
Meeting of the Eurocarers Research Working Group
30 November and 1 December 2023, Ancona - Italy
Draft Notes

DAY 1 - Thursday, 30th November 2023

Opening session

Welcome and introduction by Giovanni Lamura, National Institute of Health and Science on Ageing (INRCA) and Stecy Yghemonos, Eurocarers

Tour de table (Part 1) + Discussion

Facilitated by Henk Nies, Eurocarers VP Research

Order of presentations:

1. Selma Kadi – European Centre Austria
2. Bruno Alves - Cuidadores Portugal
3. Mahi Kozori - Alzheimer Hellas (Greece)
4. Georgia Casanova - INRCA (Italy)
5. Ludo Glimmerveen - Vrije Universiteit Amsterdam (Netherlands)
6. Maren Sogstad - Norwegian University of Science and Technology (Norway)
7. Emma Miller – University of Strathclyde (UK/Scotland)
8. Stefania Ilinca (WHO) and Valeria Spazzoli (European Commission, DG EMPL)

See all presentations [here](#)

Coffee break

Tour de table (Part 2) + Discussion

Facilitated by Maria Nilsson, Swedish National Family Care Competence Centre

Order of presentations:

1. Benedicte de Koker – Hogent (Belgium)
2. Tuija Mikkola – Folkhälsan Finland
3. Joanne Murphy - Family Carers Ireland
4. Ana Ramovs - Anton Trstenjak Institute form Gerontology and Intergenerational Relations (Slovenia)
5. Idaira Cabrera - El Tren de la felicidad (Tenerife, Spain)
6. Becky Driscoll - Centre for Care (UK)
7. Matt Bennett - University of Birmingham (UK)
8. Maria Nilsson - Swedish Family Care Competence Centre (Sweden)

See all presentations [here](#)

Lunch break

Artificial Intelligence and Care

Moderated by Henk Nies, Eurocarers VP Research

Keynote speech: Pr. Pim Haselager, Dpt. of Artificial Intelligence, Donders Institute for Brain, Cognition and Behaviour, Radboud University (NL)

See presentation [here](#)

Results of scoping review on AI in Care - Maria Nilsson post doc at Linnaeus University and researcher facilitator at the Swedish Family Care Competence Centre

See presentation [here](#)

SWOT analysis of AI in care with participants

The meeting attendees were grouped into various smaller teams, tasked with identifying the primary opportunities and threats arising from the use of Artificial Intelligence in the care sector. The following provides a summary of their feedback.

Opportunities offered by Artificial Intelligence

- Potential replacement for carers and or care professionals;
- Alleviating the stress of informal carers;
- Virtual coaching for informal carers;
- Digital companionship;
- Integration of AI as a resource for documentation;
- Assistance in service application and access to information on entitlements;
- Rehabilitation programme tailored for carers;
- Use of wearables to assist carers , including determining optimal intervention times;
- Use of smart socks/soles/sensors;
- Abundant source of valuable data;
- Tool for extracting useful data and identifying patterns;
- Access to private data;
- Drawing insights from the experiences of other sectors in AI implementation for both formal and informal care;
- Streamlining administrative processes;
- Facilitating information sharing;
- Assistance with physical tasks; and
- Personalisation of care strategies.

Threats posed by AI

- Replacement of professional carers
- Substitution of human contact
- Determining whether the use of AI will be optional or imposed
- Continuous surveillance
- Diminishing human experiences
- Losing the right to embrace irregularities or be weird
- The normative implications of AI
- Emphasis on efficiency and its impact on defining quality and quality of life
- Risks of widening of inequalities
- AI providing inaccurate or incorrect answers
- Constraints on the utilisation of AI

- Scepticism towards the adoption of technology
- Challenges in assigning responsibilities in cases of errors in the context of AI-assisted care
- Necessary skills for utilising technology
- Potential loss of the ability to care by ourselves
- Impact on the understanding of what care entails
- Redefinition of human relationships
- Moral complexity
- Power imbalances

16.15-16.45 Coffee break

16.45-17.45 Presentation of WHO's ambitions with online information hub targeted at carers

- Stefania Ilinca – Technical Officer Long-Term Care, WHO Europe
- Valeria Spazzoli - Policy Officer Long Term Care, DG EMPL

Stefania and Valeria outlined the rationale and ambitions for the upcoming OpenWHO training course designed for informal carers. This platform is a result of a recently formed collaboration agreement between the two institutions. Its objective is aligned with the EU Care Strategy and Council Recommendations on long-term care, specifically addressing the necessity to facilitate access to training in Occupational Safety and Health, counselling, healthcare, psychological support, respite care and achieving a balance between work and care responsibilities.

See presentation [here](#)

Members of the Research Working Group were invited to provide feedback on the proposed structure and content of the platform.

Here is a summary of their input:

- The establishment of the OpenWHO platform is a positive development, addressing the historical and growing needs of informal carers;
- The combined visibility and influence of the WHO and EC should enable outreach to many informal carers across the continent;
- Connecting this initiative with other efforts aimed at care professionals is crucial, recognizing the interconnectedness of informal and professional care;
- Given that many informal carers are involved in nursing care alongside personal and social care, the platform should ideally encompass this aspect;
- The sections on "Care Ecosystems" and "Sharing Caregiving" should explore the choices available to carers and their interactions with other family members;
- Effective communication with the care recipient and other care actors is a vital consideration for informal carers that should be addressed by the platform;
- End-of-life care and the specific skills required at that stage are often overlooked and, therefore, much needed;
- Similarly, the transition towards institutional care and the provision of informal care in various settings deserve more attention;
- The platform could offer opportunities for informal carers to validate and promote acquired skills transferable to other professional contexts; and

- Signposting to existing national/regional/local rights and practical support is fundamental for carers, and WHO and the EC were encouraged to populate the platform with up-to-date information in these areas (via national contact points).

Regarding the promotion of the platform, participants recommended:

- Using pre-existing communication opportunities, such as European Carers Day (6th October) or the UN Day of Care and Support (29th October);
- Rather than asking potential beneficiaries if they are carers, it may be more impactful to inquire about their involvement in a series of tasks related to caregiving, as many may not identify as carers;
- Leveraging stories and videos to convey practical and practice-oriented content is usually more valuable than theory;
- Ensuring accessibility via portable devices (smartphones, tablets) as most carers use these tools to access information; and
- Using Google-friendly language and keywords for platform communication to enhance visibility.

A majority of attendees mentioned that their organisations have already developed relevant content, eliminating the need to reinvent the wheel. The Eurocarers Secretariat will conduct a survey among Eurocarers members and selected partners to identify existing resources. Additionally, a mapping review will be undertaken in the coming weeks.

DAY 2 - Friday, 1st December 2023

Overcoming barriers to access carers support

Facilitated by Emma Miller, Strathclyde University

The objectives of this workshop were to:

- Build on the conclusions of the world café session held during our AGM in Berlin in May, and
- Look at existing deficits and difficulties in accessing carers support across the EU, based on eligibility criteria.

Results of membership survey on access to carer support - [See presentation here](#)

Discussion with attendees

Even where carers have rights, access is often restricted and eligibility criteria are very strict. This is the case in Scotland.

Portugal: Despite the recent enactment of legislation recognising carers, there is currently no established framework for its practical application. Consequently, implementation is inconsistent, with certain regions being more progressed than others. It remains crucial to communicate that support for carers extends beyond financial aspects. Additionally, sharing carers' narratives with policymakers is essential to shift perspectives. The significant contribution of NGOs should also be emphasised.

The question of measurement is something we need to explore further. We may need to use a different language to avoid mere checkbox exercises.

What works for carers? Just one country responded 'one door' for applying for help. We probably need to look a bit more into this.

Italy: Some regions have enacted specific legislation to recognise the significance of carers, enabling tailored support and validating their contributions. Acknowledging their role is crucial, as a lack of awareness regarding the importance of carers poses a significant challenge. Even in cases where adequate support exists, the absence of recognition remains problematic, highlighting the need for a cultural shift. Furthermore, the lessons learned from the COVID pandemic have yielded valuable practices that we can capitalise on.

Netherlands: There are 12 funding categories available for carers, but navigating the application process can be intricate. The government recommends raising awareness about the various types of support accessible, which is problematic as individuals often fail to recognise themselves as carers. While GPs serve as a crucial starting point in the Long-Term Care (LTC) trajectory, finding one's way through the system remains a challenge. Redirecting attention to educating social care professionals seems necessary, as expecting ordinary citizens to possess a detailed technical understanding of legislation may be unrealistic.

UK (England): while the legislation is commendable, the challenge lies in uneven support across the country, exacerbated by austerity measures that have reduced service accessibility.

Italy: The educational level of older individuals is often low and pensioners require substantial assistance. Navigating the intricacies of available support can be challenging for many individuals. A network of 'patronati' (organisations associated with trade unions) serves as a vital pillar, offering valuable information to those unfamiliar with the legal landscape. These organisations play a significant role in bridging the gap between institutions and the general public. Their existence may explain the late emergence of carer organisations in the country.

Second presentation by Emma Miller: 'Rethinking eligibility criteria for social care in Scotland' – see [here](#)

What is the relationship between fair access to care and good quality support for informal carers?

Discussion with attendees

Austria: Undergoing a care assessment can prove to be a humiliating experience for the informal carer. They may find themselves overlooked or compelled to demonstrate their limitations to qualify for assistance. Furthermore, the absence of support for the carer can adversely affect the quality of care they are able to deliver.

Slovakia: The assessment is currently based on a doctor's evaluation statement extracted from medical records (up to a maximum of 6 months old), lacking a peer-to-peer element. The entire process requires a more up-to-date, faster and seamless approach. The needs assessment should occur at the onset of needs, conducted by professionals initiating contact with the care recipient. Furthermore, the evaluation does not take the home environment into account and the safety of the carer is not factored in. Informal carers find themselves having to fight for every aspect. The assessment is carried out by a panel of 3 professionals, ensuring a lack of undue bias through a multi-disciplinary team approach.

Slovenia: There is a cultural tendency to underscore the negative aspects as a means of achieving objectives. Negotiating resources in this manner is deeply ingrained in the country's culture. Even

if the system undergoes a transformation that renders such practices unnecessary, people may persist in employing them. If there is a desire for change, a shift in culture is imperative. Typically, it falls upon the doctor to advocate for necessary care, thereby necessitating a focus on the negatives in the process.

UK: Some people find it difficult to highlight their limitations, it can be disheartening.

Italy: Securing access to high-quality care proves difficult due to a shortage of personnel in the care sector. There is a new reform in the criteria for Long-Term Care (LTC) to evaluate individuals requiring care. Some areas feature "community houses" where diverse professionals collaborate in teams to address care requirements. However, there is a concern that these hubs may remain understaffed due to a lack of professionals. Many nations face difficulties in attracting professionals to this sector, primarily because the profession is undervalued, poorly remunerated and characterised by unfavourable working conditions.

The value we attribute to care is what we should emphasise. Enhancing the recognition and portrayal of care in society might involve highlighting that care jobs (and caregiving in general) are not susceptible to automation, unlike other prominent occupations whose significance is perceived to decline with time. Additionally, care jobs are environmentally friendly, local and sustainable in the long run.

10.30-11.00 Coffee break

Discussion on the Research needed to tackle the care gap

Facilitated by Giovanni Lamura, INRCA and Henk Nies, Eurocarers VP Research

Eurocarers formulated guiding principles and identified eight research priorities back in 2015. The question is: are these priorities still relevant? We are currently undertaking a comprehensive review and update. The objective is to endorse a fresh set of research priorities during the Annual General Meeting in June 2024.

To kick off the discussion, Henk and Giovanni's shared a list of priorities, featured in an article that they recently wrote.

Discussion with attendees:

1. What are the most relevant themes for the near future?
2. What themes have been sufficiently addressed?
3. What themes should be added to the list of priorities?

Priorities identified by participants (clustered thematically):

- More applied and participatory research (involving policy makers and stakeholders from the beginning)
- Scaling up implementation of good practices
- Better support for carers (including through AI)
- Artificial Intelligence
- Opportunities offered by new technologies: GPT advisor to help carers navigate the system, identification with carers of tools for self-support, use the shortcomings of AI to emphasise the irreplaceable nature of care giving.
- Inequalities in care

- Gender balance
- Needs of informal carers (gender, migration background)
- Care and climate change: impact of environment on ageing, greener caring practices
- Legal responsibility/liability of informal carers (right to provide and receive care, human rights, civil liability and legal protection)
- Financing models for carer support: approach it as an investment and underline returns for society
- Understanding the value of care
- Navigating system eligibility criteria
- What makes carers resilient
- Carer harm
- Labour shortages and impact on informal carers
- Role of ICs in integrated care
- Recognition and identification of informal carers

Discussion on effective translation and implementation of research outcomes:

- What was the impact you are positive about, and how was it established?
- What was the context of the implementation?
- What has contributed the most?

Success factors and risks identified by Giovanni:

Success factors	Risks
Ability to translate recommendations from research into practice (top-down)	Lack of visibility
Ability to involve CSOs in a participatory way (bottom-up)	Lack of support / envy from key partners
Political willingness and humility to learn from each other	Resignation or insufficient trust

Input from participants:

Portugal: Cuidadores Portugal gained valuable experience gained with the young carers programme. Initially, there was not much attention to this issue, so colleagues took the initiative and started addressing the matter. They decided to scale up (not only one school), applied for an innovation grant and, drawing from their local insights, extended their successful solutions in collaboration with policymakers on a broader scale. While school projects face challenges, gaining support from policymakers can be a key to success. Cuidadores Portugal presented policymakers with compelling stories and statistics to persuade them of the programme's importance.

In another project, they conducted focus groups to enhance awareness of breast cancer literacy. The training was tailored to the insights gathered from these focus groups, addressing the specific needs of carers. Importantly, this was not a top-down, paternalistic approach where researchers presume to know best; instead, it was a grassroots, bottom-up initiative. The ongoing challenge lies in ensuring the sustainability of this approach and avoiding the need to start afresh with each new project.

UK (Matt): The Centre for Care (CfC) authored seven reports for Carers UK, and these reports gained widespread attention in the news, going viral. In our line of work, we frequently customise our research to align with the needs of stakeholders. By tailoring our approach to narrate the stories of individual carers in an easily understandable manner, we can create a significant impact. Crafting compelling narratives with potent statements and impactful figures on potential cost savings and more efficient practices often grabs headlines and attracts the attention of MPs and policymakers. The CfC team made sure that the messages resonated with carers, and they established a strategic pathway to impact, involving proactive engagement with the media in advance to prepare them for upcoming reports and publications. Although it demands hard work, the payoff is substantial.

European Commission: If you present a clear and compelling case for a policy needs, making it widely known, policymakers will have to address it. Subsequently, provide evidence and support for your case. Additionally, ensure that policymakers can easily access research in a simplified manner. Use research arguments effectively to capture the attention of policymakers.

Slovenia: It is important to promote practical training guided by ongoing research, incorporating a reality check to guide interventions. Presenting evidence and demonstrating the economic convenience (along with sustainability) forms a compelling case to which policymakers are receptive.

Benedicte (Belgium): Action research, grounded in design-based thinking, led to the creation of "Samen Spreken" (Talk together), a tool aimed at enhancing communication between clients and formal carers. Developed collaboratively with stakeholders, this approach enabled a shared understanding of identified issues and effective solutions. The initiative secured funding from the Flemish government and is currently being integrated into professional training programs, emphasizing goal-oriented care. The tool has become a crucial component of government training initiatives, receiving enthusiastic user responses. It is of great satisfaction to see research actively applied, with the approach allowing for tool release before perfection, enabling ongoing refinement through user collaboration.

Scotland: Outcome-focused strengths-based practices should be implemented across all management levels. At the policy level, we also seek outcome-focused discussions, steering clear of solely problem-based conversations. The emphasis should be on cultivating a culture change.

Slovenia: Collaborating with local authorities on informal caregiving involves discussions about awareness raising. Research can also contribute to the latter.

Pim: When dealing with AI, remember that you do not have to aim for perfection. It is better to create tools that can be refined incrementally from the ground up. Overly complicated tools tend to be disconnected from users and are therefore not useful.

Concluding remarks by Henk Nies:

Research is closely connected to both practice and policy, and the significance of co-creation cannot be overstated. Within Eurocarers, we have seamlessly integrated these elements. Leveraging the Eurocarers community, we aim to propel this discussion forward.

As a next step, we will draft a paper/minutes and circulate it among the community. While updating priorities may take some time, this only marked the beginning of the process. Currently we are also finalising Eurocarers' work programme for 2024.