

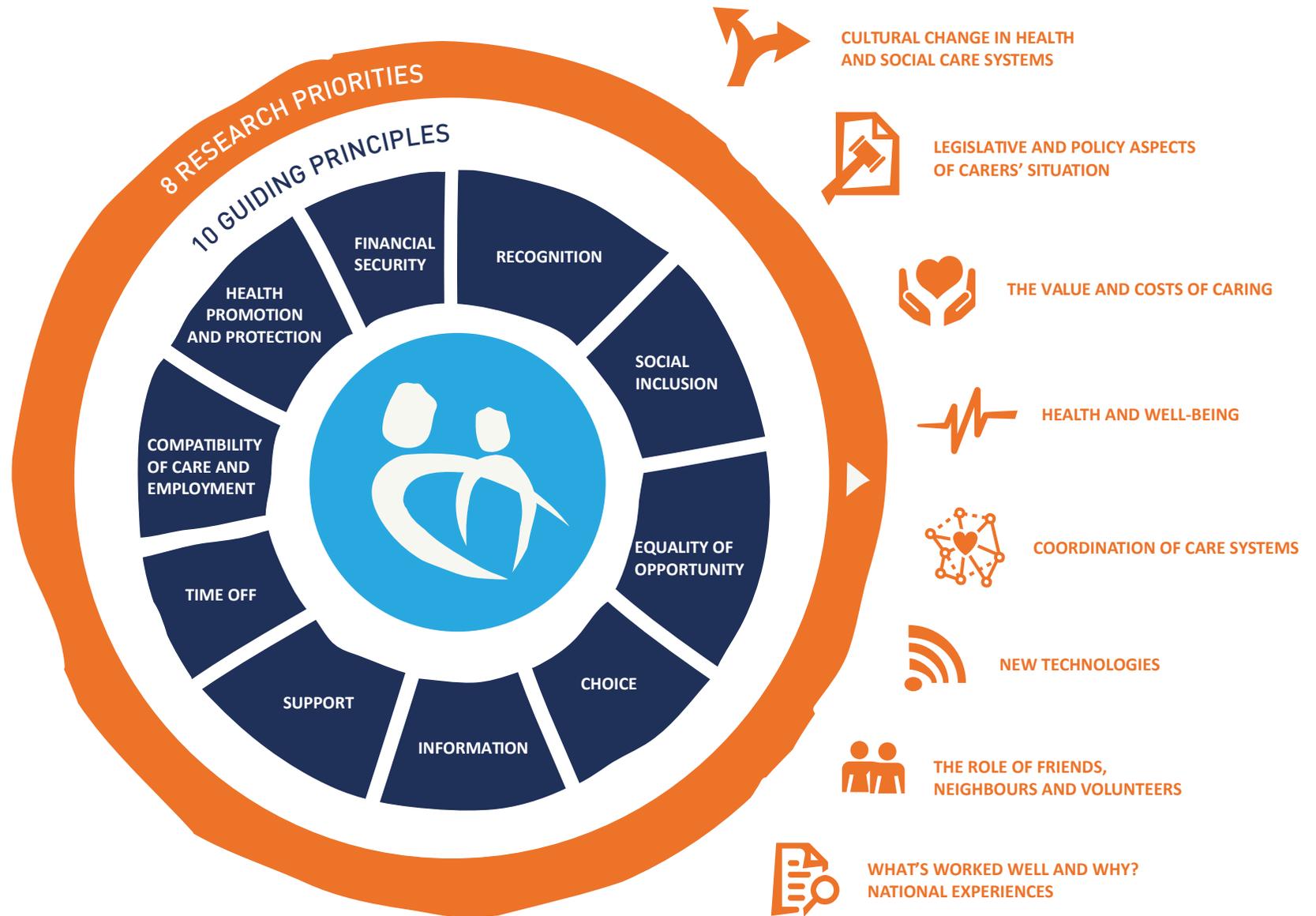
TOWARDS A STRONG EVIDENCE BASE FOR CARER-FRIENDLY SYSTEMS IN THE EU

▶ There are more than **100 million carers** in Europe, a largely underestimated figure given the (self-) recognition problem of carers.

▶ **80% of care** across the EU is provided by spouses, relatives and friends. A typical carer is a woman between **45-75 years** of age.

▶ **42% of non-working carers** are in the lowest income quartile, almost twice the proportion for non-carers.

▶ The economic value of **unpaid informal care** is estimated as **50-90%** of the overall cost of long-term care in EU Member States.



RESEARCH PRIORITIES

The vast majority of care and support of older and/or disabled people and people with long-term conditions in Europe is provided by informal carers. Ageing demographics are generating a growing demand for informal care and the intensity of the caring role is increasing. This raises urgent challenges about how best to recognise

the role of carers and support their wellbeing and quality of life. The Eurocarers Research Working Group has identified 8 research priorities to address these questions at European and national levels and help build a comprehensive, up-to-date picture of carers' situation. The full document can be read at [our website](#).



CHANGING THE MINDSET

In its proposal for an EU strategy on carers, '[Enabling Carers to Care](#)' (2014), Eurocarers made the case for the recognition of carers' contribution to the supply of care and to the economy and society as a whole. In order to sustain this crucial contribution at a macro level, policy across EU28 needs to emphasise the support required by families and communities. At the meso and micro levels, research is important to explore and document models and methods for developing formal carer support. This includes improving cooperation between carers and the formal sector.



LEGISLATIVE AND POLICY ASPECTS

Legal and ethical aspects of informal caring require attention. Growing recognition of the carer contribution is evidenced by carer policies in some EU Member States (EU MS). These include pension credits and measures such as care leave and flexible working arrangements. It is important to map the development of legal entitlements and obligations of carers in EU-28 and examine their strengths and weaknesses. The caring situation itself raises ethical issues relating 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. Research is needed into how best to develop and deliver the support needed, and how to protect carers (or care recipients) who may be at risk in difficult situations.



THE VALUE AND COSTS OF CARING

The Social Protection Committee report on Long-Term Care (2014) highlighted that the economic value of informal care ranges between 50% and 90% of the overall costs of Long-Term Care in EU MS. Consideration should be given to how the economic value of caring is measured and whether an agreed formula can be developed. We also need to understand differential impacts and access to support by socio-economic groups. Cuts in social provision have indeed amplified the direct costs of care or increased 'out of pocket' costs. The availability of financial benefits to cover such costs tends to vary widely among EU MS, with impacts on quality of life and morale. Pan-European studies on the economic impact of caring and the economic climate are therefore urgently needed.

RESEARCH PRIORITIES



HEALTH AND WELL-BEING

Research has evidenced the stress and burden of caring. Although identification and assessment of carers are weak in most EU MS, both are central to providing timely information and support and to enable systematic data collection. Across EU-28 we need to understand how professionals can work proactively to support carers. We also need to improve understanding of preventive carer support on care admissions, which includes more systematic follow-up and evaluation of services, actively involving carers as key partners. Research is needed to explore ways of promoting carer quality of life, wellbeing and resilience, and the links to informal and formal caring networks. Evaluation approaches allowing for this complexity are also required.



COÖRDINATION OF CARE SYSTEMS

Carers are often concerned by the lack of co-ordination between health and social care services. This often leads to the carer taking on an onerous role as care co-ordinator. Further research is required to explore suitable models of integrated care that actively recognise and involve carers as key partners, including consideration of whether and how these services can be mainstreamed. In the field of long term care (LTC) there is an urgent need for better and more comparable EU data on current provision and the 'ideal' mix of formal and informal LTC.



NEW TECHNOLOGIES

Carers at greatest risk of social exclusion are those providing high-intensity care over prolonged periods. Across EU MS systematic attention for particular risks of carers of working age, older female carers, young carers, ethnic minority carers and migrant care workers is needed. This should focus on the role of the formal and informal sectors to identify, reach out and support carers. The potential of ICTs to reduce social isolation by facilitating peer support has proven highly beneficial. More research is needed to support the social inclusion of carers through the life course, including the role of Information and Communication Technologies (ICT). The impact of ICT within LTC also remains sparsely documented (including delivery, coordination, cost-effectiveness). The potential role of advanced ICT systems within new models of integrated care should also be investigated.



THE ROLE OF FRIENDS, NEIGHBOURS AND VOLUNTEERS

The bulk of knowledge about informal caring tends to focus on the carer-care recipient relationship. In reality, there is often a reciprocal flow of 'give and take' at different points in time, and multiple family members may contribute to caring. We need to understand the conditions under which wider/mixed caring networks emerge, involving friends, neighbours and colleagues, the roles played within them and whether there is a role

for public policy in this. Further, the potential impact of technology to help support informal caring networks should be explored.

More broadly, volunteering in general is alive and well in EU-28. It is important to explore the extent to which (if any) there is a 'trade-off' between informal caring and volunteering.



WHAT'S WORKED WELL AND WHY? NATIONAL EXPERIENCES

Eurocarers (2014) underlined that, given variation between EU MS, there is a significant potential for learning from each other's experiences of informal and formal care provision, especially for carers at risk of burn-out and/or poverty. There is a need for an 'observatory' on policy developments affecting carers. Furthermore, there are opportunities for learning about outcomes for individuals, families, communities, systems, organisations and societies. Research findings and good practices on informal care for older, sick and disabled people are often under-utilised and should be used in the Open Method of Coordination (OMC). OMC should be utilised as a powerful tool for implementing good practice.

ABOUT EUROCARERS

Eurocarers is the European network representing informal carers and their organisations, with the aim to advance their interests, irrespective of the particular age or health need of the person they are caring for.

Eurocarers was established to advance the issue of informal care at both national and EU levels by:

- Carrying out and supporting research on issues that concern carers
- Advocating the interest of carers
- Encouraging and facilitating the development of representative and sustainable carers' organisations in all EU states
- Promoting the development of inclusive and patient-centered care systems, which fully recognise the role, contribution and added value of carers

Read more about our work at:

<http://www.eurocarers.org/Our-Work>

EUROCARERS

3, Rue Abbé Cuypers
1040 Brussels, Belgium
00 32 (0)2 741 24 05
info@eurocarers.org
www.eurocarers.org

Text: Eurocarers Research Working Group

Design: [Vilans Centre of expertise for long-term care, Netherlands](#)

10 GUIDING PRINCIPLES

1. Recognition of carers for the central role they play in community care.
2. Social Inclusion of carers which have a right to a social life.
3. Equality of opportunity of carers in all spheres of life.
4. Right of choice of people to choose freely whether they want to be a carer and of people needing care to choose who they wish to be their carers.
5. Easy access to information, guidance, advocacy, advice and training carers desire.
6. Support of carers in terms of financial, practical and emotional support and access to needed formal care.
7. Time off opportunities for carers available and tailored to carers' needs.
8. Compatibility of care and employment by policies that allow for caring activities as well as formal care available during working hours.
9. Health promotion and protection of carers' own health care needs.
10. Financial security of carers to avoid impoverishment as a consequence of caring.