

# *The Shapes of Care to Come*

## *Suggestions for the advancement of integrated care and support services in Europe and the role of person-centred digital technologies*

A European Think Tank report supported by the SHAPES project

### **Introduction**

This document was prepared by a European Think Tank convened to identify challenges for integrated care in Europe and propose solutions. Experts from 10 European countries and with different professional profiles and lived experiences of ageing, disability and digital technology use, participated between April 2022 and May 2023 in 3 meetings during which the main challenges to advancing integrated health and social care were identified, and possible solutions discussed.<sup>1</sup> The potential for digital technologies to address some of the challenges related to the increased need for high quality cost effective integrated care for an ageing population played a central role in the discussions.

The Think Tank is an initiative of the SHAPES project (H2020, GA 857159) consortium, although most participants are non-consortium members. This document was presented and further discussed, with commentary and written comments from an international panel of experts at the 2023 AAATE conference in a [policy session](#) that concludes the work of the Think Tank.

The Think Tank members:

- acknowledge and subscribe to the core principles of integrated person-centred care as outlined in 2015 by the World Health Organization (WHO), stating that care services should be Comprehensive, Equitable, Sustainable, Coordinated, Continuous, Holistic, Preventive, Empowering, Goal oriented, Respectful, Collaborative, Co-produced, Evidence-informed, Led by whole-systems thinking, and based on Ethical practice [1];
- appreciate the 2022 Communication from the European Commission for a proposed Care Strategy that states that “a strategic and integrated approach to care is needed. Approaches that are person-centred and conducive to independent living are often lacking, exacerbated by insufficient integration between long-term care and healthcare, or between informal care, home care, community-based and residential care” [2];

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<sup>1</sup> The following colleagues have actively participated in at least one of the Think Tank meetings: Luciano Colleoni (psychotherapist), John Dinsmore (Trinity College Dublin), John Farrell (LANUA IHC), Valentina Fiordelmondo (AIAS Bologna onlus), Philip Franke (Carus Consilium Sachsen), Priscille Geiser (SHAPES Project Consultant), Vassilis Giannakopoulos (SCIFY), Barbara Guerra (EDGENEERING), Ana Hannotte (EASPD), Vera Hörmann (Age platform), Anita Hogg (Northern Health and Social Care Trust), Evert-Jan Hoogerwerf (AIAS Bologna onlus), Michael Johansen (Medcom), Helianthe Kort (International Society of Gerontechnology), Mac MacLachlan (Maynooth University), Fabian Magerl (Barmer), Marco Manso (EDGENEERING), Florian Melzer (Carus Consilium Sachsen), Olaf Müller (Carus Consilium Sachsen), Klaus Niederländer (AAL Europe), Dympna O’Sullivan (TU Dublin), Silvio Pagliara (University of Warwick & AAATE), Sandra Rau (Barmer), Sari Sarlio-Siintola (Laurea University), Ivan Traina (University of Verona), Diane Whitehouse (EHTEL), Luc de Witte (The Hague University of Applied Science).

Corresponding author: *Evert-Jan Hoogerwerf (AIAS Bologna onlus): hoogerwerf@aiasbo.it*



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- endorse the recommendation of the Council of the European Union to “rolling-out accessible innovative technology and digital solutions in the provision of care services, including to support autonomy and independent living, while addressing potential challenges of digitalisation” as a way to “align the offer of long-term care services to long-term care needs, while providing a balanced mix of long-term care options and care settings to cater for different long-term care needs and supporting the freedom of choice, and participation in decision-making, of people in need of care” [3];
- acknowledge the potential advantages of widespread use of digital technologies to identify immediate and future needs, to better organise and deliver care and support services when and where needed, to connect stakeholders, to facilitate data management and exchange and to better govern service models;
- foresee the potential for digital technologies to also support the ageing care workforce in their delivery of quality care with its increasing demand across sectors and through community settings.

## Open issues, barriers, and challenges

A number of key issues or barriers for the general advancement of integrated care were identified by the Think Tank members:

1. The general **lack of awareness among many stakeholders**, including citizens with care needs and formal and informal caregivers, on the importance of integrated care approaches and their short- and long-term benefits.
2. The lack of **large-scale public investment** in innovative solutions and models for integrated care and **lack of deinstitutionalization strategies and related investments in support services**.
3. The lack of **rights-based and co-design** approaches in the rethinking of policies and practices.
4. Uncertainty among many stakeholders about the **protection and use of personal data**.
5. Uncertainty about **governance models and responsibility** in person-centred technology-supported care provision.
6. **Resistance to innovation and change** within health and social care systems, and conflict between different stakeholders.
7. The lack of **collaboration protocols and tools** and the lack of **capacity to assess the impact** of person-centred technology deployment on integrated care outcomes.
8. The lack of consideration of **Universal Design principles and accessibility requirements** in the design of new products and care services.
9. The **digital divide** and lack of access to person-centred technologies and smart solutions for certain groups in society [4].
10. **The lack of alignment between** a predominantly medical and diagnostic-related **funding system and the opportunities and needs** for interventions that are social, rights-based and/or preventative.
11. **Gaps in the education** and training of formal and informal care givers.
12. Fragmentation in interventions and **the lack of holistic person-centred approaches** able to support people in **enabling environments**.

The **multitude of possible solutions and strategies** discussed by the Think Tank members in their meetings took into consideration the complexities of differences at all levels between countries, regions, and care systems. This is the reason why the Think Tank members advocate for a stronger overarching European policy to steer innovation in the care sector towards using person-centred technologies to advance more integrated models of service provision in line with policy objectives in the domain of a digital and sustainable



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Europe and in line with human rights commitments of the EU and the Human Rights Council report on Support systems to ensure community inclusion of persons with disabilities, as well as the reports of the Special Rapporteur on the Rights of Persons with Disabilities on Transformation of Services for Persons with Disabilities and their recommendations to support the efforts towards transformative and inclusive support and care systems, integrating a disability, gender, intersectional and intercultural perspective [5].

Notwithstanding the differences in health and social care systems across Europe as reflected in the experience of the participants, it was possible for the Think Tank members to identify solutions for the challenges and to formulate these as suggestions for European, national, and regional policy in this field. To structure the suggestions the WHO framework for countries to achieve an integrated continuum of long-term care was used. This framework distinguishes between 6 elements: “Governance”, “Sustainable financing”, “Information, monitoring and evaluation systems”, “Workforce”, “Service Delivery”, “Innovation and research” [6].

## Suggestions for European, national, and regional policymakers

### Governance

- There is a strong need for a more enabling environment at regional, national and European Union (EU)-levels to provide stakeholders with the appropriate **framework to innovate, integrate and scale up** new forms of care and the use of person-centred technology for better integrated and patient/user-led care and support services, as well as a roadmap with guidance on its implementation. A central role should be played by regional governments in facilitating the development of integrated care ecosystems involving all relevant actors and by organisations representing the diversity of citizens with different levels of support needs in actively collaborating with reforms in the health and social care sector.
- There is a need for **more detailed data** both on the development of needs and the identification of support requirements in the health and social domain (related for example to chronic diseases, mental health, wellbeing, loneliness, independent living, etc) and on the outcomes and effectiveness of interventions, including governance and financing models, that aim to address those needs.
- Although space should be left for bottom-up initiatives, new services, business, organisational and governance models based on the participation of new stakeholders and actors, the further development of health and social care in Europe should see a strong and determined **involvement of the public sector**, pushing for the integration of policies, procedures and resources, and assuring equity in access to quality care and support services among groups and territories. This includes effective models to decentralise the provision of support with sufficient budget allocation, ensure effective coordination and monitoring and evaluation.
- There is a need for a framework of **ethical regulation**, standards and training for the care and technology sectors to protect disabled and older people's rights as smart technology becomes more widespread. A **Code of Practice** should be established to require decision makers to maximise choice and control and co-production for disabled and older people.
- Governance should foster coordination among diverse groups of care services users, and with care workers, to **co-produce solutions that address common priorities** while respecting requirements specific to each group, and that foster collective and inclusive responses rather than fuelling competition for access to resources.



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- **Person-centred digital technology-based solutions** allow for the development of increasingly integrated care programmes and support services structured around the needs of the care recipient and their adoption could therefore facilitate reform of health and social care towards less centralised and paternalistic and more integrated and citizen empowering models. The awareness that technology empowered citizens will have different and sometimes new needs and how to respond to those needs will have to be built in the model, as well as long term perspectives on costs and benefits. Accessibility and inclusiveness of digital/ IT investments must be ensured, to bridge the currently disconcerting digital gap experienced by persons with disabilities and older people when accessing a range of services increasingly provided online/digitally.
- In developing digital solutions for the market of person-centred care and support services, gaps and challenges in **the application of regulations** such as the Medical Device Regulations, the Artificial Intelligence Act, the GDPR and the European Accessibility Act should be better understood and addressed. Although the proposed European Health Data Space Regulation [7] could fill existing gaps, further specific regulation might be needed, including guidelines for developers with a standard of minimum requirements to comply with in terms of quality, safety, security, to safeguard the rights and interests of end users, while not depressing the bottom-up innovation climate needed to further boost technology uptake in person-centred integrated care. **An independent European authority** could support the interpretation of existing regulations relevant for the application of accessible digital technologies that support citizens and care providers in addressing health and social needs and realising the human rights to the highest attainable standards of health, the right to social protection, independent living, among others.
- The creation of living labs of startups and SMEs that could support **validation and certification activities**, should be fostered. These entities, together with others, could issue a “seal of approval” for validated solutions.
- The **distinction between certified digital health technology and apps used in formal care and well-being apps** for the large consumer market should be better clarified. The establishment of “quality labels” for technologies supporting the quality of life of citizens and their wellbeing in contexts outside the purely health domain should be considered. Quality labels should centrally integrate the respect for human rights, including accessibility to all users and respect for autonomy and dignity.
- International and inter-sectoral **collaboration** aiming at integration and standardisation at all levels and between all levels (e.g., European, national, regional, local) must be promoted. This includes collaboration in the development of standards for health data gathering and exchange.
- **Quality standards for processes** in integrated person-centred services need to be developed and implemented together with care-recipients and service users. The inclusion of person-centred technologies, where appropriate, and the assessment of their impact should be part of those standards. Service providers should be held accountable to standards by monitoring performance.
- At all levels **coordination and communication systems** for more resilient and for better integrated services should be improved.

### ***Sustainable financing***

- **More public and private resources** should be invested to boost the appropriate use of person-centred technology in integrated care, while carefully monitoring outcomes.



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- **Civil society organisations** (e.g., social enterprises, cooperatives, non-profit organisations, voluntary organisations, etc.) can play a very significant role in innovation in the care sector and they should be encouraged and supported financially by the governments to fully play that role. Through advocacy, service-user empowerment, digital education, awareness raising and other programmes they will create the conditions for the advancement of person-centred integrated services.
- High quality person-centred technologies that have proven to bring benefits to users and their care ecosystems, should be **integrated** in existing reimbursement and other funding schemes, to support a diversity of options and the exercise of choice and control by users, without substituting other forms of support.
- An increasing part of public funding should be geared towards **preventive care**, and to care and support delivered **in the community**, e.g., support services that enable independent living, taking pressure off acute services.

### **Information, monitoring and evaluation systems**

- **Awareness** about the importance of person-centred integrated care at all levels should be increased, including at the European level where the European Commission has an important role to play in driving change and boosting innovation. This should be thought of as contributions to challenge ageism and ableism and to realise the right to live independently and being included in the community.
- Lessons should be learned from **existing good practices** involving researchers and experts by experience. **Knowledge and information exchange** should be encouraged at all levels.
- Strategies and tools for successful **collaboration** between **different stakeholders and different countries** should be further developed and allowing for the comparison and exchange of results.
- Initiatives at local and regional level to **reach out** to citizens, care professionals and decision makers to highlight the advantages for all stakeholders for better integrated care and related services should be promoted.
- Monitoring and evaluation systems should be in place that are based on standards and that measure **the impact of interventions on the Quality of Life of care recipients**. This will not only lead to better services but will also provide data to authorities regarding the development of needs.
- The impact of the deployment of person-centred technology in care and support services should be carefully monitored in order to **identify downsides**, if any, in an early stage [8].
- Information about **data use, data protection and data treatment** provided by service providers to citizens needs to be accessible, understandable, correct, and complete. Citizens need to be better informed about the data protection regulations and about the benefits, and risks, of making their data available for service planning and management. Fear of misuse, if not justified, needs to be contrasted with correct information about the potential benefits of data sharing. The European Health Data Space Regulation should focus on building confidence and trust among citizens that their health data are safe and protected. As part of ensuring full control and consent, data collection interfaces and information should be accessible to all, including to all persons with disabilities, in diverse formats and languages.
- **People must have access to their own digital health records** through a range of different formats, i.e. easy to understand, available in diverse formats and languages and with no low technological or communication access barriers, but secure and controlled by the concerned individual or a legally designated person. Transparent, accessible and open-source structures through public-private



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partnerships and well-defined ownership need to be incentivised, rather than proprietary private systems.

### **Workforce**

- Resources should be made available for the **continuous professional development** of staff in the care sector, their digital skills and capacity to work in an increasingly digital environment for the benefit of the people they support.
- Changing working conditions of staff, due to the introduction of person-centred technology in services, should be **carefully managed** and staff must be appropriately supported in adapting to different roles and functions.
- The **ageing care workforce** can be facilitated to work longer (if they choose to) and to work smarter by using more remote and community focused supports and interventions.
- Service providers should invest in the development of **multidisciplinary and interdisciplinary aspects of integrated care**, fostering teamwork and regular exchanges with representatives of the diversity of care services users.
- In the further digitalisation of integrated care services attention for the **safety and security** of all stakeholders should be a priority.
- To promote cooperation and knowledge exchange in the field of person-centred integrated care, **platforms and forums** should be established at European level. These should facilitate networking, exchange of experiences and joint problem-solving among health and social care professionals, researchers, policymakers, and representatives of the diversity of people using care services.

### **Service Delivery**

- Health services, social care and support services should refer to better defined **quality frameworks and procedures**. Such frameworks should be rights-based, outcome oriented and foresee intervention monitoring procedures. The impact of interventions on the Quality of Life of service users should be a core element of goals setting and evaluation.
- Any introduction of person-centred technology in integrated care should be accompanied by an in-depth assessment of its **impact on the service delivery model** and on how outcomes are measured. Independent mechanisms should be established for users to submit feedback and complaints.
- Any introduction of person-centred technology in integrated care should be accompanied by accessible and inclusive **training programmes for staff and end-users of care services as well as informal support networks and caregivers**.
- Provision of digital person-centred technology for integrated services should be based on a "**whole-package-approach**", meaning that providers should guarantee training, maintenance, substitution of defect devices and other support services.

### **Innovation and research**

- The piloting of person-centred technologies in integrated care delivery should be supported, also at regional level, making sure that **potential end users** are **meaningfully** involved in **all stages of the research, respected and their contribution valued**, with, where possible, continued access after the pilot ends to technologies that have shown to be beneficial for them.



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- The development of (technical) **standards for innovative products and services** should be a priority for research and development supporting bodies with participatory approaches involving organisations representative of care workers and of those representing the diversity of care services users. CRPD compliance should be a core requirement of any accreditation mechanism.
- Considering the domain and the type of data treated, the risks and benefits associated with the use of **artificial intelligence and other emerging technologies** on care planning, delivery and evaluation should be continuously assessed, monitored, and critically analysed. If necessary, additional legislation should define responsibilities and regulate its use. In particular, attention should be paid to addressing the disproportionate risks faced by persons with disabilities that poorly developed AI algorithms may lead to stigma, inaccessibility or discriminatory decisions.
- There is an acute need for a network or **an infrastructure of digital incubators** that sit between universities, healthcare systems and relevant industries to support acceleration in innovation but also include patient/service user organizations. These multidisciplinary incubators can provide targeted supports for needs driven systems and technology, services like IT development, project management but also wider, more sustainable services, but also help us understand how and why organisations take up an innovation, what are the enabling factors which facilitate the uptake and embedding of the innovation and what are the impacts of adopting the innovation on organisational practices.
- **Increased collaboration** between research institutions, technology companies, care practitioners and organisations representing the diversity of support and care services users, should be encouraged to drive innovation and better meet the needs of care recipients. There is a clear need to actively engage people in the design of technology to support their independent living at home. In order to design useful, useable technology we need to speak to end users about their needs, requirements and preferences for technological solutions.
- Co-design is not sufficiently embedded in industry. It is not well embedded in the standard software design and development frameworks used in industry. There is a real need for frameworks (adapted from existing s/w development frameworks) for industry so that they can incorporate participatory or co-design methods with end users into their software development practices.
- The connection between person-centred technologies and their **interaction with more traditional assistive technologies** should be better investigated.

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