# ICWE

Informal Carers Well-Being Enhanced

# Transnational Report

## ICWE Focus Groups

Developed by RightChallenge

In collaboration with all Partner Organisations

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## Introduction and Purpose of Transnational Report

European data shows a growing trend in its aging population, increasing life expectancy, and the rising number of dependents per household. These factors significantly drive Long-Term Care (LTC) costs, with most of the care provided by Informal Caregivers (ICs). While access to institutional LTC is expected to grow, informal care remains the dominant form of care across Europe and is projected to increase further in the future (Hoffman & Rodrigues, 2010).

The ICWE project aims to improve the conditions for ICs by addressing key needs identified in research: training, professional support, effective communication with care professionals, and improving well-being (Silva et al., 2013). At the same time, the projects targets care workers, who play an important role in supporting the autonomy, competence, and self-efficacy of ICs.

ICWE proposes the development of:

- An accessible ICWE website with resources and information regarding informal care, making available all resources developed by the project;
- A training programme for care professionals working with ICs, that will cover the common needs that ICs face when caring for other people;
- A toolkit for ICs covering different thematics developed in conjunction with care professionals, for example how to manage meals/diets, understanding specific illnesses, as well as legal or financial information, and the importance of well-being in coping with informal care.

To reach the projects objectives, each project partner facilitated a focus group with ICs and care professionals to identify main barriers and needs of ICs and professionals who work with them. The primary objectives of the focus groups in Germany, Portugal, Italy, Ireland, Greece and Cyprus were to identify common themes and issues experienced by both groups, compare their experiences, and formulate recommendations for improved support and training for informal carers within the Erasmus+ cooperation project ICWE.

The present transnational report presents the findings of focus groups conducted in partner countries and analyses the experiences, challenges, and needs of both ICs and formal carers, professionals working in care and adult education. The report validates the participants experiences and address their needs to enhance caregiving techniques and ensure their well-being. This transnational report highlights the similarities and differences between participating EU countries and concludes with recommendations for future training programmes based on these results.

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## Methodology

The ICWE focus groups were implemented using a systematic methodology that covered preparation, moderation and execution, management, and analysis of collected data. This approach was chosen to gain a deeper understanding of the complex dynamics of caregiving and its impact on all participants involved.

Prior to the implementation of the focus groups, RightChallenge provided comprehensive guidelines to guide and orient all project partners in their preparation, implementation and analysis of focus groups. In these guidelines partners could find relevant information regarding organisation, moderation and the managing, analysis and documentation of obtained data. Instructions included technical aspects such as recruitment and recording, a detailed structure of the focus groups with topics and questions to guide discussion, and guidelines for the analysis and reporting of the focus group results, including a straightforward template for reporting results as a separate document. By adopting a participative methodology grounded in inclusivity and empathy, the foundation was laid for respective communication and valuable collaboration.

### Timeline and Format

All focus groups were held between April and July 2024. Due to geographical diversity of participants in Portugal and Ireland, focus groups implemented by RightChallenge and the European Health Futures Forum were held in an online format (via Teams/Zoom), while focus groups in Greece and Germany took place in their respective headquarters of EDRA in Peristeri and the iserundschmidt agency in Bonn. For Exeo Lab, the focus group for ICs was held in their facilities, while the focus group with professionals was held via Zoom, enabling participation and interaction regardless of geographical limitations.

Generally, it was challenging for some countries to coordinate a day and a time for all participants. Due to these organisational challenges, CARDET chose to schedule Zoom Meetings and several phone call appointments with both informal and formal carers. This approach ensured gathering valuable insights by participants, while accomodating diverse working schedules.

| Partner organisation | Focus group IC | Focus group professionals |
|---|---|---|
| Iserundschmidt (Germany) | 29.04.2024 | 30.04.2024 |
| RightChallenge (Portugal) | 28.05.2024 | 05.04.2024 |
| Exeo Lab (Italy) | 24.04.2024 | 29.04.2024 |
| European Health Futures Forum (Ireland) | 04.07.2024 | 03.07.2024 |
| EDRA (Greece) | 26.04.2024 | 22.04.2024 |
| CARDET (Cyprus) | Between 14–19 May 2024 | Between 16–20 May 2024 |

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## Recruitment and Participants Profiles

The objective of the ICWE focus groups was to gather information on the specific needs and realities from the point of view of ICs and professionals/adult educators working in care. To reach a diverse profile of participants, partner organisations gathered participants esuring a variety of ages and experiences withing the realm of informal and formal care work. Participants were recruited through partners network with organisations working in the field and in some cases via personal contacts from staff (e.g. in Portugal). In Ireland, participants were recruited through Family careers Ireland, the main national charity in Ireland supporting informal carers, and via the health service executive careers programme. The recruitment of the participants realised in Greece was through a call to EDRA's professionals and to people and professionals that the organisation cooperates with. Regarding ICs, EDRA reached out to possible participants through their networks, since the organisation has a dynamic presence in the local community, especially in the field of care.

Participants for the ICs focus groups were chosen based on their role as the primary caregiver for a family member or other loved one. To establish a representative sample of IC experiences, participants were selected based on their previous volunteer activities, either directly or through affiliations. If possible, final participants were identified by their experience about caring (formal or informal) and their professional relationship with the carers.

In regard to professional care, focus groups included a group of professional caregivers and adult educators from different medical and educational settings, including nursing homes, hospitals, and rehabilitation facilities. Extensive selection procedures guaranteed that the caregiving business was represented by individuals with a variety of backgrounds and degrees of expertise.

| Partner organisation | Participants IC | Participants professionals |
|---|---|---|
| Iserundschmidt (Germany) | 3 males and 3 females, with an average age of 39 years | 3 females and 2 males, with an average age of 35 years (nurses and geriatric nurses) |
| RightChallenge (Portugal) | 6 female informal carers between 21 and 54 years | 2 psychologists, 1 social worker and 2 technical managers between 26 and 40 years (all female) |
| Exeo Lab (Italy) | 5 informal carers in total: 2 communication manager and 3 employees involved in social initiative between 27 and 50 years | 7 professionals in total: 2 office worker, 2 manager and 3 social worker between 25 and 45 years |
| European Health Futures Forum (Ireland) | 4 female and 1 male informal carer between 37 and 60 years | 3 female and 1 male professional, with an average age of 47 years (Course leaders for carers sle management |

| | | |
|---|---|---|
| | | course and Irleand Health service) |
| EDRA (Greece) | 5 informal carers, with four of them older than 40 years | 10 social workers, occupational therapists and psychologists (9 female, 1 male) |
| CARDET (Cyprus) | 5 informal carers, with an average age of 57 years | 5 formal carers, with an average age of 35 years |

In Germany, participants comprised an equal mix of three males and three females, with an average age of 39 years. The group of formal carers and adult educators consisted of three females and two males, with an average age of 35 years.

Professional participants in Portugal were all feminine, working in a geriatric residence in Porto („Casa Maior“) and a rehabilitation and vocational training centre („Cercifeira“) and showed for working experience in the field between 1 and 18 years. The majority of participants indicated that they were often working directly with informal carers. All participants had a bachelor or master degree. IC participants had experience as an informal carer between 8 months and 13 years and most of IC participants were taking care of an older adult (e.g. parent, great parent or friend of the family), due to Alzheimers disease, other forms of dementia and/or reduced mobility. One participant is taking care of her 18 year old son having autism. The level of education varied between participants between primary education, secondary education, bachelor and master degree.

In Italy, the group of participants was very diverse between men and women between the ages of 25 and 50, which was good for understanding the different points of view of each of the participants. Most of the participants indicated that they often worked directly with informal carers or had to take care of one of their family members who needed assistance. Most of the participants have degrees in different fields, some have diplomas: the level of education is very diversified. For most of them it was very interesting to participate and deal with certain topics that are very close to their hearts.

In Ireland, due to either caring responsibilities or work 3 people were unable to make the group but did provide feedback via their organisation. Recruited participants preferred to remain anonymous. Due to the low number participants, they did not wish to complete forms on sexual orientation, ethnicity as they felt they could still be identified.

In Greece, all 10 professionals had experience in working with informal carers. Seven of them had working experience more than ten years. In Greece, where social policy is implementing through family, all ICs interviews were women. Four of ICs were 40+ years old and one young carer participated.

Regarding IC participants in Cyprus, all participants were female with the average age of the group 56.5 (St.D.=6.29) years old. Regarding their educational level, 3 individuals have completed high school (secondary education), 1 individual has a Bachelor’s degree and 1 individual has a Doctorate. Regarding their responses based on the years of being an informal carer, 3 people responded 5 years, 1 responded 9 years and 1 participant responded more than 10 years, resulting in an average of 6.8 years (St.D.=2.3). Regarding the type and level of disability of the care recipient the results were formed as

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follows: Advanced age, mobility issues (osteoporosis) and elderly age were ranked as low (2) severity. Depression and sadness due to deaths at home along with spinal problems, mobility issues and initial stages of memory decline were ranked as medium (3) severity, while reduced vision and Alzheimer's were ranked as high (5) severity.

## Measures and Procedures

In the beginning of each focus group, participants were informed about the confidenciality of the collected data. With the authorization of all participants, focus groups were recorded in video and/or audio, depending on the organisational conditions of each country (face-to-face vs. Online format).

To encourage an in-depth dialogue in all partner countries and obtain comprehensive answers from both groups of participants, a semi-structured discussion guide consisting of open-ended questions was used. This structured but adaptable approach ensured that the different experiences and insights of informal and professional carers were effectively captured and addressed for the ICWE project.

If being realised in the facilities of partner organisations, as in Germany, Greece and Italy, participants provided their consent by signing attendance lists. In Portugal, after the online sessions concent forms were sent to all participants to be signed. A questionnaire to evaluate the satisfaction of participants regarding the focus group was also sent to all participants after the online sessions. Focus group with professionals lasted 1 hour and 23 minutes, the focus group with informal carers 1 hour and 51 minutes.

In Greece, both focus group sessions lasted about one hour, participants were informed about their data protection and signed the consent forms before the main conversation.

Each focus group in Italy was allotted ninety minutes, allowing ample time for participants to elaborate on their caregiving experiences. To facilitate participation, prior to the discussions, all participants were provided with comprehensive instructions on how to access the Zoom link and familiarise themselves with the platform's functionalities for professional caregivers, while for informal caregivers, a session of approximately one hour was organised at the Exeo Lab premises.

Regarding online sessions via Teams in Ireland, consent forms were read to participants, and it was explained the session would be recorded and the recording deleted once it had been transcribed and themed.

## Focus Group Moderation

In all partner countries, efforts were made for moderators to create a supportive atmosphere during focus groups. Using a semi-structured approach allowed for both spontaneous exploration of emerging ideas and guided discussions on specified topics.

To achieve valid results, focus was laid on creating a comfortable and sensible atmosphere in both sessions and using different tequniques, such as mirroring, encouraging people to speak, making space for all kinds of topics and summarising most important key points or questions. By using active listening strategies and providing a nonjudgmental environment, moderators facilitated a valuable discussion about the opportunities and challenges in professional and informal caregiving.

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In Germany, both sessions were facilitated by Mr. Karl Nsengimana, a marketing coordinator at iserundschmidt. Prior to the discussions, participants engaged in team-building exercises to foster a relaxed and open-minded atmosphere.

The focus group with professionals in Portugal was moderated by Diana Filipe, while the focus group session with ICs was conducted by Elisa Klein-Peters. Holding a masters degree in psychology and both being part of the National Order of Psychologists in Portugal gave moderators the necessary skills to conduct the sessions with sensibility and emphaty towards the different work contexts and emotions regarding difficulties and challenges within individual situations. In the beginning of both focus groups each participant was asked to introduce themselves shortly, their names, their occupation and experience considering formal/informal care.

In Italy, moderators employed various strategies to create an encouraging and welcoming atmosphere, enabling participants to share their experiences with honesty and authenticity. Conversations covered the successes and advancements in the sector, as well as the emotional toll of caregiving, providing a holistic understanding of the complex factors influencing the caregiving environment. Participants received detailed explanations about the study's goals and their rights, promoting an open line of communication and promoting trust. Consent was obtained to affirm their willingness to share experiences for the betterment of caregiving practices. Moderators expertly guided the discussions, ensuring that every participant's viewpoint was acknowledged and heard. The moderator was Valeria Lavano, project manager of the ICWE project, specialised in International Political Studies with a Master's degree in International Cooperation and Global Affair & PNRR. Formerly a political analyst. She has a decade of experience in the world of volunteering and multiple lived experiences in Italy and abroad. She specialises in the field of local development and cooperation policies.

In Ireland, focus groups were facilitated by Jim Phillips who has extensive experience of developing resources for carers and group facilitation. As the numbers were small each participant had time to share their views in depth and a wide-ranging discussion was facilitated. There was a very high level of agreement on key issues facing carers and being in a paid capacity.

In Greece, the first focus group was moderated by a sociologist - researcher and the second one by a social worker and educator. Both moderators were experienced in working with people in vulnerable situations and therefore sensitive on important ethical issues like confidentiality, active hearing, nonjudgmental approach and a gender sensitive approach. The focus groups started with some ice-breakers activities for the participants to familiarise themselves with the group and feel comfortable expressing their opinions. The moderators began the sessions by introducing themselves and explaining the purpose of the focus group. They also encouraged the participants to introduce themselves and share a bit about their experiences related to caring. In addition, it was made clear to all participants that there are no right or wrong answers and that all perspectives are valued. Then, the conversation about their experience in caring started and everyone shared their experience. Active listening and making eye contact on behalf of the moderators were very important for the smooth implementation of the conversation. Moreover, summarising the key points was very helpful for the development of the discussion. Finally, the moderators emphasised giving space to people who were more introverted and put some limits to others who tended to interrupt others.

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Focus groups in Cyprus were facilitated by Ms. Andri Agathokleous, an experienced external collaborator of CARDET - a licensed psychologist and Systemic/Family Psychotherapist with more than 10 years of experience in the field of wellbeing.

## Focus Group Management and Analysis

Following provided guidelines, after obtaining consent by focus group participants, project partners recorded their sessions, transcribed the data and analysed them following the thematic analysis framework outlined by Braun and Clarke (2006). This framework helps to summarise findings using codes and labels that indicate what is being contributed or discussed by each statement. These can be key-ideas or concepts, referring to behaviors, values or emotions. After coding, partners identified themes, being the final output of the analysis. Through this method, the lengthy data captured from the various participants can be summarised and reported in a concise manner, but one which accurately reflects and meaningfully captures the responses collected for each question. In each partner country, recorded audio and/or video material was transcribed into partner languages, transcribed and findings summarised using categories to define key-ideas, concepts and themes.

# Results Focus Groups Informal Carers

The following section will present the key themes from each focus group with informal carers (ICs), organised by partner country. Subsequently, a summary will highlight the similarities and differences in the identified themes across the participating EU countries.

## Theme Results Germany

### 1. Lack of Recognition and Respect

Caregivers expressed their frustration at being called an informal caregiver and the feeling that this terminology undermines their contribution compared to professional caregivers.

### 2. Financial Strain

ICs were explaining that they had to quit their job to care for their parents, indicating that financial support from the state is inadequate. Another IC shared that they do not receive any financial aid because the state does not recognise the need for it in their situation, adding to their financial burdens.

### 3. Emotional and Psychological Stress

The role reversal in caregiving relationships was discussed, with one caregiver highlighting the difficulty of imagining being cared for by their children. Several caregivers noted the emotional challenges of watching their loved ones suffer.

### 4. Impact on Personal and Professional Life

Two caregivers spoke about the strain on their personal lives and careers, indicating that caregiving responsibilities have led to significant lifestyle changes and sacrifices.

### 5. Discrepancies Between Legal Rights and Reality

ICs pointed out the gap between the legal support supposed to be provided by the state and the actual support received, leading to additional challenges for caregivers.

## Theme Results Portugal

### 1. Challenges of the Informal Carer: Psychological Burden and Impact on the Family

*Availability*: Informal carers frequently discussed the need to "always be available." Since they care for a family member who, in most cases, is in a situation of total dependence, informal carers expressed their burden of not having time for other activities, friends, or family events. They continue their care work after their "paid work." Some participants had to stop or leave their jobs to look after a family member full-time, feeling like they had nothing else to do outside of work and care. The feeling of always being available also made it difficult for them to value breaks and take time for themselves to rest.

*Emotional and Psychological Burden*: Along with always being available, informal carers reported psychological fatigue and detrimental effects on their mental health. Being restricted in taking time for themselves, they were neglecting their own health (both physical and mental). Additionally, most of them expressed a feeling of being alone in their care duties and feeling solely responsible for the care work. When it comes to older adults, such as the parents of informal carers, they were regularly confronted with changes in their parents' personalities, for example due to Alzheimer’s, and the possible death of the family member they care for. In this sense, a sense of "grieving" is always present. At the same time, many expressed feelings of guilt; guilt for feeling tired and exhausted, and guilt for not being able to do more to comfort their loved ones. One participant talked about having anxiety attacks and crying frequently in their daily life. Informal carers find themselves in a caring situation that is constantly changing and evolving, which requires competencies in adaptation and effective coping behaviour. All these situations can lead to a feeling of being overwhelmed and incapable.

*Impact on the family*: Most informal carers reported that the situation at home required significant adaptation for the whole family. Participants stated that the emotional connection to a family member in their care made many situations even more challenging. Especially grandchildren would suffer from the situation at home, and it certainly had some impact on family relationships. On the other hand, a lack of family support was described, along with a feeling of being disappointed by the family in the context of one daughter taking care of a parent alone.

*Work and dedication*: Despite the demands of the care situation on all family members, participants stated that their dedication stems from love and affection for their loved ones. They feel like they are giving something back to their parents. At the same time, caring for someone was described by most participants as "something new," and they expressed difficulties due to their lack of knowledge in the area.

### 2. Lack of Support, Resources and Overwhelming Bureaucracy

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*External support and resources*: Alongside a feeling of lacking support from their own family members, a central topic during the focus group was the lack of resources and knowledge about the official status and rights of the informal carer in Portugal. Participants felt a lack of tools to deal with the situation at home and often lacked knowledge of support networks and national and regional help resources. On the one hand, they missed certain external public support; on the other hand, they felt it necessary to raise awareness of the situation of informal carers – including among professionals. They asked for help on how to reach support organisations and expressed the need for, for example, an online platform for support and exchange of ideas. Often, they did not feel "heard" and sensed a lack of communication and information about external support possibilities.

*Training and knowledge*: As the care situation was somewhat unexpected and new for most participants, they expressed a lack of experience and knowledge on certain topics. They reported often not being prepared for the care situation at home and the need to educate themselves and prepare family members about possibilities and structures (e.g., preparing parents for nursing homes).

*Communication and bureaucracy*: Participants described complicated bureaucratic processes and a lack of communication between external services. They stated it would be useful to create a support network and/or application to address this matter.

### 3. Specific Challenges in Care: Violence and Aggression, Mental Illness and Prejudices

*Violence and aggression*: A central topic that was mentioned in different contexts was the occurrence of physical and verbal violence and aggression in the care environment. As mentioned before, caring for a family member is demanding, and participants reported feeling exhausted and unable to take time to rest. Often, due to dementia symptoms in family members (especially parents), participants described situations at home where they were exposed to verbal or physical violence by their parents and did not know how to deal with them. Even though they knew it was part of the illness, they felt incapable and overwhelmed.

*Care and mental illness*: Especially when it comes to Alzheimer’s or dementia, participants described difficult situations in their daily care work. They expressed a lack of knowledge about mental symptoms, including those of dependent adults with disabilities or functional diversity. Participants felt there were prejudices towards adults with disabilities and also towards the elderly (ageism). They sensed a need to receive more knowledge about different mental illnesses.

*Prejudice and communication*: Often, informal carers found themselves in situations where they had to talk about difficult topics. This could be in situations where they were confronted with issues such as violence and death, but also when discussing with their parents the possibility of going to a nursing home. Participants expressed the need to work on prejudices about the elderly (ageism) and the need to know better how to communicate with parents. Often, these situations caused feelings of guilt or the lack of competence to set boundaries between themselves and their parents.

## Theme Results Italy

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### 1. The Emotional Impact of Caregiving

The focus group discussions revealed a significant emotional toll experienced by both informal caregivers and professional caregivers. For informal caregivers, the emotional rollercoaster of tending to loved ones was openly discussed, with many reporting feelings of worry, anxiety, and burnout. These conversations highlighted the immense psychological burden that comes with being an informal caregiver. Participants emphasised the need for empathy and support from social networks and medical professionals, as well as the importance of validation in overcoming emotional challenges. Despite feeling overwhelmed by their responsibilities, ICs also expressed a profound sense of satisfaction and meaning derived from caring for their loved ones. They stressed the necessity of compassionate and respectful treatment from both medical professionals and community members, noting that a lack of understanding and empathy exacerbated feelings of isolation and frustration.

### 2. Financial Stress, Workplace Difficulties, and Resource Constraints

Apart from the emotional complexity of caregiving, participants highlighted significant financial stress and career obstacles faced by both informal and professional caregivers. Informal caregivers shared experiences of sacrificing professional advancement, reducing work hours, or even quitting their jobs to fulfill their caregiving responsibilities. The financial burden of caregiving, including out-of-pocket expenses for medical supplies, transportation, and home modifications, was a major source of stress and anxiety. Many participants expressed frustration over the lack of financial resources and assistance, particularly for those without adequate insurance or savings. Balancing work and caregiving duties was another significant challenge, often leaving ICs feeling torn between their job and caregiving roles. This issue was exacerbated by employers' lack of understanding and flexible work schedules, contributing to financial insecurity and a sense of being unsupported.

### 3. Services for Temporary Care and Interdisciplinary Collaboration

During the focus group discussions, informal caregivers and professional caregivers both identified crucial needs that could enhance their caregiving roles. For ICs, the need for respite care services emerged as a significant theme. They stressed the importance of having access to temporary caregiving support to relieve the pressures and obligations of their roles, even if only temporarily. In Italy, respite care services are provided through a collaboration of respite care agencies, community groups, and local healthcare practitioners. These services, which can include in-home care support, day programs, or short-term residential care options, allow ICs to take necessary breaks and prioritize their own well-being. The ICWE project acknowledges the critical role of informal caregivers and aims to provide them with the resources and support they need to sustain their caregiving efforts over the long term by addressing the demand for respite care.

## Theme Results Ireland

### 1. Access to Formal Support

Issues such as accessing respite care, ongoing support and reliability of formal care was a key issue. This has wide ranging impacts on different levels:

*Financial Impact*: Not being able to rely on formal care for some made it impossible to work. The one exception was the participant who could work from home. Otherwise for the majority the unreliability made employment very difficult.

> *"But I tried to go back to work at the start,*
>
> *but it just like then the carers didn't turn up*
>
> *and I was back to square one again"*
>
> - IC Participant Ireland –

*Impact on Emotional wellbeing:* Lack of access to respite care leads to increased levels of stress. This impacts on all areas of life. In addition, the difficulties in applying for formal care support are very emotionally draining with participants having to appeal against first decisions. It should be noted though that once formal care had been secured there was a high satisfaction with what they received.

> *"So even when you do manage to get the support you're legally entitled to, it doesn't necessarily manifest fully in the way I should. But even when you've gone through that, there's an issue that just not resources there to actually give you, to actually then give you what you needed"*
>
> - IC Participant Ireland -

This was equally expressed by people in a formal capacity, they expressed feeling frustrated by the limitations placed on them.

### 2. Financial Impact of Caring

As mentioned above the restrictions on employment opportunities left many reliant on state allowances having a significant impact on financial situation. This is further exacerbated by higher running costs such as heating etc. Income and means Testing-where either the carer's own income, their partners income, or household income exceeds eligibility thresholds was also discussed and a significant factor.

### 3. Carer Health and Wellbeing

This was broad ranging covering both mental and physical health. Issues such as loneliness and isolation trough to stress and depression.

> *"It's the time limitations, stress and just the fatigue and isolation,*
>
> *that lack of connection with others,*
>
> *you know, losing connection with others"*

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- IC Participant Ireland -

Wellbeing was a key theme, often people were dealing with their own long term illness or had others in the household. The combination of lack of formal resources to rely on, finance and the additional emotional burden of caring al combine to have a significant impact.

### 4. Resources

A long discussion was help on what resources would be useful. There was agreement that there are a wide range of resources available already - key issue is time and access. It was also recognised that information on its own would not solve many of the issues faced Information needs to be able to be read and understood quickly- noy having to scroll through large amount of text or webpages. Simple design with clear sections you could access when needed.

Key areas participants would find helpful were:

- Where to access peer support in a safe confidential space (both IC and professionals)
- Access to high quality information on legal status and how to apply for support
- Menu of options covering range of support issues:
  - Mental and emotional
  - Physical wellbeing
  - Practical help- housing, aids
  - Support lines.

## Theme Results Greece

### 1. How Being a Caregiver Changes your Life

All the participants made it clear that being an informal caregiver is mentally exhausting. As one participant put it, “*it's like losing yourself in the process*”. Relationships are affected, self-care is neglected, and work life is also affected. It was shocking hearing from one participant that “*I did not enjoy my children's childhood because I was taking care of my father*”. This phrase shows in a strong way that the caregiver's relationships are affected, and he needs support to connect with his environment and feel empowered. Informal carers are forced to dedicate themselves in caring their person in need that they leave behind taking care of themselves and the rest family. They forget about their wellbeing as their priority becomes the person who needs the care. This situation results in feelings of fatigue, emotional exhaustion and depression. Many informal carers choose to leave their work to take care of their person as their alternative is private care centers that they cannot afford.

### 2. The Need of Support from the State

All without exception the participants underlined the need to receive support from the state and their social environment. Both informal carers and the professionals confirmed that the state is totally absent regarding the practical support of the informal carers and the people that need the care. There are no public services to support the informal carers, and this means that they are alone to cope with the difficult task of caring their person. In addition, most informal carers don't know where to ask for support as there is no guidance from the hospitals or the doctors. The support they need is wide from the provision of medical aid and psychological support to raising awareness among the community about the particularities of being a carer and education about the different types of care regarding the health problem of the patient. For example, a physically disabled person needs different care from a person with dementia. There are some associations of informal carers that they claim benefits of a welfare nature and the opening of guest house for people who need continuous care. However, they don't organize training that would be very helpful for the informal carers.

### 3. Lack of Officially Trained Carers

There is no official training from the state for caregivers. Most of them learn how to care in practice while it is a very important job with big responsibilities and many challenges. A very common phenomenon in Greece is that many families choose to hire migrant women to take care of their members in need of continuous care. These women live with the patient for 24 hours and they usually take care also of the housework. They have not received training on how to care for the patient according to his/her needs and most of the time; they don't even speak the language of the person they take care of. Therefore, communication between them is very difficult and this fact causes another problem for the cared person. This phenomenon is result of the lack of public infrastructure that can host and care people who need it. There are some private centres, but they are very expensive and families with average incomes cannot afford them.

### 4. Care Giving as an Empowering Process

One other result that emerged during the focus group with the informal carers is that through the process of caring, they also gain things. As one participant put it "*You become a more responsible person. You appreciate what you have. It's a valuable experience that made me stronger and more capable of going through difficult situations*." One other participant said that «*I became more resourceful; I found new ways to cook suitable foods for my sick father*». To sum up, as emotional exhausting the caring can be, when it finishes, informal carers are stronger, and they have gained useful skills. One other participant stated: "*After the loss of my father whom I had been taking care of for years, I decided to become a formal carer working with people with dementia. I had the experience and the skills to take over this job*".

## Theme Results Cyprus

### 1. Juggling Numerous Responsibilities and Impact on ICs Health

Caregivers often find themselves juggling numerous responsibilities, from scheduling healthcare appointments to managing finances and facilitating social interactions for their elderly loved ones. This juggling act takes a toll on their mental and physical health.

> "*As people get older and their mobility decreases, the demands on their caregivers skyrocket.*

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*Making sure they're fed and looked after becomes a bigger challenge*."

- IC Participant Cyprus -

### 2. Struggles with Technology

Moreover, many elders struggle with technology, relying on caregivers for tasks requiring digital skills. As one caregiver put it, "*Helping family members with tech stuff and other tasks they can't handle alone is a big part of caregiving*."

### 3. Putting Social Life on Hold

In addition, caregivers often put their own social lives on hold to meet their caregiving responsibilities, leading to feelings of isolation and a lack of personal time for self-care.

"*It's important to keep them company, but that also means*

*I have less time for my own social life."*

- IC Participant Cyprus -

### 4. Finding Fulfillment in Caregiving

Despite the challenges, many caregivers find fulfilment and purpose in their roles, driven by love and the desire to support their family.

"*Being a caregiver is not just about necessity;*

*it's about love and wanting to help and support my family*."

- IC Participant Cyprus -

The altruistic nature of caregiving, where assistance is given without expecting anything in return, deepens caregivers' sense of humanity and connection.

"*We rely on each other as human beings and selfless assistance means a lot* […]"

- IC Participant Cyprus -

### 5. Need for Support and Frustration with Healthcare System

Participants also voiced frustration with the hurried nature of the healthcare system, especially the limited time allotted for consultations. This rushed approach, particularly challenging for seniors with sensory impairments and limited medical knowledge, was seen as a significant hurdle. It was perceived as marginalizing the elderly and adding to the burdens faced by informal caregivers. They stressed the need for more support and assistance from the government, pointing out the lack of dedicated services for the elderly and other vulnerable groups like Community Nursing in Cyprus.

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## Similarities and Differences between EU countries

### Common Themes Across Countries

*Emotional and Psychological Burden*: A significant theme present across all partner countries is the emotional impact of caregiving. ICs spoke about emotional exhaustion, anxiety, and burnout, often resulting from the constant demands of caregiving. In Germany, caregivers mentioned the emotional stress of role reversals, while in Portugal, ICs experienced ongoing grief and guilt. Italian ICs highlighted feelings of anxiety and worry, similar to the emotional strain expressed by Irish and Greek caregivers. ICs often neglect their own well-being, a sentiment particularly emphasised in Greece and Cyprus.

*Impact on Personal and Professional Life*: The caregiving role often leads to significant personal sacrifices, with many ICs having to quit their jobs or reduce working hours to provide care for their loved ones. This was reported in Germany, Portugal, Italy, and Ireland, where the inability to balance work and caregiving responsibilities contributes to financial strain and professional setbacks. Caregivers in Cyprus also noted how caregiving responsibilities impact their social lives and contributed to feelings of isolation. The effects of informal caregiving on personal and family life were deeply felt in all partner countries.

*Financial Strain and Lack of State Support*: ICs in all six countries expressed concerns regarding inadequate financial and institutional support. In Germany, ICs faced insufficient financial aid, while in Portugal, Ireland, and Greece, the lack of support from the state and overwhelming bureaucratic processes were commonly frustrating. Greek caregivers were particularly upset about the absence of public services, and Irish participants stressed the financial burden due to unreliable formal care. Across the board, ICs reported that state support, when available, often does not provide of what is needed.

*Need for Respite and Professional Support*: Caregivers in nearly all countries discussed the need for respite care to alleviate the demands of caregiving. Italian participants specifically called for respite care services, while caregivers in Ireland expressed frustration with the difficulty of accessing formal support. This was also expressed in Cyprus, where caregivers feel the lack of healthcare system and governmental support. The demand for respite care and formal assistance highlights a need for institutional intervention and support across all partner countries.

### Differences Across Countries

*Cultural Context and the Role of Family*: In Portugal and Greece, the emotional connection to family members appeared to intensify the caregiving burden. Portuguese ICs often spoke about guilt and anxiety, especially in the face of familial expectations, while in Greece, the emotional impact of caregiving was described as mentally and emotionally exhausting. In contrast, caregivers in Cyprus and Italy expressed a sense of fulfillment in their roles, despite the challenges, seeing caregiving as an act of love and duty.

*Technology and Bureaucracy*: A notable difference emerged in Cyprus, where caregivers frequently dealt with elders' struggles with technology, adding another layer to their responsibilities. In contrast, ICs in other countries did not emphasise this issue as much. Furthermore, bureaucratic challenges were

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more pronounced in Portugal and Ireland, where the complexity of applying for state support or formal care services added to caregivers' stress.

*Prejudice and Societal Views*: In Portugal and Greece, there was a focus on the societal prejudices faced by ICs and the elderly. Portuguese caregivers discussed the stigma surrounding mental illness and ageism, while Greek ICs mentioned the challenges of finding trained caregivers, particularly migrant workers, who often face communication barriers and lack formal caregiving training.

*Access to Formal Support*: In Ireland, participants highlighted the difficulties of accessing reliable formal care, which was seen as essential for balancing caregiving with work. The financial impact of inadequate formal support was a central issue, contrasting with Italy, where respite care services, though limited, were available. In Cyprus and Greece, the lack of structured state services for elder care was particularly expressed.

Overall, despite some differenced within identified themes, the key themes of emotional strain, financial stress, lack of state support, and the impact on personal and professional lives were consistent across all six partner countries. While cultural factors, the role of family, and access to state and formal support may vary between countries, these insights point to the need for more robust, universally accessible support systems, specified as well to the cultural and bureaucratic landscapes of each country.

## Results Focus Group Formal Carers

The following section will present the key themes from each focus group with formal carers, health professionals and adult educators, organised by partner country. Subsequently, a summary will highlight the similarities and differences in the identified themes across the participating EU countries.

### Theme Results Germany

#### 1. Integration of Formal and Informal Care

Collaboration between formal and informal caregivers is essential. The role of formal caregivers working with other healthcare providers was highlighted as crucial for addressing patients' long-term needs through effective integration and communication.

#### 2. National Long-Term Health System

Significant issues within the national long-term health system were identified, including fragmentation and uneven distribution of resources. These structural inefficiencies lead to disparities in care delivery and negatively impact the efficiency of long-term care services.

#### 3. Challenges Faced by Informal Carers

Informal carers face substantial challenges, such as feeling overwhelmed and lacking sufficient support. Specific issues like lack of support, financial burdens, and insufficient resources contribute to the stress and difficulties faced by informal carers, impacting their quality of life and ability to provide care.

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### 4. Complementary Roles of Formal and Informal Carers

Improved communication and coordination between formal and informal carers are crucial. Effective teamwork and information sharing are necessary for ensuring that care recipients receive the best possible support, leading to more comprehensive and effective care delivery.

### 5. Improvements Needed to Support Informal Carers

Increased financial support and better access to respite services for informal carers are necessary. Additionally, broader structural improvements within the long-term care system are essential to reduce the pressures on informal carers and enhance their overall care environment and quality of life.

## Theme Results Portugal

### 1. Burnout of Informal Carers

Throughout the focus group discussion, the influence of informal carer's burnout and burden was heighted, with care workers most notably disclosing physical and communicational violence, negligence and impulsivity towards the care recipient as effects of the no longer ability of the families' members in dealing with the disease symptoms, needs and requirements.

*"And I think that even the response of physical violence also happens the other way around, namely from the caregiver to the person being cared for, which often comes from the result of a state of such exhaustion that impulsiveness comes out, that aggressiveness comes out. And it is precisely these issues that need to be addressed"*.

- FC Participant Portugal -

Participants further shared those difficulties in managing the care recipient diagnosis, symptomology required, on behalf of informal carers, Information and Training and Psychosocial, Institutional and Community support, giving rise to these themes.

*"I also have a case here, a family member of which, when his wife, who has dementia, was institutionalized, came here completely fragile. He came in here crying, and not because of the institutionalization, but because he said "I can't take it anymore. Our relationship was no longer healthy", because he no longer responded in a normal way, as would be his personality and the relationship they had."*

- FC Participant Portugal -

### 2. Information and Training

Care workers and adult educators were clear and consistent on the social, legal and technical needs of informal carers, mentioning that they most notably lack training and information in the caring scope. Information and training needs were heavily rooted in environmental challenges that pose barriers to the informal carer in obtaining relevant information and developing caring competences. These challenges regarded to a lack of training opportunities; to an inaccessibility of social information, of which was significant associated with informal carers literacy level; to information not being well distributed for informal carers from the relevant sources (i.e., social security); to the erratic nature of the legislation and to the inexistence of standard set of criteria that leads to social benefits to every informal carer and in an equal manner.

The difficulty in accessing to information has led to a high demand from informal carers to social organisations, of which, unfortunately, they also seem to not be able to respond. The Institutions' Role emerged as mediating the relationship between a default environment and a disinformed and untrained informal carer. From one side, if informal carers believe that is the role of the institutions to support their informational needs, the institutions themselves believe that this is also a responsibility of theirs. Therefore, institutions devote a significant part of their activity to become knowledgeable of the most recent updates, so they are able to provide information to the informal carers and to forward to the specific services.

Information and Training of the informal carer was seen as a facilitating point for their own support. Adult educators and care workers shared that such training would allow the informal carers to have the needed access to the existence support options, to norms and legislation and to the existence of support services and how this work. Participants also mentioned that training addressed to an understanding of the disease and how to manage the diagnosis influence on the life of the care recipient and informal carer would play a very important role. The management of the diagnosis was mostly addressed to the support of the care recipient in adapting to a new identity, and to the development of communicational and mediation skills in the informal carer to better deal with the high and overall optimistic expectations of the care recipient.

Participants during the discussion explored that informal carer's risk for burden is heightened when the care recipient has difficulties accepting their diagnosis, needs and systemic barriers that come from it, leading the informal carer's inability to say "no" to their loved one when they want something at their own terms, leading the care recipient to manage everything in the family circle.

### 3. Psychological Support

Psychosocial Support was a theme that emerged during the care workers discussion. This theme was mostly addressed regarding the cases in which informal carers battle against the decision of permanent institutionalisation. Therefore, the Elements of Resistance to Institutionalisation and Signalisation subtheme gave rise. Care workers in the group mentioned that this internal contesting occurred more promptly due to personal feelings, and from difficulties in understanding when it is time to institutionalise their loved one.

Feelings of guilt and embarrassment and fear arose as individual motivators for not signalising domestic violence cases. Informal carers in this context don't want further to compromise their loved

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one, whether due to fears of hurting back physically the care recipient, or feelings of guilt. Participants significantly addressed the importance of psychoeducation, sensibilisation and psychological support in the informal carer.

Participants further added the role key-professionals have in the providence of psychosocial support to the informal carer. They highlighted the importance case managers, health professionals, specifically the ones in primary care facilities, and psychologists have. Whilst psychologists were introduced as the primary elements to offer psychological support, case managers were introduced as supportive elements within families where there is a clear disproportion of responsibilities and roles within the care of the care recipient, and health carers as elements whose adoption of a biopsychosocial approach could support the prevention of caregiver's burden or the handle the symptoms in an early stage.

### 4. Role of Institutions - Public and Private

The role of institutions in informal carer's well-being ran through most care workers talk about their needs. Institutional support was depicted as necessary to alleviate families from their duties, roles and responsibilities and to have time for themselves and their own needs. Informal carers face difficulties in managing their professional, personal and care spheres. The Portuguese economic system was displayed as a factor contributing for informal carer burden, as the regular informal carer is not privileged enough to abdicate from a professional income to fully provide care. Institutionalisation was then seen as an alternative response to care for the care recipient needs and to not overburden the informal carer with its own professional and personal concerns.

Not only institutionalisation, but the importance of social services valences was focused by our participants in supporting informal carers managing their work-life realms. While these social services valences benefit the care recipient in developing key-competences (whether basic or instructional), also alleviate families by giving them time for their own duties and responsibilities, such as professional work. Unfortunately, care professionals revealed that long-term facilities, specifically permanent and temporary institutions are not being capable of answering to the amount of informal carer's requests on institutionalization vacancies.

Moreover, Portuguese Social Security Services does not allow from residential services to use the nonoccupation vacancies that are exclusive to emergent situations, in a temporary regime, and so to use it in benefit of the informal carer's much needed rest. This left room to participants share that there is a lack of vacancies exclusively to the informal carer's rest. Unfortunately, informal carers shared that the lack of vacancies dedicated to family's rest was also influenced by the great weight families are putting into long-term care residences in requesting more vacancies for the care recipient institutionalisation. Additionally, the lack of availability of institutional vacancies meant a higher burden for families that care for highly aggressive care recipients under 18, as a significant proportion of them are expelled from the school institutes and there are not any permanent residence prepared for such cases, leaving no social responses options for these families.

The barriers considering the extent of support, whether residential or other, provided from social and health institutions to care recipients' families discussed within the focus group differed from public

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and private institutions. Public care providers significantly mentioned that, if, from one side, their intervention and action are only possible due to public funding and partnerships that they create with relevant stakeholders – hospitals, Public Ministry, Commission for the Protection of Children and Young People at Risk and so on -, from the other, the extension of their support to the care recipient and informal carer, when the funding stops, are highly dependent on the institutional teams' values and motivations, own resources and volunteers.

Public workers shared, within this scope, that, unfortunately, projects are temporary because there is a lack of response from the dedicated entities to continue funding for the projects. This means that whilst the project is funded families and care recipients benefit from the project activities and resources, but as soon as the funding ends, care within the same conditions stops being delivered. This obligates institutions to actively search for other financing sources and projects that guarantee them to best support their target-groups, otherwise, they will no longer be available to deliver the needed care.

On a different note, care workers from the private sector shared that being viewed as competition from and to the public institutions did not allow for a collaborative work, further limiting the provided support to care recipients and their families.

Further systemic barriers were addressed by care workers, whose imposed significant difficulties for informal carer's well-being. This discussion led to the (lack of) support informal carer's who are victims of domestic violence from the care recipient because of disease symptoms (i.e., memory loss and disorientation from dementia cases), receive from the official services and institutes when they are signalised. Most notably, the discourse revolved around the absence of monitoring and timely intervention to stop the abuse and initiate the needed measures, such as the institutionalization of the care recipient.

### 5. Relationship between Care Workers and Informal Carers

The relationship between social and health technicians and care recipient's families was addressed as a factor contributing to a quality care. If, from one side, the family must be responsible for and an active member of care decisions regarding their loved one, from the other, the extensiveness of the things they are responsible for, needs to be delimited along with the formal carer. The discussion concentrated in a shared and articulated relationship, whose responsibilities are well delineated for each agent and limited to the context in which they deliver care. In this sense, both agents should not impose own's conditions and wishes in a context in which they don't work in.

### 6. Community Support

Community Support was a theme that arose as an ideal measure that would allow to fully meet the necessities of informal carers and care recipient's families, and "(…) to best serve the other". Needs such as the Institutional support, arising from difficulties in work-life balance and finding residential vacancies for the care recipients, required, from the care workers point of view, a higher involvement of the community in caring for someone. Community care was perceived as involving home-care services, neighborhoods, Private Social Solidarity Institutions, Parish Councils, volunteers.

Unfortunately, as some participants highlighted, volunteering experiences are undervalued in the national context of Portugal, and institutional-community care paradigm is still yet to change.

## Theme Results Italy

### 1. The Emotional Impact of Caregiving

The focus group discussions revealed a significant emotional toll experienced by both informal caregivers (ICs) and professional caregivers. Professional caregivers often shared highly satisfying experiences that demonstrated the significant impact of their profession. They recounted moments of joy and accomplishment, such as witnessing a patient's recovery after months of intensive care and therapy. These stories highlighted the deep bonds formed between caregivers and patients, underscoring the emotional fulfillment that comes from providing care. Participants spoke of the comfort and companionship they offer to patients during difficult times, noting how small acts of kindness, like holding a patient's hand or listening to their concerns, can significantly enhance the quality of life for those they care for. While acknowledging the emotional difficulties inherent in their work, professional caregivers also emphasized the resilience and strength they gain from their experiences. They highlighted the supportive camaraderie within the caregiving community, where colleagues offer mutual support and encouragement during challenging times.

### 2. Financial Stress, Workplace Difficulties, and Resource Constraints

Apart from the emotional complexity of caregiving, participants highlighted significant financial stress and career obstacles faced by both informal and professional caregivers. Professional caregivers also faced resource constraints that affected their ability to provide optimal care. Some caregivers reported having to ration essential medical supplies due to shortages, which negatively impacted the quality of care provided to patients. Others spoke about the stress of managing multiple tasks simultaneously, leading to feelings of anxiety and exhaustion. Participants proposed several solutions to address these resource limitations, such as increasing budget and resource allocation, streamlining the procurement process to ensure timely delivery of supplies, and implementing innovative staffing models to optimize workforce utilization.

Together, the themes of financial hardship, workplace difficulties, and resource constraints underscore the diverse challenges faced by both informal and professional caregivers. They highlighted the urgent need for systemic changes, including better financial support, flexible work arrangements, and improved resource management, to alleviate the burdens on caregivers and enhance the quality of care they provide.

### 3. Services for Temporary Care and Interdisciplinary Collaboration

During the focus group discussions, informal caregivers (ICs) and professional caregivers both identified crucial needs that could enhance their caregiving roles. For professional caregivers, the theme of interdisciplinary collaboration was highlighted as essential for delivering comprehensive and integrated care. Participants underscored the benefits of working alongside professionals from various fields to create cohesive care plans tailored to patient needs. One caregiver shared an example of successful collaboration with social workers and physical therapists to develop a personalized care plan for a patient recovering from a stroke, demonstrating the synergy that can be achieved through multidisciplinary teamwork. However, challenges in coordination and communication among different healthcare teams were also noted. To enhance interdisciplinary collaboration, participants suggested regular multidisciplinary team meetings, clear definitions of roles and responsibilities, and the use of technology to facilitate collaboration and information sharing across departments.

## Theme Results Ireland

### 1. Financial Impact of Caring

The focus group with formal carers identified similar challenges and needs regarding the reality of ICs, ranging impacts on financial level and regarding their emotional well-being. Not being able to rely on formal care often makes it impossible to work for ICs. Exceptions were discussed, regarding ICs who could work from home. Restrictions on employment opportunities leaves many ICs reliant on state allowances, having a significant impact on financial situation. This is further exacerbated by higher running costs such as heating etc.

### 2. Impact on Carer Health and Emotional Well-being

Lack of access to respite care leads to increased levels of stress experienced by ICs. This impacts on all areas of life. In addition, the difficulties in applying for formal care support are very emotionally draining with participants having to appeal against first decisions. This was equally expressed by people in a formal capacity, they expressed feeling frustrated by the limitations placed on them. Experienced health difficulties seem to have a broad ranging covering both mental and physical health. Issues such as loneliness and isolation trough to stress and depression. The combination of lack of formal resources to rely on, finance and the additional emotional burden of caring al combine to have a significant impact.

### 3. Lack of Resources

A long discussion was help on what resources would be useful, with ICs and formal carers as well. There was agreement that there are a wide range of resources available already - key issue is time and access. It was also recognised that information on its own would not solve many of the issues faced Information needs to be able to be read and understood quickly- noy having to scroll through large amount of text or webpages. Simple design with clear sections you could access when needed.

Key areas participants would find helpful were:

- Where to access peer support in a safe confidential space (both IC and professionals)
- Access to high quality information on legal status and how to apply for support
- Menu of options covering range of support issues
    - Mental and emotional
    - Physical wellbeing
    - Practical help- housing, aids

- Support lines

## Theme Results Greece

### 1. Being a Caregiver Changes ICs Life

Participants made it clear that being an informal caregiver is mentally exhausting. ICs often forget about their wellbeing as their priority becomes the person who needs the care. This situation results in feelings of fatigue, emotional exhaustion and depression. It was discussed that many informal carers choose to leave their work to take care of their person as their alternative is private care centers that they cannot afford.

### 2. The Need of Support from the State

All without exception the participants underlined the need to receive support from the state and their social environment. Both informal carers and the professionals confirmed that the state is totally absent regarding the practical support of the informal carers and the people that need the care. The professionals that work with the informal carers like social workers and psychologists need training how to work with the informal carers. Professionals highlighted that many times informal carers don't cooperate with the professionals because they don't feel confidence that professional will take care of their person as they would do, or they feel guilty because they leave the care of their person in "strangers" (this happens especially to older people that have grown up with the mentality that they must take care of their parents). This results in many difficulties in the cooperation of the professionals with the people who need the care. Therefore, informal carers need training how to care their person but also how to cooperate with the professionals that work with them for the caring.

### 3. Lack of Official Care Trainings

There is no official training from the state for caregivers. Most of them learn how to care in practice while it is a very important job with big responsibilities and many challenges. A very common phenomenon in Greece is that many families choose to hire migrant women to take care of their members in need of continuous care. It exists a lack of public infrastructure that can host and care people who need it. There are some private centres, but they are very expensive and families with average incomes cannot afford them. Recently, a Pilot Program "Personal Assistant for people with disabilities" concerns the provision of Personal Assistance to people with disabilities was announced by the government. However, it is still not shown if there will provide training to the people will be hired.

## Theme Results Cyprus

### 1. Need for Improvement of Carers Quality of Life

Improving the quality of life for carers was a key aspect that wasn't fully explored. Informal carers tended to focus more on the practical support they provide for their elderly loved ones rather than reflecting on their well-being and how it could be enhanced. When asked about facilitators for

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themselves, they highlighted the importance of practical assistance with tasks like shopping, medical appointments, medication management, and arranging social outings for their loved ones.

> "Assisting an elderly person with shopping, doctor visits,
>
> and medication is vital for their upkeep."
>
> - FC Participant Cyprus -

## 2. Need to Maintain Elderly Socially Integrated

Ensuring that the elderly maintain social connections through visits with friends and companionship from carers was also seen as crucial for their overall happiness and well-being.

> "Taking them for walks for socialization
>
> and keeping them company is essential for their well-being"
>
> - FC Participant Cyprus –

## 3. Promoting Good Relationships and Communication between Informal and Formal Carers, and the State

Establishing a relationship with a trusted healthcare professional was identified as crucial for receiving immediate support. Participants advocated for greater involvement and assistance from the state in caring for the elderly and vulnerable populations. They emphasised the need for comprehensive support systems to ease the burden on informal carers. Participants underscored the significance of medical visits and medication management for the well-being of the care recipient. Effective communication with healthcare professionals was deemed essential to ensure understanding and implementation of necessary care practices when the carer is alone with the recipient, serving as a potential barrier and facilitator.

## 4. Desire for a Comprehensive Support Platform Online

While the internet was recognized as a valuable resource for accessing information and support, participants acknowledged its limitations in providing immediate solutions compared to direct interaction with specialists. They expressed a desire for a comprehensive online platform offering practical advice on various aspects of daily caregiving, including health, entertainment, mental well-being, and strategies for maintaining morale and psychological resilience. Seeking specific advice and support was deemed essential, although participants noted challenges in accessing immediate assistance, such as securing hospital accommodations or contacting specialists outside of regular business hours. Participants also commended the explanatory approach of the nurses they interacted with, particularly in guiding hygiene-related care tasks.

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## Similarities and Differences between EU countries

### Common Themes Across Countries

*Need for Better Collaboration Between Formal and Informal Carers*: In every country, there was a shared emphasis on the need for improved communication and collaboration between formal and informal caregivers. Participants in Germany, Portugal, and Cyprus stressed the importance of integration and effective teamwork to deliver optimal care. Health professionals and formal caregivers highlighted that when communication is difficult, the quality of care suffers, and informal carers feel unsupported.

*Emotional and Psychological Stress*: Formal caregivers across the countries reported emotional strain similar to the expression of informal carers. In Italy and Portugal, professional caregivers noted burnout and emotional exhaustion, particularly in handling the long-term demands of caregiving. The emotional burden was linked to the challenge of forming strong emotional bonds with patients, which, while fulfilling, added to their mental health burden.

*Training and Education Needs*: Formal caregivers consistently mentioned that informal carers lacked adequate training and information, hindering their ability to manage caregiving effectively. In Portugal and Greece, formal carers underscored the absence of state-provided training programmes. Formal caregivers themselves expressed a need for more training to enhance their work with both care recipients and informal carers.

*Structural Deficiencies in Long-Term Care*: Partner countries identified systemic issues within their respective long-term care systems. In Germany, the fragmentation of the national long-term care system was highlighted, while Portugal and Greece reported a lack of state support, leaving both formal and informal carers to deal with insufficient resources. These structural deficiencies contributed to high levels of stress and burnout among caregivers.

*Financial Difficulties*: Formal and informal caregivers both reported financial difficulties in managing caregiving responsibilities. In Ireland and Italy, participants spoke of the strain caused by a lack of financial support, particularly when informal carers had to reduce their working hours or quit their jobs.

### Differences Across Countries

*Role of Institutions and Public Services*: The role of institutions in supporting caregivers varied slightly between countries. In Portugal and Germany, institutions were seen as critical for providing necessary respite and support services to informal carers, but these services were often not sufficient. In Greece and Cyprus, the absence of sufficient public services and infrastructure to support caregivers was a major concern. Public institutions in these countries were viewed as underfunded and unable to meet the demands of carers, especially in rural areas.

*Burnout and Aggressive Behaviour:* In Portugal, formal caregivers highlighted the issue of informal carers facing burnout to the extent that they sometimes displayed aggression towards care recipients. This was linked to insufficient psychological support and training in dealing with the emotional and behavioral challenges of care recipients, particularly those with dementia or Alzheimer’s. This issue was less prominent in countries like Ireland and Cyprus, where discussions around burnout focused more on emotional stress rather than violent incidents.

*Institutionalisation and Family Resistance*: In Portugal and Greece, formal carers discussed the reluctance of families to institutionalise their loved ones, often driven by feelings of guilt and emotional resistance. This created additional stress on families and caregivers who were unprepared to handle the care demands. In contrast, in countries like Italy and Cyprus, the focus was more on the lack of available institutional spaces, with caregivers willing to seek institutional care but unable to access it due to resource limitations.

*Role of Technology*: The role of technology in caregiving was discussed more prominently in Cyprus, where caregivers struggled with the technological needs of elderly care recipients. Formal carers noted that providing assistance with tasks like managing medical appointments or using devices was an increasing part of their role. In contrast, this issue was not as heavily discussed in countries like Germany or Ireland, where systemic issues took priority over technological concerns.

*Psychosocial and Community Support*: Psychosocial support was a key theme in Portugal and Italy, where formal caregivers identified the need for both emotional and psychological assistance for informal carers, especially regarding decisions about institutionalisation. In contrast, countries like Greece and Cyprus focused more on the practical support needed from communities, such as ensuring social integration for elderly care recipients and relieving caregiving burdens through neighborhood and community involvement.

While the overall caregiving experience in all countries shared common themes and challenges like emotional and psychological stress, financial difficulties, and the need for better collaboration, there were found some differences in how these challenges were manifested and addressed. Countries with more developed care infrastructure, like Germany, still faced issues of system fragmentation, while countries with less institutional support, like Greece and Cyprus, struggled with fundamental service provision. These insights pointing to a need for systemic reforms across all countries, emerging themes were mainly focusing on better training opportunities, improved collaboration between formal and informal carers, and greater financial and psychosocial support.

## Conclusions and Recommendations for IC Training

The ICWE project seeks to improve the conditions for ICs by addressing their needs, as identified: better access to training, professional support, effective communication with care professionals, and improvements to their overall well-being. The focus groups held across Germany, Portugal, Italy, Ireland, Greece, and Cyprus provided valuable insights into the challenges faced by ICs, as well as the role formal carers, health professionals, and adult educators play in supporting them.

One of the most prominent needs identified across all countries was the requirement for training, both for informal and formal carers. In several countries the lack of structured training programmes was highlighted, leaving informal carers to manage complex care situations without preparation. A need for training that equips ICs with practical skills and knowledge about legal frameworks and available support networks was enforced during implemented focus groups. The lack of training often leaves ICs feeling overwhelmed and unable to cope with the daily demands of caregiving, resulting in experiencing emotional and psychological distress. High levels of emotional exhaustion among ICs were identified across Europe, with many ICs struggling to balance caregiving responsibilities with their

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personal and professional lives. Feelings of isolation, guilt, and burnout were common, as informal carers felt unsupported both emotionally and logistically. Nevertheless, in some countries ICs expressed the dual nature of their emotional experience: while caregiving led to stress and anxiety, it also provided moments of deep personal fulfillment, where caregivers found a sense of purpose and fulfillment through their roles but were equally overwhelmed by the physical and emotional demands.

To alleviate this burden, focus group participants across countries emphasised the need for increased psychosocial support for reducing stress and preventing burnout. At the same time, professionals working with ICs require also more training, to understand how to work effectively with ICs, addressing their needs and challenges.

Another reocurring theme was effective communication between informal carers and formal care professionals and the need for better coordination between ICs and healthcare professionals was emphasised. Often, informal carers felt left out of important care decisions or lacked clear guidance on how to manage their caregiving responsibilities. Furthermore, ICs seem to often have to reduce their working hours or quit their jobs entirely to care for their loved ones. This lack of financial support, coupled with the absence of adequate respite services, contributed to high levels of stress. In some countries it was also noted that complicated bureaucracy prevented ICs from accessing essential services, leaving them feeling unsupported.

Formal caregivers play an important role in supporting the autonomy, competence, and self-efficacy of informal carers. They are able to empower ICs through education and collaboration, helping them feel more competent in their roles. The need for formal carers to provide not only practical but also emotional support to ICs was highlighted, especially in cases where ICs struggled to manage the emotional burden of their responsibilities.

All these findings reinforce the ICWE project’s goal to promote training programmes that empower both ICs and professionals to ensure they have the necessary skills to provide and manage care effectively and to improve ICs' well-being generally, by ensuring they have access to the necessary support systems. Training, professional support, better communication with care professionals, and improved emotional well-being were recognised as critical for improving the caregiving experience.

The main objective of the focus groups was the identification of the needs and realities of informal care from the point of view of informal carers but also adult educators and formal care workers. By addressing identified themes through a specific training programme, the ICWE project will have a meaningful impact on improving the quality of life for both informal and formal caregivers and in this way enhance care outcomes in general for those in need.

Based on the present results, the ICWE consortium proposes the following *recommendations* for the care situation in partner countries and the further development of the ICWE project and its resources:

- Develop a comprehensive training programme that covers the legal, social, and technical aspects of caregiving in partner countries. This programme should include information on managing specific illnesses, such as dementia and Alzheimer’s, communication skills, stress management and personal techniques. It should also include a part on how to deal with verbal and physical violence at home and provide tools and knowledge for the specific care situation, how to value breaks etc.

- Generally, the resources shall raise awareness and value the role of informal carers in our society – for the public, other informal carers and professional caregivers. They shall reduce prejudice about mental illness, disabilities and age-related discrimination.
- Ensure that informal carers have easy access to relevant information about support services, legal rights, and care resources. They shall know about the legislation and rights of the Informal Carer Statute in their countries. This could involve creating an online platform or helplines that provide up-to-date information and connect carers with necessary services.
- Find support groups and counselling services for informal carers to help them cope with the emotional and psychological demands of caregiving. Providing psychoeducation can help carers understand and manage their feelings of guilt, fear, and stress.
- Promote community involvement in caregiving through volunteer programmes and partnerships with local organisations. Encouraging community support can help alleviate some of the burdens on informal carers and provide additional resources the people who receive care.
- Promote better collaboration between public and private institutions to create a more cohesive support network for informal carers. This includes improving the accessibility of temporary and permanent institutional care options to provide respite for carers when needed.

## Limitations

The execution and analysis of the focus groups faced some limitations across countries. Across all partner countries, the small sample size may limit the ability to generalise the present results.

Additionally, in Germany the strong emotional connection between informal caregivers and care recipients may have biased responses, impacting the objectivity of the findings. Cultural, social, and financial factors also contributed to the diversity of caregiving experiences.

In Portugal, the absence of male participants restricted the diversity of perspectives, and participants found it challenging to discuss sensitive topics such as domestic violence in a group setting. The focus on caregiving as a labor of love further limited discussions on those who may not have strong emotional bonds with care recipients.

In Italy some demographic groups might have been underrepresented, and although privacy measures were in place, participants may have hesitated to share sensitive information. Additionally, conducting part of the focus groups online may have reduced the depth of interaction compared to face-to-face discussions. In Ireland, the lack of younger carers in the study and the group setting's limitation on addressing sensitive issues were noted.

Greece reported difficulty in recruiting informal carers for the focus group, while Cyprus faced limitations regarding the virtual setting of the discussions, which might have affected group dynamics and interaction. Phone-based interviews further may have reduced the participants engagement.

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## Participants Feedback

Generally, participants from all countries expressed a high level of satisfaction with the focus group process. In Germany, participants rated their satisfaction on a scale of 1 to 5, with 5 indicating "Completely satisfied." Overall, participants expressed a high level of satisfaction, particularly in the following areas: Clarity of information regarding the focus group; Understanding of their roles and responsibilities; Effective coordination within the group and clear and supportive communication with the project manager/coordinator.

In Portugal, informal carers shared positive feedback, particularly regarding the opportunity to exchange experiences with others. Participants appreciated learning about some new strategies for dealing with caregiving challenges and receiving information about available support. It seemed like the objectives of the focus groups were all explained well to the participants, and they understood well what was expected of them. They gave the feedback that the most valuing part of the discussion was “listening to the various situations shared and the support they can ask for”; “Sharing and obtaining previously unknown information”; “Experiences told...that we carry with us for life”; “Positive exchanges of experiences”; “It was an asset to be able to share our situation in a group, we were able to be understood”. However, one participant mentioned that the discussion could have focused more on the rights and duties of informal carers under Portuguese legislation.

In Italy and Greece participants provided a highly positive feedback regarding all anonymous ratings scales on a scale of 1 to 5 (mostly 4/5 ratings), while also in Ireland, the majority of participants indicated a high level of satisfaction. They appreciated the clarity of information about the focus group, their roles, and the effective coordination.

In Cyprus, participants also rated their satisfaction highly, with all aspects of the focus group receiving positive feedback. The clarity of information, understanding of roles, effective coordination, and supportive communication were all highlighted as strengths. Participants appreciated the pleasant atmosphere, good communication among participants, and the respect shown by the project leader. No negative comments were provided, and only one participant suggested a focus on the support needs of caregivers and the elderly.

Across all countries, participants generally expressed high satisfaction with the focus groups, particularly in terms of clear communication, well-structured coordination, and the opportunity to share their experiences.

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## About ICWE

ICWE aims to develop an easy to use and accessible website with resources and information regarding informal care, while delivering efforts towards the advancement of a training program for care professionals working with ICs and a toolkit for ICs, designed at covering their common faced needs when caring for other people. Looking at data for Long-Term Care (LTC) (European Commission, 2021), there are growing trends in aging population, life expectancy, and number of potential dependents in the household, that contribute to the increase of LTC needs in Europe, which, as evidence shows, is mainly done by ICs. Even though there is an expected growth in access for institutionalized assistance for LTC, the fact remains that the estimates for the raise in informal care far outweighs other forms of care availability. Informal care is currently the main form of care provided by people across Europe (Hoffman & Rodrigues, 2010). The project looks to address these barriers and ICs needs by developing an initial website where informal carers and care workers, as well as any relevant stakeholder, can get information on local/national/international policies and organisations working in LTC and informal care, as well as get concrete, up-to-date information on issues of informal care, common questions, and practical tools and considerations to help them in theals and a toolkit for adult educators (specifically those working in care professions) and for informal carers respectively, so that we can bridge the knowledge and skills gap identified, by capacitating adult educators so they can work with ICs efficiently, addressing their own needs, and by providing ICs with a practical, easy-to-use tool that they can utilize in their own contexts as caretakers, focusing not only on concrete issues of informal care, but also on aspects of well-being. The ICWE project is an Erasmus+ funded project, under the Key-Action 2, from December 2023 until December 2025. The ICWE consortium consists of six partners from six different countries: Germany, Portugal, Italy, Ireland, Greece and Cyprus.

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