



# Eurocarers Research Priorities

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## Table of Contents

Background.....	2
Strategic aims .....	2
Target audience.....	2
EU-context- relating to EU priorities .....	2
Skills	3
Promoting employment	3
Social Exclusion	3
Fairness	4
Eurocarers Research Priorities .....	4
Cultural change in health and social care systems	4
Legislative and policy aspects of carers’ situation	5
The value and costs of caring	6
Health and Well-being	7
Coordination of care systems	7
New technologies	8
The role of friends, neighbours and volunteers	8
What’s worked well and why? Documenting and exchanging national experiences	9
Methodological Issues.....	9-10

## Background

The vast majority of help, care and support of older and/or disabled people and people with long-term conditions in Europe is carried out by family members (especially spouses and adult children) and by neighbours and friends<sup>i,ii</sup>. However, the fundamental role played by these ‘informal’ carers (hereafter ‘carers’) is still not widely recognised in all Member States (MS), even though recent EU policy on long-term care (LTC) acknowledges that it is crucial that carers are valued and fully supported in their role, particularly in view of key societal challenges - ageing demographic trends and fiscal constraints. Research is urgently needed at pan-European and national level to build a comprehensive, up-to-date picture of carers’ situation. This knowledge base will be critical in informing policy in all areas affecting carers, especially in health, care, education, employment, social protection, transport and housing. It will also inform evidence-based practice concerning support services for carers and dependent persons.

This need for research and information provided the impetus for establishing a Eurocarers Research Working Group (ERWG) whose inaugural ‘face-to-face’ meeting was held on April 22<sup>nd</sup> 2015 in Dublin. The Group, which consists of Eurocarers’ research members and carer organisation members, agreed that an important initial task of the group was to define current research priorities in the area of carers, care and caring in the EU. The Eurocarers’ Research Priorities document was presented, revised and agreed at the Eurocarers AGM on September 3<sup>rd</sup> 2015 in Gothenburg.

## Strategic aims

The overall aims of the Eurocarers’ Research Priorities document are to:

- Identify current research priorities, including gaps in knowledge and scientific challenges regarding care, carers and caring in Europe
- Serve as a basis for more cohesive and strategic collaborative work by Eurocarers’ members within the identified research priorities
- Enable Eurocarers to work proactively and influence the wider EU-level research agenda in the areas of care, carers and caring , for example, the Horizon 2020 programme
- Provide evidence and analysis on care, carers and caring in Europe in order to help inform EU policy-making
- Inform evidence-based practice in the areas of care, carers and caring within MS.

## Target audience

This document is intended primarily, but not exclusively, for the following audience:

- Eurocarers’ members
- Public policy makers
- EU Institutions, including the European Parliament, Council and European Commission.

## EU context relating to EU priorities

As a European Association, Eurocarers relates to and shares many of the EU priorities to promote employment, to combat poverty and social exclusion, and to promote social justice.

## Skills

There is little research that explores cost-effective and responsive ways of providing training and education for carers of working age who may have left the labour market to care, and may need to update their professional qualifications when they are ready to re-join the labour force. Equally, it is important to establish what works for carers who have been unable to enter the labour market due to their caring responsibilities, and who may need support to secure formal qualifications and access to the labour market.

It is important to explore ways of providing flexible and appropriate training and education for carers on care and caring, including accreditation of the skills they use in their caring role. There is a need to examine systematically what skills will enable domiciliary care workers, migrant care workers, and care workers in LTC settings in MS to work effectively with or alongside carers.

Experienced carers often become expert in the care of the person they care for, but those new to caring often lack the skills and knowledge needed to ‘do caregiving well’<sup>iii</sup>. Research is needed on how to effectively support family members to take on a caring role and to acquire core caring skills (e.g. lifting and handling; coping with caring; knowledge of specific conditions; common symptoms and their management; administering and monitoring medical prescriptions and procedures).

## Promoting employment

There is a lack of research directed at formal employment for carers of working age. More individualised, flexible services need to be researched and developed that target the preferences and situation of working carers (that is, those carers who combine paid work and care, which includes both women and men). The effectiveness of a range of supportive measures for working carers, including the role of public authorities, companies, and trade unions, also requires further study. In particular, research is needed to explore supports for carers to reconcile work and care so they can enter/remain in paid work in all MS; and to identify any incentives/disincentives to paid work in financial assistance offered to carers. At a macro level, there is a need to ensure wider and more consistent recognition of carers in terms of labour legislation (at EU and national level) and informal provisions in social dialogue (at EU, MS and sectoral levels).

Research has already shown some of the negative impact of high intensity caring over time on working carers’ physical and mental health and well-being and their ability to stay in paid work; many carers reduce their working hours or leave the workplace altogether – thereby reducing their income and pension entitlements<sup>iv,v</sup>.

## Social Exclusion

Systematic mapping of current practices and further research and development of innovative and responsive initiatives are needed in EU-28, targeted at different groups of carers, to help ensure their social inclusion and societal participation in education, work and leisure opportunities throughout the life course. The potential of Information and Communication Technologies (ICT) <sup>vi</sup>for the social inclusion of carers warrants more in-depth study, particularly at meso and macro levels (see New Technologies p. 8).

Older spousal carers may find themselves housebound and experience their social networks to dwindle as they are unable to maintain social and family networks as previously. Carers of working age who are not in employment are at greater risk of social exclusion as they are not only at a financial disadvantage, but they are also excluded from the social support provided by colleagues and the support of their manager/employer<sup>vii</sup>. For some working carers, paid work acts as a form of respite from caring. Young carers are at greater risk of not completing their formal education and are less able to enter into higher education reducing their life chances and increasing their social exclusion. Carers from ethnic minority backgrounds and migrant care workers may be at greater risk of social exclusion as a result of living at a distance from family and friends and due to cultural and language differences making it difficult to establish new social networks. The vulnerable situation of migrant care workers in terms of their life situation and opportunities for further education and job opportunities is highlighted but deserves more systematic attention across MS.

The potential of ICTs to reduce social isolation by facilitating peer support has proven to be beneficial for carers. Nevertheless, older female carers, ethnic minority carers and migrant care workers are at greater risk of experiencing digital exclusion as they often lack sufficient digital skills and/or may lack direct access to ICTs. Community-based schemes that provide access to computers and offer digital skills training together with continuous technical back-up facilities represent a potential way forward to remedy this widespread barrier. However, further sustainable models need to be explored, including sharing the major lessons learned from innovative EU funded projects in this area (such as Discover4Carers<sup>viii</sup>, Carer+<sup>ix</sup>). The recent launch of the online directory of ICT-based services for carers housed on Eurocarers website is an important step forward in this regard (JRC & Eurocarers, 2015).

## Fairness

Further studies are necessary at a pan-European level that focus on particularly disadvantaged and under-researched groups of carers. The vast majority of carers wish to care for the person they support, but research is needed to document and understand how they can be enabled to do this without being treated unfairly, being discriminated against or disadvantaged compared to non-carers, or excluded from the opportunities enjoyed by other citizens. Research is needed into why caring has particularly negative outcomes for certain groups of carers, and what can be done to address this. Issues which require further investigation include the impact of caring on socialisation processes, educational opportunities, family relationships and employment prospects.

## Eurocarers Research Priorities

Taking into account the EU context outlined above, and based on the current knowledge gaps and scientific challenges in the area of carers, care and caring, Eurocarers have identified the following eight research priorities: 1/ Cultural change in health and social care systems, 2/ Legislative and policy aspects of carers' situation, 3/ The value and costs of caring, 4/ Health and Well-being, 5/ Coordination of care systems, 6/ New technologies, 7/ The role of friends, neighbours and volunteers and 8/ What's worked well and why? Documenting and exchanging national experiences.

### Cultural change in health and social care systems

At a macro level, public policies still focus most of their attention on paid workers in health and social care systems, giving relatively little attention to the services and supports required by families and

local communities in providing care. Research is needed to address this and to explore models and methods for how best to develop formal care which is supportive of the unpaid care provided within families and communities.

Nevertheless, research must also examine how to change attitudes and expectations of formal health and care providers. Evidence on effective measures which can change the culture within health and care systems and practices (which in EU-28 countries currently focuses predominantly on the patient/service user to the exclusion of the carer/family) is needed. Eurocarers has set out elsewhere ('Enabling Carers to Care' 2014<sup>x</sup>) the need for cultural change in and across MS to recognise and support carers' contribution and to improve cooperation between carers and the formal sector. Research should demonstrate how health and social care professionals can be encouraged to recognise and respect the role of carers and work with them as equal partners in care (see 'Coordination of Care Systems' p. 8).

### Legislative and policy aspects of carers' situation

More systematic research is needed to map and monitor the development of legal entitlements and obligations affecting carers in EU-28 and to examine the strengths and weaknesses of these<sup>xi</sup>. The legal and ethical aspects of caring also remain a largely unexplored area.

Recognition in policy and legislation of the importance of carers and their contribution to health and social care systems, to society and to the economy as a whole is slowly increasing. Some MS have developed specific policies and law on carers and/or have put national carers' strategies in place (as in the UK, Ireland, The Netherlands and Belgium). Not all MS provide specifically targeted carer support however, and those in place vary greatly in scope and coverage. For example, carers' legal rights have been secured within some pension systems and several governments have put measures in place to help carers combine paid employment with caring. The latter vary from measures allowing time off work in a family emergency, through to paid leave in specified circumstances (e.g. terminal illness) to rights to request flexible working arrangements. There is as yet very little evidence of the take-up and effectiveness of these measures, their comparative benefits, and how they affect carers in different working and caring circumstances.

Formal support services in the home are subject to legal and quality assurance frameworks in most MS, but carers may have little information about this or their rights in relation to formal services. As evaluation of direct support services for carers gradually develops across Europe, the issue of how to improve and monitor the quality of care provided by carers is increasingly being raised and deserves closer attention. Ethical issues relate to the suitability and skills of family members/friends/neighbours to provide care and how best to ensure consistency and quality in the care provided. Some studies have shown that educational interventions that equip carers with core caring skills 'to do caregiving well' can be effective (see 'Skills' p. 3), while others indicate that not all family members are suited for caring, for example where there has been conflict or abuse in the past, or where the carer's own health or circumstances make caring difficult. Research is needed into how best to develop and deliver the support needed, and how to protect carers (or cared for persons) who may be at risk in difficult situations.

## The value and costs of caring

At a macro level, more studies of the economics of formal care in different care regimes across Europe are needed. The SPC report (2014) on adequate social protection for LTC highlighted that the economic value of unpaid informal care as a percentage of the overall costs of LTC in MS ranges from 50%-90%<sup>xii</sup>. Pan-European studies focusing on the economic impact of caring and on how the current economic climate is affecting carers' financial situation are urgently needed. These studies need to complement those focused on 'recognition' and 'valuing carers' to ensure all the economic and financial aspects of carers' circumstances are understood. They should include evidence of both the financial/material consequences of caring and of how these affect carers' attitudes, values and morale.

Research questions might include:

- How is the economic value of caring (EVC) measured and can an agreed formula be developed for this?
- What do national variations in the EVC mean (for whom)?
- What is the relationship between the EVC (as a % of total LTC cost) and public expenditure and policy arrangements for LTC in the country / locality?
- Which socio-economic groups have the highest EVC and why? What can be done about this?
- Can improved ways of measuring and managing the economic, health and other costs of caring be found?
- What measures are effective in limiting the health and opportunity costs of caring, and how does this vary between systems and between population groups?

Many MS offer some kinds of financial support for carers and it is important to identify the full range of these and their benefits, disadvantages and consequences. This should include issues of awareness and take-up, as one of the most frequent questions raised by carers concerns the nature and range of the financial support available to them. Research issues within this theme include how financial support issues interact with other factors such as: education; wealth/income; the cost of caring; choice/values; and what combinations of support work best, for whom, and why. What are the information needs of carers and how can these be met?

Many carers of working age experience financial hardship and poverty, due to direct loss of income, limited access to social security and reduced pension entitlements in later life. Some studies show that single women and high-intensity carers are at greatest risk, but much more information is needed to fully understand which carers are particularly at risk and what measures in social protection can mitigate the situation. Other financial pressures may arise from reductions in social provision, higher direct costs of care or increased 'out-of-pocket' costs associated with caring; all of these require further study to fully understand their impact and consequences. The availability of support to cover such costs varies widely among MS, and many carers bear the brunt of these additional costs. Carers are known to value economic benefits, even when modest/tokenistic, as they indicate some formal recognition of their role in society. Some are long-established but are being reduced or cut in the present financial climate and it will be important to track the impact of these changes, so that any increase in poverty among carers, including those who have been out of the paid workforce for a long time can be assessed.

There is evidence of growing socio-economic differences concerning informal caring as for instance those older people with higher socio-economic status are more likely to purchase home help and home care services, whilst those older people with few economic resources rely on family members for regular help, care and support. Scandinavian studies highlighted that older people themselves often prefer a formal carer to carry out personal care rather than a family member. In several MS, it is increasingly common for those older people who can afford to do so to buy 'live in' help, often 'migrant care workers', raising many questions about quality for carers, dependent persons and workers.

### Health and Well-being

The impacts of caring on physical and mental health are consistently documented. However, there is a need for more systematic use of validated measurement scales and more sophisticated development of these; the language of some scales is outmoded (e.g. 'burden scale') and creates divisions between carers and older/disabled people. Overall, there remains a lack of evidence on services for carers in Europe which are preventive in nature and focus on carer resilience and well-being. It is important to examine the long term effects of preventive carer support measures on maintaining the health of carers, and the link to emergency hospital admission and long term institutional care. Allied to this, is the need for more systematic follow-up and evaluation of support services which actively involve carers as a key partner in this process. In particular, to examine ways in which professionals, particularly in primary health care, are enabled to work proactively, reaching out to carers, offering comprehensive carer assessments and signposting carers to appropriate sources of support.

Research has mainly focused on carers' stress and burden with little attention being paid to concepts such as carer's satisfaction, resilience and wellbeing. The health and well-being of carers is a complex subject, in part related to the degree of availability of appropriate support from both the formal sector and informal caring networks. Further, perceived stress or satisfaction appears to be related to personal belief systems about the nature of caring (such as, its level of perceived meaningfulness or not), in addition to the nature of previous relationships with the cared-for member and the carer's personal repertoire of coping resources and strategies. Nevertheless, the risk of developing physical and mental ill-health is consistently higher among high-intensity carers.

Research has highlighted the beneficial effects of flexible, quality (as perceived by users) respite care on high-intensity carers' physical and mental health. Routine health 'check-ups' targeted at carers are generally appreciated by carers themselves, yet firm evidence is lacking concerning their efficacy and cost effectiveness. However, it is recognised that a holistic carer assessment is an important step in being able to provide timely, responsive information, advice and support that matches the preferences and situation of the individual carer concerned. There are a range of carer assessment tools available, but their use in EU-28 remains patchy. Research should assess what measures or incentives enable more systematic data collection from carers, helping to target carers and inform them of the range of support available.

### Coordination of care systems

Coordination is key, but what models of integrated care actively recognise and involve carers as a key partner? Research must document examples of sustainable, effective coordination and identify how this can be implemented.

There is an urgent need for better and more comparable data on the current provision of formal and informal LTC. Research should examine the boundaries between informal and formal caring and the 'ideal' mix of formal and informal care. Many carers and domiciliary care workers employed by private households operate outside of the formal support system and as a result they remain unknown or 'hard to reach' by the formal support system. Yet, as a result of economic constraints, informal care is increasing even in MS where care for dependent individuals has traditionally and essentially been a state-based responsibility. One of the most frequent concerns voiced by carers is the lack of communication and co-ordination with and between health and social care services. This lack of co-ordination of services for the sick/disabled person appears common and often leads to carers taking on board an onerous role as co-ordinator of their significant other's care. The potential role of advanced ICT systems within new models of integrated care is emphasised within the Horizon 2020 programme (SC 'Health, Demographic Change and Wellbeing) (2014-15), but the impact of ICT at organisational and system levels (what it means in terms of service delivery, coordination, cost effectiveness) within LTC remains scarcely documented.

### New technologies

There is much expectation but a lack of evidence about what ICT helps, how it helps and how the information generated by technology can be better used to support carers. So far, the analysis of the benefits of ICT-based services has primarily focused on the micro level only i.e. what it means for patients and carers in practical terms, such as their satisfaction and acceptance with the service/product and its perceived impact on their everyday quality of life. Nevertheless, significant information gaps remain about awareness, availability, access and take-up issues which require further investigation. Also, the potential impact of technology to help support wider informal caring networks (such as other family members, relatives, neighbours and friends) has not received much attention.

Despite a strong EU focus on the potential of new technologies for LTC, evidence remains inconclusive. There are calls for more realistic forms of evaluation, including observation studies of everyday life, when dealing with complex social innovations such as telecare and telehealth services, paying due attention to organisational context and change processes. In particular, robust business models and more end user-focused procurement models within health and social care services are welcomed. In order to advance our understanding of how best to implement and evaluate new technologies within health and social care it is suggested that all key stakeholders (including patients/service users and carers and/or their organisations) have opportunities to engage in learning communities, to discuss different viewpoints, priorities and accountabilities, to share experiences and learn from each other.

### The role of friends, neighbours and volunteers

It is increasingly important to recognise the wider role of friends, neighbours and work colleagues within extended informal caring networks. It is important to explore how informal caring in wider caring networks and volunteering are developing:

- Under what conditions do wider/mixed caring networks emerge to support someone with care needs?
- Who initiates and/or maintains the formation of a caring network?
- Is there any role for public policy in assisting them to do this?
- What roles do different network members play, and why?



- What make networks effective/beneficial (and for whom)?
- How are wider caring networks related to care by family?
- In what ways can new technologies help to support wider caring networks?

The bulk of knowledge about informal caring tends to focus on relations between one family member (usually the primary carer) caring for one other family member. Not infrequently, neighbours and friends carry out 'discrete' yet highly significant caring activities on a regular basis for the dependent person which are highly valued and which often enable the person to remain in their own home. One question for research relates to the development and maintenance of these wider voluntary networks and whether there is a place for more formal organisation of them.

### What's worked well and why? Documenting and exchanging national experiences

Systematic research is needed which routinely collects and analyses examples of good practices and policies for carers, care and caring among EU-28. MS can learn from each other's experiences of improving both formal care provision and support of carers, in particular how to meet the full range of needs of carers, especially those at risk of experiencing burn-out and/or poverty. The Open Method of Coordination (OMC) should use research findings and be utilised as a powerful tool for implementing good practices for carers. There is also a need for an 'observatory' on policy developments affecting carers and for the development of a repository of policy evaluation studies. Methods for knowledge transfer need to be comprehensive and include both traditional approaches (newsletters, conferences and meetings) and the use of social media in order to reach out to all major stakeholder groups.

The Commission (2013) underlined the significant potential benefits of EU-collaboration and policy coordination in the complex area of LTC. Eurocarers (2014) noted that, given variation between MS in terms of care provision models and the roles of formal and informal care within these, there is a major potential for exchange of experiences, ideas and good practices. Research findings and good practices on informal care for older and disabled people are often under-utilised. The research tends to be published in separate academic fields, often in national languages, and as a result it tends not to be incorporated in international databases.

## Methodological Issues

The methodological issues are mainly concerned with the importance of comparative research and the need for more standardised conceptualisation and operationalisation of key concepts within informal care. The development of comparative Research and analysis in informal care calls for:

- More up-to-date comparative studies in the field of carers, care and caring to determine the extent and characteristics of informal caring in EU-28, and to compare the effects of different systems and methods of supporting carers. In particular, to pay attention to diversity, examining socio-economic, gender and cultural differences concerning informal caring.
- Documenting the availability, use impact and acceptability of support services across the different formal care regimes in Europe, taking into account the experiences and lessons learned from the earlier EUROFAMCARE project (2003-2005) study<sup>xiii</sup>. Such studies would help inform all relevant EU policies affecting carers, care and caring.
- Methodologies for comparative research on carers, care and caring should be standardised. The availability and quality of national data on carers in general and support services in particular vary

considerably. Currently, only Ireland, England and Luxembourg have up-to-date national statistical sources designed specifically to describe the provision of informal care. Common definitions of carers and the characteristics of care should be established. Specific questions about informal care should be incorporated in routine household surveys in MS.

- Legal requirements should be put in place across MS, in order to apply similar procedures for data collection and data protection.

With regard to conceptualisation and operationalisation issues:

- Issues of cost effectiveness as well as efficiency and quality (especially from a user's perspective) need to be examined for a range of ad hoc services to support carers, including respite care solutions, training, education and newer, innovative technology based support services for carers.
- Outcome measures need to be developed to determine the effectiveness of support services/interventions for carers that move beyond a stress-burden model and that incorporate a wider empowerment, resilience/strengths based approach.
- Assessment of interventions should go beyond a 'one size fits all' approach to measuring the effects of more flexible, targeted support to determine which types of support services/interventions suit which groups of carers best and why, when in the caring trajectory/phase of caring, how are they best delivered and where are they best delivered.
- Due to the complexity and multi-dimensionality of social innovations and their implementation that are directed at carers and the cared for person, randomised control trials are often hard to apply in this area. Mixed methods approaches and realistic evaluation methodologies are called for which actively take into account the role of context, systems and processes. The use of new research approaches, such as co-design, co-production and narrative approaches should be considered where appropriate.
- Longitudinal studies and databases are required in order to explore the experience of caring and its correlates over time.

Elizabeth Hanson, input from Eurocarers members, including amendments by Sue Yeandle and Rob Anderson, fourth draft version, 7/8/15.

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<sup>i</sup> Adequate social protection for long-term care needs in an ageing society, Report jointly prepared by the Social Protection Committee and the European Commission, 2014

<sup>ii</sup> Second European Quality of Life Survey – Overview – Anderson et al. 2009

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<sup>iii</sup> Knowledge and skills needed by informal carers to look after terminally ill patients at home, Josaleen Connolly, Dr Stuart Milligan, BMJ, 2014

<sup>iv</sup> Help Wanted? Providing and Paying for Long-Term Care, Colombo, F. et al OECD, 2011

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<sup>v</sup> Draft Joint Employment Report accompanying the Communication from the Commission on Annual Growth Survey 2014 [http://ec.europa.eu/europe2020/pdf/2014/jer2014\\_en.pdf](http://ec.europa.eu/europe2020/pdf/2014/jer2014_en.pdf)

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- <sup>ix</sup> <http://carerplus.eu/>
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- <sup>xiii</sup> <http://www.uke.de/extern/eurofamcare/>