighbours, etc.)</i>	55
<i>Public or private health and/or social care services professionals</i>	33.8
<i>Personal care assistant(s) working part-time</i>	22.5
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
<i>Support in preparing an emergency care plan</i>	90.8
<i>Call for national legislation to recognise and support informal carers</i>	87.1
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	

<i>Reduction of working hours/tasks</i>	22.8
<i>Job lost/Closure of carer company</i>	7.1
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	31.9
TWO MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Paid/unpaid leaves</i>	51.3
<i>Flexible working arrangements</i>	42.7
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	19.1
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	35.7


PORTUGAL

Item	%
GENDER	
Female	80.5
Male	19.5
MEAN AGE OF CARERS	51.8
MAIN CARE RECIPIENT	
Parent	58.7
Son/Daughter or Son/Daughter-in-law	13.6
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	26.1
GENDER OF THE MAIN CARE RECIPIENT	
Female	62.4
Male	36.9
MEAN AGE OF THE MAIN CARE RECIPIENT	72.6
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	24.6
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
Quality of life	79.2
Mental health/psychological state of mind	73.2
Physical condition	68.8
THREE MOST INCREASED CARING ACTIVITIES	
Emotional support	63.4
Practical help in person (e.g. preparing meals, shopping, laundry, housework, etc.)	51.4
Remote communication (e.g. by telephone, mobile phone, PC, etc.)	50.4
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
What would happen to the care recipient(s) should the carer have to self-isolate or become ill	78
Physical and cognitive decline of the care recipient(s)	56
CARERS EXPERIENCING HEALTH AND/OR CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	33.8
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
Health care	61.5
Practical help (e.g. preparing meals, laundry, housework, etc.)	25.6
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
Other informal carer(s) (e.g. family members, friends, neighbours, etc.)	56.3
Public or private health and/or social care services professionals	26.7
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
Including the needs of family carers in national government COVID-19 planning	86
Support in preparing an emergency care plan	85.5
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
Reduction of working hours/tasks	22.4

<i>Job lost/Closure of carer company</i>	5.3
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	25.6
MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Flexible working arrangements</i>	62.3
<i>Flexible working hours</i>	23
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	25.3
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	39.3



Item	%
GENDER	
Female	77
Male	22.7
MEAN AGE OF CARERS	62.8
MAIN CARE RECIPIENT	
Spouse/Partner	46.4
Son/Daughter or Son/Daughter-in-law	26.9
INFORMAL CARERS CARING FOR TWO OR MORE PEOPLE	22.1
GENDER OF THE MAIN CARE RECIPIENT	
Female	44.3
Male	54.6
MEAN AGE OF THE MAIN CARE RECIPIENT	61.3
CARERS STARTING PROVIDING CARE AS A RESULT OF THE COVID-19 OUTBREAK	14.7
THREE MAIN INFORMAL CARERS' LIFE REALMS WORSENERD DUE TO THE COVID-19 OUTBREAK	
Social network/participation	83.5
Quality of life	78.5
Mental health/psychological state of mind	61.6
THREE MOST INCREASED CARING ACTIVITIES	
Emotional support	54.5
Remote communication (e.g. by telephone, mobile phone, PC, etc.)	46.5
Practical help in person (e.g. preparing meals, shopping, laundry, housework, etc.)	36.5
CARERS' FEELINGS AND WORRIES DUE TO THE COVID-19 OUTBREAK	
What would happen to the care recipient(s) should the carer have to self-isolate or become ill	62.1
Physical and cognitive decline of the care recipient(s)	43.8
CARERS EXPERIENCING HEALTH AND/OR SOCIAL CARE SERVICES DECREASE DURING THE COVID-19 OUTBREAK	25.4
FIRST TWO MOST USED SERVICES DURING THE COVID-19 OUTBREAK	
Health care	73
Social care	43.3
PEOPLE MAINLY SUPPORTING CARERS DURING THE COVID-19 OUTBREAK	
Other informal carer(s) (e.g. family members, friends, neighbours, etc.)	61.4
Public or private health and/or social care services professionals	52.5
FIRST TWO MOST HELPFUL SUPPORTS NOT RECEIVED DURING THE COVID-19 OUTBREAK	
Including the needs of family carers in national government COVID-19 planning	75.9
Call for national legislation to recognise and support informal carers	68.4
IMPACT OF THE COVID-19 OUTBREAK ON CARERS' EMPLOYMENT STATUS	
Reduction of working hours/tasks	10.3

<i>Job lost/Closure of carer company</i>	3.6
CARERS EXPERIENCING INCOME DECREASE DUE TO COVID-19 OUTBREAK	13
MAIN SERVICES/MEASURES RECEIVED FOR WORK-CARE RECONCILIATION DURING THE COVID-19 OUTBREAK	
<i>Flexible working arrangements</i>	42.3
<i>Flexible working hours</i>	26.1
CARERS WHO HAVE NOT BE ABLE TO RECONCILE WORK AND CARE DURING THE COVID-19 OUTBREAK	22.3
CARERS WHO HAVE NOT USED NEW HEALTH CARE TECHNOLOGIES AND WOULD LIKE TO LEARN	21

