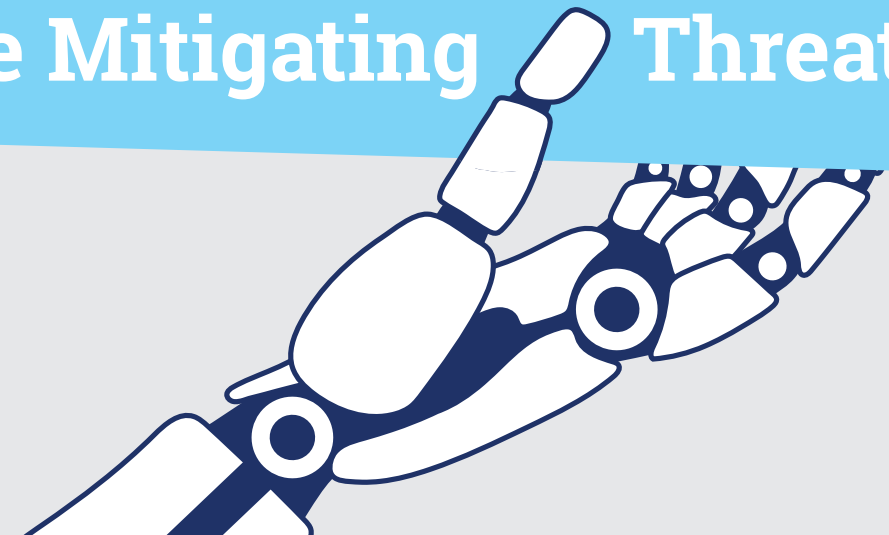
INTEGRATING ARTIFICIAL INTELLIGENCE

within Informal Care and Long-Term Care

Enhancing Opportunities while Mitigating Threats



EURO CARERS

European Association Working for Carers

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(ERWG) at their Ancona meeting, December 2023.

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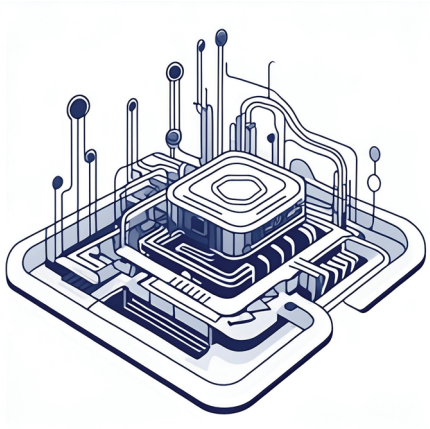
Introduction

Although substantial progress has been achieved in leveraging Artificial Intelligence (AI) for healthcare technology, its application in the realms of informal care and long-term care (LTC) remains relatively embryonic. AI-systems offer promising benefits to informal carers, including enhanced care coordination, improved health outcomes and reduced carer stress. However, it can still be quite a challenge for AI systems to be genuinely useful in the everyday communication and workflows of informal carers and LTC workers. Moreover, the integration of AI systems within informal care and LTC also poses ethical and legal challenges, such as privacy concerns, data security and associated issues.

There is no clear red line defining what AI is and what it is not. For example, some technologies such as optical character recognition (OCR) that employ textbook AI methods are no longer considered AI, at least not by the general public and it is increasingly recognized that new techniques and applications are likely to emerge in the future, expanding the AI definition (Grobelnik, Perset & Russel, 2024). Nevertheless, with this caveat in mind, the OECD (2024) provides the following newly updated definition: "An AI system is a machine-based system that, for explicit or implicit objectives, infers, from the input it receives, how to generate outputs such as predictions, content, recommendations, or decisions that can influence physical or virtual environments. Different AI systems vary in their levels of autonomy and adaptiveness after deployment." The term AI systems includes several categories of techniques such as machine learning, natural language processing and robotic systems and this updated definition of AI encompasses systems from simple to complex ones (OECD, 2024).



Informal care, provided by family or friends, plays a vital role in supporting individuals requiring long-term care, contributing significantly to the economies of European Union Member States. However, care provided by women of working age can lead to decreased workforce participation in the labour market (Carrino et al., 2023). High-intensity caring responsibilities can negatively impact carers' health, wellbeing and financial security. Carers may experience immediate income reductions and, in the long term, encounter challenges such as diminished pension benefits (Eurofound, 2022; Vicente, 2023).

The demand for long-term care (LTC) is rising in the EU (Pavolini, 2022). LTC encompasses a range of services and assistance provided to individuals who, due to mental and/or physical frailty and/or disability, require help with activities of daily living and/or permanent nursing care over an

extended period (Eurofound, 2020). However, the formal LTC sector faces staffing shortages attributed to recruitment and retainment challenges, stemming from poor working conditions, such as irregular and/or extended hours, heavy workloads and exposure to adverse social behaviours (Florek, 2022; Eurofound, 2023b). LTC workers are typically older compared to other sectors, with women constituting 81% of the workforce (Eurofound, 2023b).

The European Care Strategy advocates for a strategic and integrated approach to care, encompassing both formal and informal LTC (European Commission, 2022). Presently, 6.3 million people are employed in the LTC sector, primarily as personal care workers, qualified nurses and assistant nurses in certain countries. Furthermore, over 52 million adults (14.4% of the adult population aged 18-74 in the EU) provide informal care on a weekly basis, with women comprising two-thirds of all informal carers (European Commission, 2021). To address the growing care demand and skills gap, digital technologies — including information and communication technologies (ICTs), assistive technology and AI systems — have been proposed to enhance care service access and support independent living (European Commission, 2022).

This position paper aims to highlight the opportunities and challenges associated with AI systems in the LTC sector, specifically focusing on informal care, but also paying attention to care recipients and formal LTC workers, recognizing, in keeping with the European Care Strategy, that ideally in fact all three parties form a collaborative care partnership. The paper endeavours to initiate a dialogue on desired outcomes and effective management of potential threats, informing policymakers about the prerequisites of AI systems to improve the health and wellbeing of informal carers, formal LTC workers and care recipients. Enhancing the health and wellbeing of these groups is not only a humanitarian imperative but also a sustainable investment for communities and society at large (United Nations, 2023).

The paper is grounded in a rapid review of recent literature reviews on AI applications in formal and informal LTC published from 2019 to 2023, enriching the understanding of this emerging field and setting the stage for future systematic reviews and policy frameworks (for methodological details, see Appendix I). Furthermore, insights from discussions during a seminar session at the Eurocarers Research Working Group meeting in Ancona, Italy, on 30th November 2023, including perspectives from Professor Pim Haselager at the Radboud University in the Netherlands, have informed the content.

The paper commences with a concise introduction to the topic, followed by key findings from our rapid literature review. It then delineates relevant policies, identifies opportunities and challenges from the literature and seminar discussions, and concludes with recommendations and potential policy directions for the future.

Digital Health, AI, and Socioeconomic Inequalities in Care

The WHO Global Strategy on Digital Health emphasises that digital technologies are essential components and enablers of sustainable health systems and universal health coverage (WHO, 2021). There are high expectations for AI-powered digital technology to enhance economic viability and improve healthcare quality, prompting governments worldwide to develop policy frameworks aligned with these expectations (Kannelønning, 2023). Examples include AI Sweden's "A Handbook for Information-Driven Care" (AI Sweden, n.d.) and the NHS AI Lab (NHS, 2024). However, it is important to acknowledge that digital technologies can introduce and exacerbate existing social disparities. Previous studies have highlighted how social determinants of health can impact an individual's ability to access and benefit from services provided via digital technology (Kickbusch et al., 2021).

To advance our understanding of how new technologies amplify existing sociodemographic inequities, Chidambaram et al. (2024) propose a new construct: the digital determinants of health, that is factors intrinsic to the technology that impact disparities, inequities and outcomes of care. These digital determinants include digital health literacy (the ability to find, understand, appraise and use information and services), telemedicine (virtual visits, remote patient monitoring and mobile healthcare), Artificial Intelligence (data-driven technology for collecting, using and analysing data; communication and support agents), technologies for atypical patients (addressing diverse needs beyond the standard white Caucasian reference) and data richness (or lack of it) and information (a)symmetry (the ability for groups or populations to benefit from innovations depending on the representativeness of the datasets) (Chidambaram et al., 2024).

It can be argued that these determinants will significantly impact the health outcomes of informal carers who depend on accessible and efficient health and social care for their family members or significant others. Consequently, it is crucial to understand and address these digital determinants to ensure that technological advancements do not exacerbate existing disparities. This approach aligns with the concept of social protection, which seeks to ensure that all individuals have access to essential resources and services to meet basic needs, protect against risks and alleviate rather than exacerbate inequalities (EC, 2024). Highlighting the digital determinants of health as a pivotal framework for policymakers and healthcare providers, this perspective is crucial for sustainability in informal and formal long-term care systems.

Furthermore, digital health systems including AI systems, present a unique opportunity to overcome accessibility challenges in rural areas where long distances and limited transport options hinder access to care services (European Commission, 2022). Rural areas are disproportionately affected by demographic imbalance, with high proportions of older residents but low rates of working-age individuals (Eurofound, 2023a). However, realising this potential is hindered by several issues, including a digital divide between rural and urban areas regarding skills and access (Eurofound, 2023a). There also remains a digital gap between older and younger generations, as well as within the older population itself depending on formal education levels and social class (König et al., 2018). Moreover, general technological advancements are transforming markets into knowledge economies, focusing on skilled and well-educated workforces located in urban areas. This shift risks exacerbating rural-urban inequalities, reminiscent of those observed during the industrial revolution (Eurofound, 2023a).

Additionally, the rural-urban income gap has widened by approximately 19% over the past decade, with a higher share of the rural population at risk of poverty (Eurofound, 2023a). This socioeconomic context significantly impacts informal carers' poverty and social exclusion, health and social care needs (Eurocarers, 2022), as well as their ability to access and utilise digital health and AI systems in remote areas. In summary, understanding and addressing digital determinants will be essential to ensure that technological advancements in care promote greater equity and do not widen existing disparities.

Research regarding AI and informal and formal long-term care

A rapid review of literature reviews conducted by the first authors suggests that in long-term care and informal care settings, many AI systems focus on the group of older people and people with care needs and/or chronic conditions. Some services also target persons based on specific diagnoses, in the same way that many healthcare AI systems also tend to do. Employing the search term 'long-term care' in queries for AI-systems yielded significantly fewer results compared to using 'healthcare.' This suggests that limited research has been conducted on or directed towards AI applications within the long-term care context. For detailed aims of the rapid literature review and the search strategy employed, refer to Appendix I.

AI-systems in long term care can be thematically categorised into four groups (Table 1), namely Monitoring, positioning and human activity recognition, Clinical decision support systems for early prevention/identification/detection, Preventive treatment or support for other treatments for chronic disease and Smart homes/Ambient Assistive Living
[Add table 1 about here]

The main findings of many research papers concern system performance and optimisation. For example, Li et al. (2022) noted that most studies concentrate on algorithms rather than the clinical value for the care recipient. They also point to challenges for the systems, with only a few studies advancing beyond proof-of-concept (i.e., a basic version of the system to assess functionality before full development) (Li et al., 2022; Seibert et al., 2021). This emphasis on research output reflects the infancy of the field. Consequently, this presents a challenge if our goal is to enhance our understanding of how AI can directly support informal carers, long-term care workers or indirectly benefit care recipients through high-quality care and support. Studies should prioritise outcomes that are meaningful for and enhances the wellbeing of care recipients and their informal carers, such as improvements in health outcomes or satisfaction with received care, rather than solely on the efficiency or functionality of the technology used.

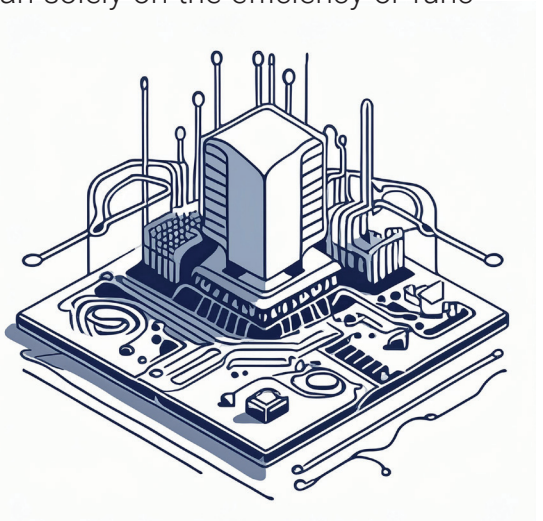


Table 1. AI intervention themes, descriptions and illustrative references

	Groups of interventions:	Description	Examples of research reviews that highlight the interventions:
1	**Monitoring, positioning and human activity recognition**	This group includes both environmental and wearable sensors that collect information about the environment and the individuals living within it. Environmental sensors are installed in different parts of a home and can monitor elements such as temperature, humidity, and air quality. They can alert residents if it gets too hot or if there is smoke that might indicate a fire. Environmental sensors can also detect falls or changes in movement patterns that might indicate a decline in a care recipient's health. Wearable sensors are small devices that people can wear, like a wristband or a clip. They monitor heart rate, activity levels and even sleep patterns to help the care recipient and the carer keep track of their health.	▸ Bibbò et al. (2022). An Overview of Indoor Localization System for Human Activity Recognition (HAR) in Healthcare. Sensors (Basel, Switzerland), 22(21). https://doi.org/10.3390/s22218119 ▸ Loveys et al. (2022). Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies. Lancet Healthy Longevity, 3(4), E286-E297. https://www.thelancet.com/pdfs/journals/lanhl/PIIS2666-7568(22)00034-4.pdf
2	**Clinical decision support systems for early prevention/identification/detection**	This group focuses on supporting decision-making and early warning systems for clinical deterioration. Various clinical decision support systems are currently being developed and applied, aimed to identify early signs of deterioration in dementia, COPD, or rheumatic diseases, alternatively to provide warnings to the user before an epileptic seizure.	▸ Choudhury et al. (2020). Use of machine learning in geriatric clinical care for chronic diseases: a systematic literature review. Jamia Open, 3(3), 459-471. https://doi.org/10.1093/jamiaopen/ooaa034 ▸ Li et al. (2022). Seizure detection based on wearable devices: A review of device, mechanism, and algorithm. Acta Neurologica Scandinavica, 146(6), 723-731. https://doi.org/10.1111/ane.13716
3	**Preventive treatment or support for other treatments for chronic disease**	These systems provide preventive treatment or offer support for the treatment of chronic diseases in the form of virtual carers (provided by health and social care providers), chatbots, virtual coaches, or AI-enhanced robots. For example, these virtual carers assist both care recipients and care providers in education and self-care for managing diabetes, depression, or heart failure.	▸ Bin Sawad et al. (2022). A Systematic Review on Healthcare Artificial Intelligent Conversational Agents for Chronic Conditions. Sensors, 22(7), Article 2625. https://doi.org/10.3390/s22072625 ▸ Tropea et al., (2019). Rehabilitation, the Great Absentee of Virtual Coaching in Medical Care: Scoping Review. Journal of Medical Internet Research, 21(10), Article e12805. https://doi.org/10.2196/12805
4	**Smart homes/Ambient Assistive Living**	This group comprises networks of various technologies and services specifically designed to assist care recipients in compensating for any physical or mental challenges they might face and for helping to keep the residents safe in the home environment, for example, through visual or audio reminders or remote monitoring of daily activities.	▸ Gao et al. (2023). Assistance from the Ambient Intelligence: Cyber-physical system applications in smart buildings for cognitively declined occupants. Engineering Applications of Artificial Intelligence, 123, Article 106431. https://doi.org/10.1016/j.engappai.2023.106431 ▸ Maresova et al. (2020). Health-Related ICT Solutions of Smart Environments for Elderly-Systematic Review. IEEE Access, 8, 54574-54600. https://doi.org/10.1109/access.2020.2981315

Policies in the area of AI and care

This section provides an overview of policies related to AI and care. In particular, the AI Act (European Commission, 2024) which established regulations for AI use across Europe, and the WHO's global strategy on digital health (WHO, 2021) that aims to guide the integration of digital technologies in health systems worldwide. This is followed by an outline of the WHO's ethical principles for AI in healthcare which are aimed at ensuring fair and safe usage of AI. Finally, recent relevant literature in the field of policy and AI is highlighted to provide the reader with insights into current trends concerning AI and care.

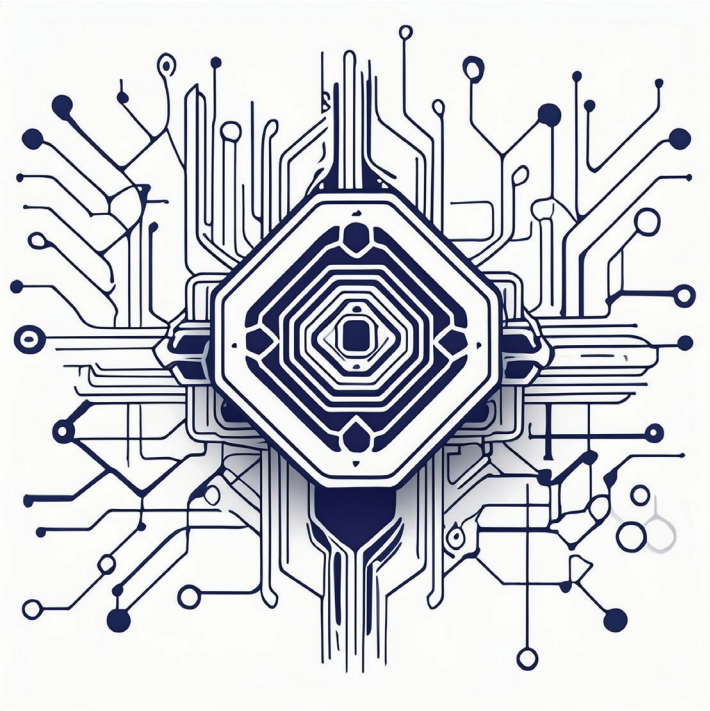
The European AI Act was initially proposed in 2021 to tackle challenges associated with technological advancements and risks related to AI. However, significant revisions were required in late 2022 following the emergence of generative AI (i.e., AI that uses machine learning to analyse large datasets and generate new data). Independent legal experts in the field have argued that there is an inherent contradiction in the legislative framework's aim of fostering ethical and human-centric AI while also promoting innovation and competitiveness (Fernhout & Duquin, 2024). Ethical and human-centric AI principles prioritise the protection of fundamental rights, privacy, and societal well-being. This approach may involve implementing stringent regulations and safeguards to ensure AI systems are deployed responsibly. On the other hand, promoting innovation and competitiveness often requires a more permissive regulatory environment to encourage experimentation and rapid development of new technologies, potentially prioritising economic growth and market competitiveness over ethical considerations. Ideally, incorporating ethical values into the design of applications will in the long run not detract but add to their commercial success, in large part due to their increased trustworthiness for users. The European Parliament approved the Artificial Intelligence Act on 13th March 2024, making it the first major economic bloc to regulate this technology (European Parliament, 2024).

The AI Act aims to protect fundamental rights, democracy, the rule of law and environmental sustainability using a risk-based approach. The framework defines four levels of risk—minimal, limited, high and unacceptable—and categorises all AI systems accordingly. Currently, most AI systems in use fall into the minimal risk category (European Commission, 2024). The regulation aims to ensure the protection of workers' and citizens' rights, representing a new model of governance centred around technology.

This next section provides an overview of relevant healthcare policies addressing AI, as these policies could be deemed useful in enhancing our understanding of AI's potential role in the context of formal long-term care (LTC) and informal care. In the WHO publication "Global Strategy on

Digital Health" (WHO, 2021), AI is included in the definition of digital health and the global strategy aims to strengthen health systems through the application of digital health technologies. The strategy emphasises the importance of sharing health data, classified as sensitive personal information, thus requiring legal protection systems to be in place. Sharing data is considered vital as it can contribute to improved health outcomes and continuity of care for patients. The strategy highlights how digital determinants of health — digital literacy, telemedicine, Artificial Intelligence, technologies for atypical patients and data poverty (see p. 4) (WHO, 2021) — become more relevant as digital health advances.

The WHO (2024) proposed a set of ethical principles to guide the development and deployment of AI, namely to: (1) protect autonomy; (2) promote human wellbeing, safety and the public interest; (3) ensure transparency, explainability and intelligibility; (4) foster responsibility and accountability; (5) ensure inclusiveness and equity; and (6) promote AI that is responsive and sustainable. The WHO paper highlights how AI has the potential to reduce the workload of healthcare providers ("keyboard liberation") and provide virtual health assistance to patients. However, it notes that these strengths come with corresponding risks, such as the risk of inaccurate or incomplete guidance or responses. The WHO provides a comprehensive list of recommendations to governments to uphold ethical standards and human rights.

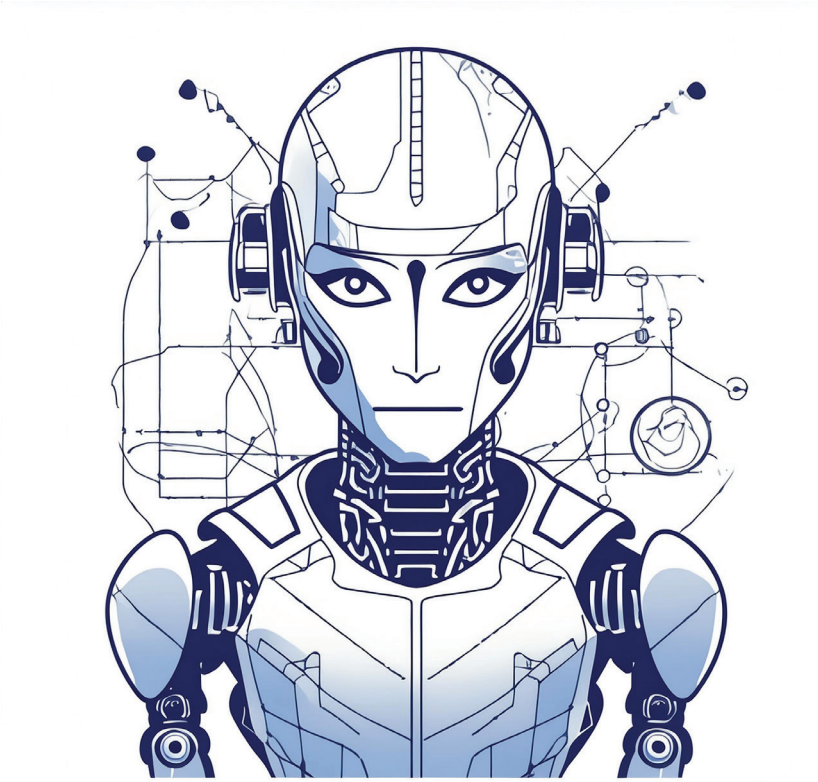


The need for ethical awareness is further emphasised by Sartor and Lagioia (2020), who argued that AI has become data-hungry, spurring data collection, as AI systems presuppose and foster the creation of vast datasets (i.e., big data). The authors recognize that while these large datasets can deliver societal benefits, they also entail risks such as pervasive surveillance, behaviour influence and polarisation. In this way, Sartor and Lagioia (2020) argue that all types of personal data can be used to analyse, forecast and influence human behaviour, presenting opportunities for social knowledge and governance, but also posing risks such as surveillance capitalism and a surveillance state. The study highlights the tension between traditional data protection principles and the full deployment of AI, since AI systems may involve collecting and processing data for purposes not fully determined at the time of collection (Sartor & Lagioia, 2020). This

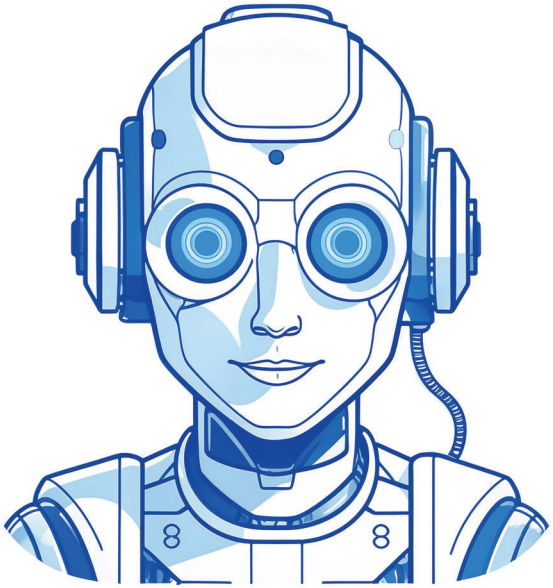
issue is highly relevant in the context of formal and informal care, involving data concerning patients/service users and their social relationships, such as health trackers collecting health data, calendar data concerning appointments and meetings or social media interactions. Concrete examples need to be scrutinised and discussed publicly and Sartor and Lagioia (2020) recommend applying data protection principles to ensure successful AI implementation by generating trust and preventing risks.

Dutton (2018) explained that AI policy serves a dual purpose: governments should invest in AI to secure benefits for their population and, at the same time, respond to risks and challenges posed by AI systems. He also highlights that there are currently no established best practices in this emerging field of AI policy. In addition to global strategies involving AI, several countries have introduced their own national strategies to promote AI use and development. For example, Canada has the Pan-Canadian AI Strategy, Singapore has the National AI Strategy, Germany has its own AI Strategy and Finland has the Aurora AI project (Galindo et al., 2021).

Dutton (2018) observed that these strategies vary widely in their approach, a view shared by Galindo et al. (2021) who showed that national strategies and policies tend to focus on certain sectors, like transportation and logistics, energy, agriculture or health. The European Care Strategy (2022) underscores that the digital transition, including AI, offers numerous opportunities but should not replace human interaction and should be integrated at the core of care work.



Potential opportunities and challenges



Having presented an overview of formal and informal care in the EU, alongside an examination of AI applications and a summary of the policy landscape relevant to AI in this context, this position paper proceeds to outline opportunities and challenges associated with introducing AI into both informal and formal LTC. This section draws on insights gathered from a dedicated seminar session held during the Eurocarers Research Working Group (ERWG) meeting in Ancona, Italy, in December 2023. During this seminar, the Group discussed potential opportunities and threats associated with upcoming AI systems in care. The discussion began with a presentation by Professor Pim Haselager, who provided an overview of AI systems. This was followed with a presentation by Maria Nilsson of the main insights derived from a rapid review of reviews in the area (see p.5). The seminar focused on the potential implications primarily, but not exclusively, for informal carers supporting individuals with LTC needs. While AI impacts most societal domains and thus informal carers in numerous ways, this overview selectively focuses on areas relevant to long-term care, excluding discussions solely centred on medical implications, democratic effects and changes in the labour market.

Opportunities

AI assistants:
Enhancing stress management and providing assistive services

Informal carers often face significant stress due to their responsibilities in coordinating health and social care services for their loved ones. The introduction of AI assistants holds great potential in alleviating this challenge by providing timely reminders and effective calendar management solutions.

Moreover, AI assistants can be invaluable resources, assisting carers in understanding and navigating available services and helping them to assert their rights and entitlements. Recent advancements in AI, especially in text generation, offer promising tools to empower carers with more effective application writing and benefit claims processes. A potentially useful initiative here for example could be the development of a website for informal carers with a top ten of most useful prompts to present to GPTs. These innovations could serve as pivotal equalizers, simplifying administrative tasks for carers and promoting more equitable access to support services.

Assessing the needs, preferences and goals of informal carers

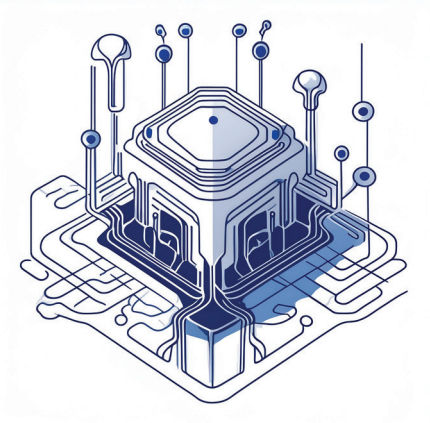
Providing timely and early support is crucial for informal carers, starting with a thorough discussion/assessment of their caring situation. AI-systems could be developed to assist in these assessments, enabling personalised support measures that could help to facilitate positive change. Well-designed AI systems could assist professionals and/or NGOs in conducting assessments and offer recommendations for appropriate actions and services. However, it is essential that health and social care staff are actively supported in the use, control, and dissemination of these tools. Moreover, such tools need regular quality controls regarding their usefulness and effectivity, in order to establish that they genuinely help to alleviate the workload of staff and add value for informal carers themselves.

Supporting the LTC workforce, facilitating coordination and easing administrative burden

In home-based settings, the LTC workforce often faces the challenge of limited peer support, leading to feelings of isolation (Eurofound, 2020). AI systems can tackle these issues by offering support services, access to expert advice and fostering community connections. Moreover, AI has the potential to streamline interactions between formal and informal carers, optimising the use of support resources in a manner that upholds sustainability for all involved. A well-supported LTC worker, working in coordination and partnership with informal carers, enhances safety and security for both informal carers and care recipients. In essence, this requires not much more than technology which is currently available, i.e. small-scale social messaging apps (Signal, WhatsApp), supported by note- and agenda-keeping language models.

Another significant area where AI could make an impact is in reducing the administrative workload of LTC workers. By leveraging technology to separate caregiving from administrative paperwork, AI can improve working conditions in this field (Eurofound, 2020). In other words, contribute to keyboard liberation, i.e. increasing the time spent on care and decreasing time spent typing on a keyboard. This approach has the potential not only to improve job satisfaction but also to contribute to the overall sustainability of LTC practices. However, meaningful human control over the AI's contributions, in order to avoid responsibility gaps (Santoni de Sio & Mecacci, 2021) will be required.

Finally, AI technologies offer promising avenues for developing decision support systems and task automation tools currently designed for the healthcare sector. These innovations could be adapted to meet the needs



of informal and formal carers in the LTC sector, expanding the scope of support and enhancing care delivery effectiveness. For instance, an informal carer could use an AI-powered application to manage medication schedules, monitor health data such as blood pressure and sleep patterns, and receive reminders for medical appointments. Similarly, AI can automate routine administrative tasks for LTC workers, such as updating patient records and managing scheduling.

AI-Enhanced Support in Dementia Care: Continuous Engagement and Respite for Carers

In the context of caring for individuals living with dementia, the sometimes-repetitive nature of conversations can be a source of stress for their co-habiting informal carer/s. AI technology could offer support by developing chat functions capable of engaging in repeated conversations without signs of fatigue. These AI companions could alleviate the emotional toll on carers by serving as a consistent and understanding presence for individuals living with dementia. For instance, envision an AI friend—tailored to recognise and adapt to the person's preferences and history, capable of initiating and sustaining conversations in a familiar manner at any hour. This AI entity could not only provide companionship but also offer high-intensity carers a form of respite. Of course, genuine human-human interaction is of irreplaceable value, but this scenario suggests a potentially useful complementary approach for situations where carer responsibilities may be onerous and formal LTC is limited.

Enhancing the knowledge of Informal Carers and Persons with LTC needs via AI

AI could facilitate access to information and advice about care, caring and care-life balance. For example, it could provide informal carers with access to training and documentation to value and accredit their caring skills. Indeed, it is recognised that inadequate training or preparation is associated with perceived burden of care and low levels of life satisfaction among informal carers (Eurocarers, 2023). The recent Eurocarers position paper, entitled "Exploring the physical & mental health implications of informal caregiving" (2023) emphasises the need for training in core caring skills, manual handling, coping, as well as knowledge of conditions, managing complex medication prescriptions, and coordinating medical procedures. AI systems, particularly LLM models (Large Language Models, i.e. a generative type of AI, such as GPT, Claude or Gemini), could break down these procedures into step-by-step instructions in a language adapted to the individual's needs and preferences. An inventory of best practices and most useful instructions, for example could be a practical first step in this direction.

Regarding the autonomy of individuals with LTC needs, AI holds the potential to augment their understanding of medical conditions, potentially through the creation of virtual health assistants (i.e. computer programmes simulating conversations in a human like style). Tudor Car et al. (2020) identified several studies of health assistants providing healthcare services for mental health support, diabetes management or providing symptom checking, as well as assistants focused on educating care recipients on various health-related topics. These assistants could serve care recipients, as well as both informal and formal carers, by offering tailored information that is most accessible to them — whether through text, speech or video. The WHO recognises the importance of such innovations in healthcare education and support (WHO, 2024).

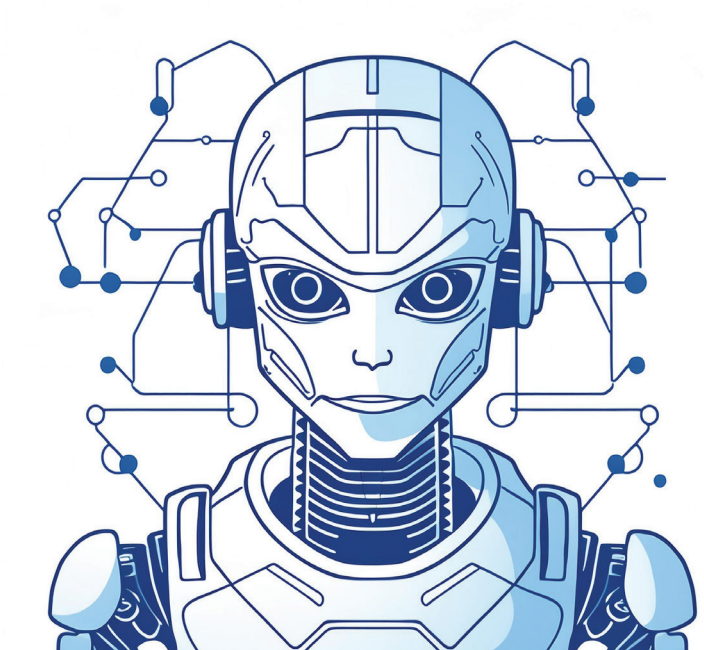
Crucially, the adaptability of AI in modifying its communication style to match the receiver's preferences, be it a carer or care recipient, offers a promising avenue for enhancing informal carer's, LTC workers' and care recipients' understanding and knowledge. This nuanced approach could potentially foster a more inclusive educational environment, accommodating diverse learning needs and preferences. For example, AI can help address variability in learning, adapt the language and engage in the learning process beyond providing feedback on correct or incorrect answers (U.S. Department of Education Office of Educational Technology, 2023).

AI for supporting Instrumental Activities of Daily Living (IADLs)

AI can contribute to developing interactive activity boards, which are visual calendars displaying daily or weekly activities. These tools are currently used in elder care facilities and settings for people with intellectual disabilities, for example. Further development of these tools could help with activities of daily living (ADL) among persons with LTC needs in homecare settings, promoting a holistic approach to care and education. Specifically, recent developments in voice mode and live vision capacities (e.g. ChatGPT-4o; https://openai.com/index/hello-gpt-4o/) enable supportive real-time on-site interactions with AI. An AI-enhanced activity board could automate reminders for bill payments, integrate with banking apps, schedule public transportation, create shopping lists, arrange home delivery of groceries, provide meal planning with step-by-step cooking guides or videos, and assist with medication intake using instructional videos for techniques such as asthma inhalations. Such support could benefit informal carers living nearby or facilitate care from a distance.

Challenges

The emergence of AI technology, like any significant technological innovation, presents and embodies a double-edged sword, offering opportunities for advancement while posing potential threats. This duality is particularly relevant in the context of LTC, where both formal and informal care sectors can benefit from AI capabilities. The World Health Organization (WHO, 2024) cautions against overreliance on LLMs and what they call "technological solutionism" — the belief that every social or human problem can be solved through technology, particularly new or innovative digital tools in a one-size fits all approach. Such a mindset may overlook inherent challenges. Integrating AI into LTC requires a balanced approach that acknowledges its potential to enhance care delivery while managing associated risks. The following section outlines some of the challenges identified in our rapid literature review and subsequent discussions with ERWG members within the context of informal care and formal LTC.



Balancing Support, Surveillance and Human Interaction in Care

Adopting AI in care introduces a complex array of ethical dilemmas, particularly in balancing enhanced support with surveillance implications and reduced human interaction. There is a risk that AI could be leveraged to rationalise reductions in other forms of support, shifting the burden of data interpretation from professional care providers to informal carers. This raises fundamental questions about choice and consent in care. Is acceptance of AI assistance truly optional or might informal carers and care recipients feel compelled to agree due to stretched health and care services?

Regarding ethical issues of AI surveillance technologies, while some individuals may experience a heightened sense of independence and security through AI monitoring, the impact on informal and LTC workers must be carefully considered. The prospect of working or living under constant surveillance raises critical questions about the balance between safety and the right to privacy and autonomy of all involved parties.

The potential trade-offs between increased security and reduced personal integrity and privacy are complex. Navigating these challenges requires engaging in a thoughtful dialogue that weighs the benefits of AI-enhanced safety and independence against privacy and responsibility risks and the essential human elements of care for all key parties involved.

The normative impact of AI

The deployment of AI systems in monitoring and care settings raises significant concerns about their normative effects on individual behaviours and freedoms. These systems, proficient at detecting deviations from established patterns, inherently possess the capability to enforce a certain "normalcy". While beneficial for ensuring safety, this capability raises ethical questions about its impact on individual autonomy and the right to engage in harmless, albeit different and/or irregular, behaviours.

Consider a scenario where AI monitoring flags an individual's preference for late-night snacks, long late-night walks or talking to oneself as irregularities, triggering alerts. Although well-intentioned for safety, subsequent interventions may inadvertently limit the person's freedom to explore and interact with their environment on their own terms. Such instances highlight a critical ethical dilemma: the potential for AI to unintentionally restrict individual freedoms and civil liberties under the guise of protection and care.

This normative effect of AI underscores the importance of adopting a balanced approach to technology implementation—one that safeguards care recipients against risks without excessively infringing upon their rights to autonomy and self-determination. It invites a broader debate on how we, as a society, value and prioritise the interplay between collective safety and individual freedoms.

Bias in datasets

The use of extensive datasets, such as electronic healthcare registers for training AI systems to make predictions and recommend personalised treatment, carries the inherent risk of embedding biases. These biases can significantly reduce the applicability of AI to diverse population sub-groups, potentially exacerbating existing health inequalities or even creating new ones. Such unintended consequences have historically led to poorer health outcomes for underrepresented, underserved and under-resourced groups (Abràmoff et al., 2023).

To mitigate these risks and enhance the equity of AI applications within LTC, it is essential to adopt a rigorous approach to the validation of AI models. This process should include comprehensive testing across a variety of population groups and subgroups to ensure that AI tools perform effectively and fairly for all segments of the population. Furthermore, ensuring that the data used to train AI includes heterogeneous groups of people is crucial. This would contribute to ensuring that AI systems (e.g. those implemented within LTC) are fair and accessible to all citizens (Anderson & Sutherland, 2024).

Reducing trust in human knowledge and experience

AI systems, such as conversational agents, pose a risk of reproducing cognitive and social biases (Laacke, 2023). These biases can lead to certain individuals or groups, typically those from dominant social backgrounds, being overrepresented in AI datasets, thereby having their views and knowledge recognised and valued more frequently. This situation can result in forms of "epistemic injustice" (Fricker, 2007), where biases influence the extent to which we trust what someone says, or where gaps in collective understanding hinder certain groups from sharing their experiences.

De Proost and Pozzi (2023) highlighted the risk of epistemic injustice with the use of AI systems in the form of conversational agents in mental health care. For example, if the conversational agent misunderstands a care recipient's exact meaning, the individual may gradually lose confidence in themselves, feeling unheard or unacknowledged. The authors further note that a person's lived experience may not align with the conceptual categories programmed into the AI, posing a significant risk for individuals from disadvantaged groups if the training data lacks representation and only reflects the majority norm. If a person is unable, for various reasons, to fully articulate their experiences, the AI system may not recognize these as issues requiring further attention. This can marginalize the lived experiences of disadvantaged and underrepresented groups (De Proost and Pozzi, 2023). This situation is further exacerbated if professionals place more trust in the AI's assessment over the care recipient's account, thereby marginalising the care recipient's voice. Laacke (2023) also raises this issue, noting that some individuals or groups may be better understood than others, depending on their representation in the datasets.

While both Laacke (2023) and De Proost and Pozzi (2023) focus on the use of conversational AI in psychotherapeutic settings, we argue that the concerns they raise also apply to disadvantaged groups of informal carers and LTC workers, such as migrant care workers. These groups often struggle to have their voices heard and their knowledge and lived experiences validated. Therefore, it is imperative to actively involve individuals from diverse socio-economic and cultural backgrounds in the research and development of AI systems intended for use in health and social care more broadly and, more specifically, within formal LTC and carer support services.

Internet connectivity and digital skills

The deployment and effectiveness of AI systems are significantly influenced by internet connectivity and digital literacy levels. Despite the high rate of internet access (92%) in European households, notable disparities exist between rural and urban areas regarding internet speed and reliability. These discrepancies are not only persistent but appear to be widening over time (Eurofound, 2023a). Additionally, as outlined earlier above (pgs. 4-5), digital skills, crucial for effectively leveraging AI systems, tend to be more developed in urban areas. This urban-rural divide in digital skills and internet connectivity is a consistent trend across all EU countries (Eurofound, 2023a).

These disparities have profound implications for health equity, highlighting access to the internet and digital literacy as pivotal digital determinants of health. Moreover, in the context of demographic shifts, where rural areas are experiencing rapid ageing alongside a decline in the working-age and younger populations (Eurostat, 2020), this demographic trend exacerbates the challenge, as it correlates with reduced access to public services, further marginalising rural communities.

The widening digital divide threatens to deepen existing inequalities between urban and rural areas, affecting both informal carers and LTC workers who currently and/or in the future will increasingly rely on digital resources for information and support.

In an era where AI systems could offer significant potential for improving carer support, ensuring equitable access to the internet and necessary digital literacy skills among informal carers, as well as care recipients and LTC workers, is paramount.

The Efficiency-Quality Trade-off in Care: The Role of Data and Algorithms in Shaping LTC Standards

Currently, AI algorithms are more adept at identifying solutions or improvements for efficiency rather than for quality. As a result, there exists a trade-off, making it increasingly challenging to advocate for quality in care due to potentially insufficient data to demonstrate quality improvements. It is crucial for researchers and policymakers to lead the way in setting the agenda by clarifying the necessary data requirements and measurements for assessing LTC quality.

Cybersecurity risks in AI implementation

With AI technologies and their underlying datasets becoming increasingly integral to healthcare (Anderson & Sutherland, 2024), they also emerge as potential targets for cyber threats. Risks associated with these technologies include manipulation of training data, ransomware attacks on data and prompt injection. Prompt injection occurs when unauthorised or unexpected data is entered into an AI system, causing unintended behaviour and resulting in errors or manipulated outcomes (WHO, 2024). These vulnerabilities not only jeopardise the integrity of AI systems but also raise significant privacy concerns, as cyberattacks can compromise personal data, leading to the identification of individuals and violations of privacy.

Therefore, health and LTC care systems must implement privacy-enhancing measures such as encryption and stringent access controls (Anderson & Sutherland, 2024). These measures ensure that data is accessible only to authorised individuals within appropriate contexts and at appropriate times.

Carbon and water footprints

According to data from the World Resources Institute, growing populations, rising temperatures and industrial use of water will strain citizens' access to freshwater (Penney & Muyskens, 2023). Given the urgency of climate change as a global health challenge (WHO 2024), it is essential to consider its effects on care situations affecting care recipients, informal carers and LTC workers.

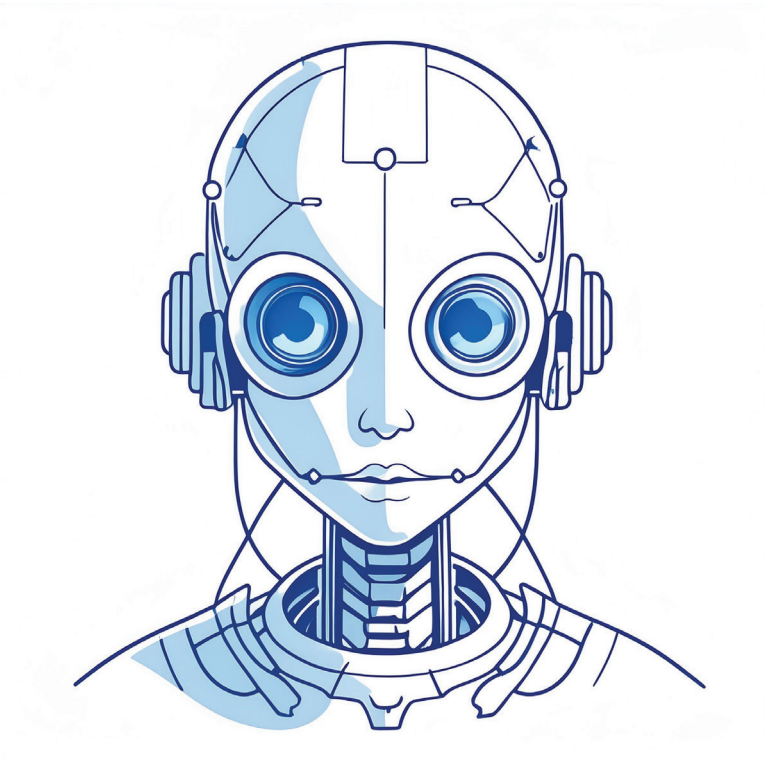
Against this broader societal context, it is timely to take an interest in the environmental aspects of AI. The operation of AI systems demands significant energy resources. For instance, training a single AI model can consume as much energy in two months as 300 US households consume annually (Ananthaswamy, 2023). Although some data centres utilise renewable energy, a considerable number still rely on electricity from fossil fuels, according to a recent survey by Luccioni & Hernandez-Garcia (2023). Moreover, it is estimated that by 2027, global AI operations could account for water withdrawals ranging between 4.2 and 6.6 billion cubic meters annually, surpassing the total yearly water usage of countries such as Denmark (Li et al., 2023).

This aspect of AI's environmental impact, particularly concerning water use, has yet to gain significant attention but it is increasingly important to recognise both water and carbon footprints in discussions about AI sustainability (see Li et al., 2023).

Inaccurate, incomplete or false statements

Informal carers, as well as LTC workers and care recipients, with lower levels of formal education, face a heightened risk of being unable to detect inaccurate, incomplete or false information generated by LLM models designed to respond to linguistic input and generate human-like text based on the data it has been trained on. This increased risk stems from limited access to alternative information sources and potentially lower proficiency in critically evaluating information. Furthermore, LLM models can generate text that is more readable and understandable compared to human-written text, making it challenging for individuals to discern whether the content was authored by an LLM or a human (Spitale et al. 2023). This ambiguity can contribute to overall scepticism and distrust in information, exacerbating public health issues through the spread of misinformation. Therefore, there is a pressing need for strategies to identify misinformation produced by LLM models.

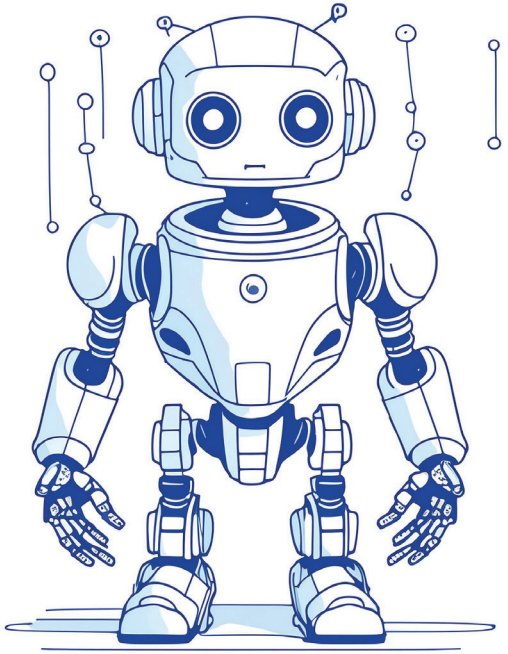
For example, if carers cannot trust the accuracy of the information they receive — whether medical advice, caregiving tips or health updates — it could impair their ability to provide effective care. Misinformation may lead to the adoption of inappropriate care strategies that could subsequently adversely affect the health and wellbeing of the care recipient. Additionally, issues may arise regarding the responsibility or accountability for AI supported recommendations, diagnoses, treatments or actions. The EU's AI act requires meaningful human control (Santoni de Sio & Mecacci, 2021; Enqvist, 2023; Hille et al., 2023) over AI actionable outcomes. Implementing this in an efficient and effective way will require serious research efforts and practical field evaluations.



Concluding recommendations

We recognise that a comprehensive approach is needed to guide the integration of AI systems within LTC and informal care, where care recipients, informal carers, LTC workers, providers, developers, governments and civil society all have significant roles to play (Anderson & Sutherland, 2024).

Eurocarers will continue to work towards ensuring that policies support and accelerate (where appropriate) the implementation of AI systems that have the potential to improve the quality of life for informal carers, individuals with LTC needs and LTC workers. Concurrently, policies must be closely monitored to effectively mitigate and draw attention to the risks and threats to equal rights and opportunities for all three target groups.
In this digital era, possessing digital literacy skills — the ability to locate, comprehend, evaluate, and utilise information and services — is increasingly vital (Chidambaram et al., 2024). From a public health perspective, society must develop these competencies to prevent further health and social inequalities (van Kessel et al., 2022). To address this, policy measures should focus on providing comprehensive digital literacy programmes accessible to all citizens, emphasising tailored approaches for informal carers to ensure no one is left behind.
We believe that AI systems hold significant untapped potential in both informal and formal LTC. At the same time, we also recognize the challenges involved. Aung et al. (2021) emphasize that the quality of care should take precedence over the attraction of groundbreaking technology, advocating for the use of AI systems only when they are appropriate and beneficial to care recipients. We would like to extend this consideration to include not only care recipients but also informal carers and LTC workers, ensuring that AI implementation supports all stakeholders involved in the caregiving process.



Based on the rapid review and synthesis of the ERWG Ancona discussion, we propose three core recommendations for future policy and practice:

1) Maximise Benefits and Mitigate Risks

It is essential to establish a robust framework for AI systems in LTC that harness the capabilities of AI systems while incorporating stringent oversight mechanisms. This framework should include standards and protocols for the ethical use of AI in LTC, encompassing privacy protections, data security and meaningful human control. Continuous monitoring systems should evaluate AI performance and its impact on care quality and outcomes for care recipients, informal carers and LTC workers. The limitations of AI systems underscore the unique qualities of human capacity and intelligence. Despite this, humans are not infallible and are prone to serious errors and lapses in judgment. In these instances, AI systems can play an important role, offering significant advantages by mitigating human errors and enhancing decision-making processes.

2) Promote Equitable Access to AI-enhanced LTC Services

Access to high-quality care must be made available to underserved groups by implementing tailored training programmes for informal carers, care recipients and LTC workers at varying technical proficiency levels to ensure effective utilisation of AI tools.

AI systems should be developed to be multilingual and culturally sensitive, accommodating diverse populations. Financial support should be provided to ensure technology access for under-resourced carers and care recipients.

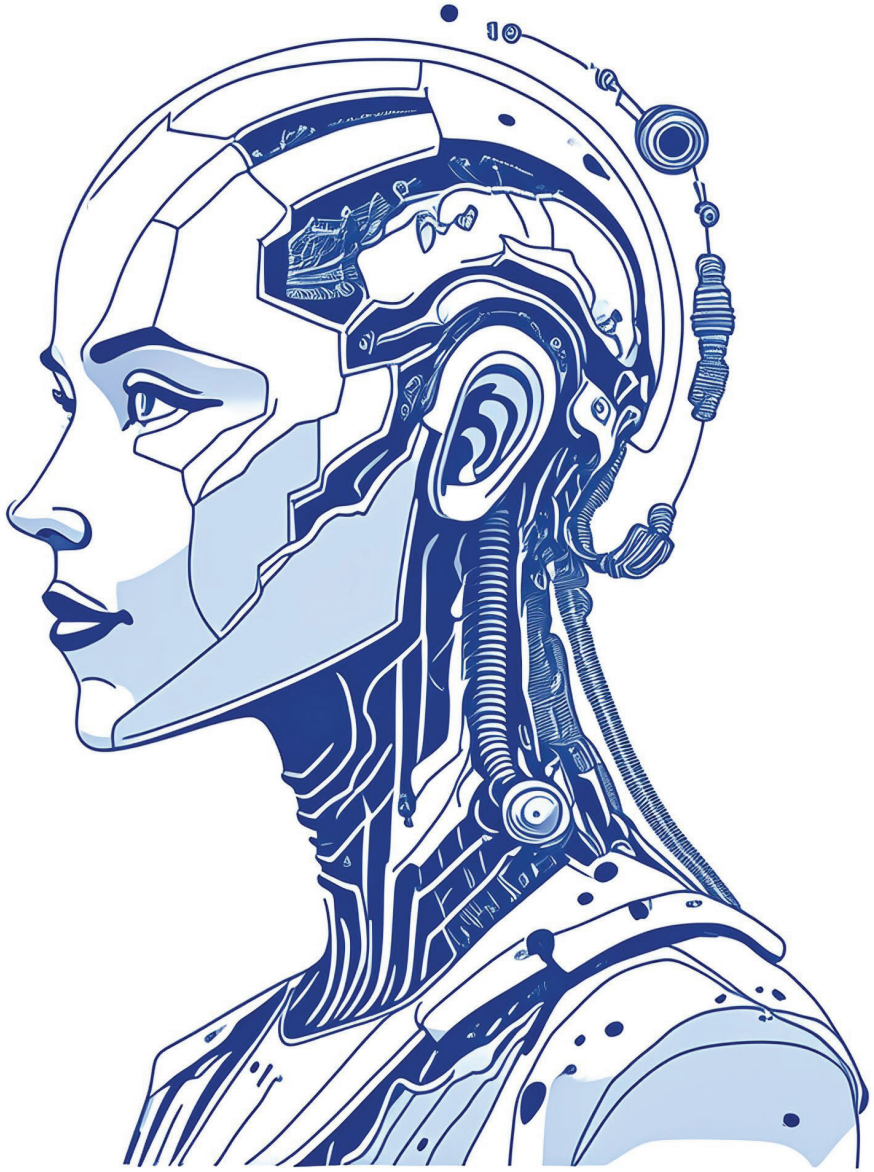
Additionally, establishing a direct feedback loop between informal carers and service providers, in collaboration with care recipients, is recommended to ensure timely intervention and care adjustments (for more details, see 3) below).

AI systems have the potential to expand LTC access by automating routine tasks, providing remote monitoring services and offering predictive insights that optimise resource allocation. This approach allows available resources to be allocated where they are most needed, with a long-term focus on sustainability and predictability for the care recipient and the informal carer.

3) Explore the potential of AI systems to Improve LTC Coordination

AI systems can serve as a bridge between informal and formal care providers by automating routine tasks and offering predictive insights that optimise resource allocation. For example, by analysing data, AI can predict times when LTC workers are most needed in daily care or when respite care is essential throughout the year.

Integrated platforms that facilitate real-time sharing of the care recipient's data and care plans (with the care recipient's permission) enhance coordination and participation among all key stakeholders involved. AI-powered systems could help to manage care schedules, assess optimal planning based on multiple factors, alert informal carers to care recipients' needs and provide critical information across different care settings, such as homecare or assisted living facilities.



References

- Abràmoff, M. D., Tarver, M. E., Loyo-Berrios, N., Trujillo, S., Char, D., Obermeyer, Z., Eydelman, M. B., Maisel, W. H., Foundational Principles of Ophthalmic, I., & Algorithmic Interpretation Working Group of the Collaborative Community for Ophthalmic Imaging Foundation, W. D. C. (2023). Considerations for addressing bias in artificial intelligence for health equity. Npj Digital Medicine, 6(1), 170. https://doi.org/10.1038/s41746-023-00913-9
- AI Sweden. (n.d). A handbook for information-driven healthcare. Retrieved 04/05/24 from https://www.ai.se/en/sector-initiatives/healthcare/information-driven-healthcare/handbook-information-driven-healthcare
- Ananthaswamy, A. (2023). In AI, is bigger always better? Nature, 615(7951), 202-205. https://doi.org/10.1038/d41586-023-00641-w
- Anderson, B., & Sutherland, E. (2024). Collective action for responsible AI in health. OECD Artificial Intelligence Papers, No. 10. https://doi.org/10.1787/f2050177-en
- Aung, Y. Y., Wong, D. C., & Ting, D. S. (2021). The promise of artificial intelligence: a review of the opportunities and challenges of artificial intelligence in healthcare. British medical bulletin, 139(1), 4-15.
- Carrino, L., Nafilyan, V., & Avendano, M. (2023). Should I Care or Should I Work? The Impact of Work on Informal Care. Journal of Policy Analysis and Management, 42(2), 424-455. https://doi.org/https://doi.org/10.1002/pam.22457
- Chidambaram, S., Jain, B., Jain, U., Mwavu, R., Baru, R., Thomas, B., Greaves, F., Jayakumar, S., Jain, P., Rojo, M., Battaglino, M. R., Meara, J. G., Sounderajah, V., Celi, L. A., & Darzi, A. (2024). An introduction to digital determinants of health. PLOS Digit Health, 3(1), e0000346. https://doi.org/10.1371/journal.pdig.0000346
- De Proost, M., & Pozzi, G. (2023). Conversational Artificial Intelligence and the Potential for Epistemic Injustice. The American Journal of Bioethics, 23(5), 51-53. https://doi.org/10.1080/15265161.2023.2191020
- Dutton, T. (2018). An Overview of National AI Strategies. Retrieved 2024-03-06 from https://medium.com/politics-ai/an-overview-of-national-ai-strategies-2a70ec6edfd
- Enqvist, L. (2023). 'Human oversight' in the EU artificial intelligence act: what, when and by whom? Law, Innovation and Technology, 15(2), 508-535. https://doi.org/10.1080/17579961.2023.2245683
- Eurocarers. (2022). Informal care, poverty and social exclusion. https://eurocarers.org/publications/informal-care-poverty-and-social-exclusion-2/
- Eurocarers. (2023). Exploring the physical and mental health implications of informal caregiving. https://eurocarers.org/wp-content/uploads/2024/02/Eurocarers-Exploring-the-Physical-and-Mental-Health-Implications-of-Informal-Caregiving.pdf
- Eurofound. (2020). Long-term care workforce: Employment and working conditions. Luxembourg: Publications Office of the European Union.
- Eurofound. (2022). COVID-19 and older people: Impact on their lives, support and care. https://www.eurofound.europa.eu/en/publications/2022/covid-19-and-older-people-impact-their-lives-support-and-care
- Eurofound. (2023a). Bridging the rural–urban divide: Addressing inequalities and empowering communities. Luxembourg: Publications Office of the European Union.
- Eurofound. (2023b). Social services in Europe: Adapting to a new reality. https://www.eurofound.europa.eu/en/publications/2023/social-services-europe-adapting-new-reality
- European Commission. (2021). Study on exploring the incidence and costs of informal long-term care in the EU. Luxembourg: Publications Office of the European Union. https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8423&furtherPubs=yes
- European Commission. (2022). COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS on the European care strategy. (COM(2022) 440 final). Brussels Retrieved from https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52022DC0440

- European Commission. (2024, 6 March 2024). AI Act. https://digital-strategy.ec.europa.eu/en/policies/regulatory-framework-ai
- European Commission. (2024, 29 May 2024) Social protection. https://international-partnerships.ec.europa.eu/policies/human-development/social-protection_en
- Artificial Intelligence Act. (2024). https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=EP%3AP9_TA%282024%290138
- Eurostat. (2020). Ageing Europe – statistics on population developments. Retrieved 05/05/24 from https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Ageing_Europe_-_statistics_on_population_developments#Older_
- Fernhout, F., & Duquin, T. (2024, 13 Feb 2024). The EU Artificial Intelligence Act: our 16 key takeaways. https://www.stibbe.com/publications-and-insights/the-eu-artificial-intelligence-act-our-16-key-takeaways
- Florek, K. (2022). The Crisis in Long Term Care: Effects of private provision. https://publicservices.international/resources/publications/the-crisis-in-long-term-care---effects-of-private-provision?id=12878&lang=en
- Fricker, M. (2007). Epistemic injustice: Power and the ethics of knowing. Oxford University Press.
- Galindo, L., Perset, K., & Sheeka, F. (2021). An overview of national AI strategies and policies. Going Digital Toolkit Note, 14. https://goingdigital.oecd.org/data/notes/No14_ToolkitNote_AIStrategies.pdf
- Grobelnik, M., Perset, K., & Russel, S. (2024). What is AI? Can you make a clear distinction between AI and non-AI systems? OECD AI Policy Observatory. https://oecd.ai/en/wonk/definition
- Hille, E. M., Hummel, P., & Braun, M. (2023). Meaningful Human Control over AI for Health? A Review. Journal of medical ethics, jme-2023-109095. https://doi.org/10.1136/jme-2023-109095
- Kannelønning, M. S. (2023). Contesting futures of Artificial Intelligence (AI) in healthcare: formal expectations meet informal anticipations. Technology Analysis & Strategic Management, 1-12. https://doi.org/10.1080/09537325.2023.2226243
- Kickbusch, I., Piselli, D., Agrawal, A., Balicer, R., Banner, O., Adelhardt, M., Capobianco, E., Fabian, C., Singh Gill, A., Lupton, D., Medhora, R. P., Ndili, N., Ryś, A., Sambuli, N., Settle, D., Swaminathan, S., Morales, J. V., Wolpert, M., Wyckoff, A. W., . . . Wong, B. L. H. (2021). The Lancet and Financial Times Commission on governing health futures 2030: growing up in a digital world. The Lancet (British edition), 398(10312), 1727-1776. https://doi.org/10.1016/S0140-6736(21)01824-9
- König, R., Seifert, A., & Doh, M. (2018). Internet use among older Europeans: an analysis based on SHARE data. Universal Access in the Information Society, 17(3), 621-633. https://doi.org/10.1007/s10209-018-0609-5
- Laacke, S. (2023). Bias and Epistemic Injustice in Conversational AI. The American Journal of Bioethics, 23(5), 46-48. https://doi.org/10.1080/15265161.2023.2191055
- Li, W., Wang, G. M., Lei, X. Y., Sheng, D. Z., Yu, T., & Wang, G. (2022). Seizure detection based on wearable devices: A review of device, mechanism, and algorithm. Acta Neurologica Scandinavica, 146(6), 723-731. https://doi.org/10.1111/ane.13716
- Loveys, K., Prina, M., Axford, C., Domènec Ò, R., Weng, W., Broadbent, E., Pujari, S., Jang, H., Han, Z. A., & Thiyagarajan, J. A. (2022). Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies. Lancet Healthy Longev, 3(4), e286-e297. https://doi.org/10.1016/s2666-7568(22)00034-4
- Luccioni, A. S., & Hernandez-Garcia, A. (2023). Counting carbon: A survey of factors influencing the emissions of machine learning. arXiv preprint arXiv:2302.08476.
- NHS. (2024). NHS AI Lab programmes. Retrieved 04/05/24 from https://transform.england.nhs.uk/ai-lab/
- OECD. (2024). Explanatory memorandum on the updated OECD definition of an AI system. OECD Artificial Intelligence Papers, 8. https://doi.org/10.1787/623da898-en

- Pavolini, E. (2022). Long-term care social protection models in the EU. https://op.europa.eu/en/publication-detail/-/publication/670f407f-3572-11ed-9c68-01aa75ed71a1/language-en
- Penney, V., & Muyskens, J. (2023). Here's where water is running out in the world — and why. The Washington Post. https://www.washingtonpost.com/climate-environment/interactive/2023/water-scarcity-map-solutions/
- Santoni de Sio, F., & Mecacci, G. (2021). Four Responsibility Gaps with Artificial Intelligence: Why they Matter and How to Address them. Philosophy & Technology, 34(4), 1057-1084. https://doi.org/10.1007/s13347-021-00450-x
- Sartor, G., & Lagioia, F. (2020). The impact of the General Data Protection Regulation (GDPR) on artificial intelligence. STOA | Panel for the Future of Science and Technology, EPRS | European Parliamentary Research Service. https://doi.org/10.2861/293
- Seibert, K., Domhoff, D., Bruch, D., Schulte-Althoff, M., Furstenau, D., Biessmann, F., Wolf-Ostermann, K., & Seibert, K. (2021). Application Scenarios for Artificial Intelligence in Nursing Care: Rapid Review. Journal of Medical Internet Research, 23(11), Article e26522. https://doi.org/10.2196/26522
- Spitale, G., Biller-Andorno, N., & Germani, F. (2023). AI model GPT-3 (dis)informs us better than humans. Science Advances, 9(26), eadh1850. https://doi.org/10.1126/sciadv.adh1850
- Tudor Car, L., Dhinagaran, D. A., Kyaw, B. M., Kowatsch, T., Joty, S., Theng, Y. L., & Atun, R. (2020). Conversational Agents in Health Care: Scoping Review and Conceptual Analysis. J Med Internet Res, 22(8), e17158. https://doi.org/10.2196/17158
- United Nations (UN). (2023). Leaving No One Behind In An Ageing World. World Social Report 2023. United Nations Department of Economic and Social Affairs. https://desapublications.un.org/publications/world-social-report-2023-leaving-no-one-behind-ageing-world
- U.S. Department of Education Office of Educational Technology. (2023). Artificial Intelligence and Future of Teaching and Learning: Insights and Recommendations. https://tech.ed.gov/files/2023/05/ai-future-of-teaching-and-learning-report.pdf
- van Kessel, R., Wong, B. L. H., Clemens, T., & Brand, H. (2022). Digital health literacy as a super determinant of health: More than simply the sum of its parts. Internet Interv, 27, 100500. https://doi.org/10.1016/j.invent.2022.100500
- Vicente, J. (2023). Combining informal care with paid work : An exploration of working carers' situation with regards to their health status, gendered patterns of care, support and the impact of the COVID-19 pandemic (Publication Number 476) [Doctoral thesis, comprehensive summary, Linnaeus University Press]. DiVA. Växjö. https://doi.org/10.15626/LUD.476.2023
- WHO. (2021). Global strategy on digital health 2020-2025. World Health Organization.
- WHO. (2024). Ethics and governance of artificial intelligence for health. Guidance on large multi-modal models. World Health Organization.

Appendix I

Overview of the Aim and Methodology of the Rapid Review of Literature Reviews

The aim of the review was to synthesize recent literature reviews on the application of artificial intelligence (AI) within informal and formal LTC, thereby enriching the understanding of this emerging field, laying the groundwork for future systematic reviews and guiding future policy frameworks. The review sought to answer the following questions: What is the current state of the literature on the application of artificial intelligence in informal and formal LTC? And within what types of services are they tested and used?

An initial limited search of Web of Science was undertaken to identify articles on the topic. The keywords in the titles and abstracts of relevant articles and the index terms labelling the articles were used to develop a full search strategy for PubMed, Cinahl, Social Services Abstract, IEEE Xplore and Web of Science. The search strategy, including all identified keywords and index terms, was adapted for each of the five included databases.

The two settings were searched separately in the databases:

- No 1 Informal Care[1] AND AI[2]
- No 2 Long term[3] Care AND AI

Inclusion criteria: Studies published in English, published since 2019 and studies designed as reviews.

Following the search, all identified citations were collated and uploaded into EndNote and duplicates were removed. Titles and abstracts were screened by two or more independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources were retrieved in fulltext and their citation details were imported. The fulltexts of selected citations were assessed in detail against the inclusion criteria. The results of the search and the study inclusion process provided 30 articles.

The data extracted included specific details about the participants, concepts, contexts, study methods and key findings relevant to the review questions.

The articles were grouped into thematic categories based on populations, interventions and outcomes.

Maria Nilsson, Elizabeth Hanson, Swedish Family Care Competence Centre, Linnaeus University, Autumn 2023.

1. "caregiver" OR "family care"* OR "unpaid care"* OR "working carer" OR "unpaid carer" OR "family care support" OR "family carer" OR "municipal care" OR "family caregiver" OR caregiver OR "next of kin" OR "carer" OR "informal care"*
2. artificial intelligence" OR "AI" OR "machine learning" OR "natural language processing" OR "neural networks" OR "deep learning" OR "activity recognition" OR "smart homes" OR "smart home care" OR "Augmented Intelligence" OR "Reinforcement Learning" OR "Unsupervised Machine Learning" OR "Supervised Machine Learning" OR "Symbolic Artificial Intelligence" OR "Symbolic AI"
3. "Long term care" OR "long-term care" OR "home care" OR "LTC" OR "municipal care" OR "residential care" OR "geriatrics" OR "long-term care facilities" OR "eldercare"

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