

# The Shapes of Care

## 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> As anticipated, 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. This is the reason why this document has the advancement of person-centred technologies in integrated care pathways as its focus.

The Think Tank is an initiative of the SHAPES project (H2020, GA 857159) consortium, although most participants are non-consortium members. This document will be presented and further discussed at the 2023 AAATE conference (Paris, 30/8-1/9/2023), 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, Ethical [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];
- 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

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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), Vassilis Giannakopoulos (SCIFY), Barbara Guerra (Edgeneering), Vera Hörmann (Age platform), Anita Hogg (Northern Health and Social Care Trust), Evert-Jan Hoogerwerf (AIAS Bologna onlus), Michael Johansen (Medcom), Mac MacLachlan (Maynooth University), Fabian Magerl (Barmer), Florian Melzer (University of Dresden), Olaf Müller (Carus Consilium), Klaus Niederländer (AAL Europe), 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).



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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.

## Open issues, barriers, and challenges

However, many open issues or barriers for the general advancement of integrated care were identified by the Think Tank members, among which the main ones are:

1. The general lack of **awareness** 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.
3. Uncertainty among many stakeholders about the **protection and use of personal data**.
4. Uncertainty about **governance models and responsibility** in person-centred technology-supported care provision.
5. **Resistance to innovation and change** within health and social care systems and their services.
6. Possible **conflicting interests** among stakeholders.
7. The lack of **collaboration protocols and tools**.
8. The lack of **capacity to assess the impact** of person-centred technology deployment on integrated care outcomes.
9. **The lack of alignment between** a predominantly medical and diagnostic-related **funding system and opportunities and needs** for intervention with social impact that are also preventive in nature.
10. **Lack of awareness and education** among citizens with care needs and formal and informal caregivers.

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 Europe.

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, without the pretension to write a comprehensive policy paper. To structure the suggestions in a logical order the WHO framework for countries to achieve an integrated continuum of long-term care was selected. This framework distinguishes between 6 elements: “Governance”, “Sustainable financing”, “Information, monitoring and evaluation systems”, “Workforce”, “Service Delivery”, “Innovation and research” [4].

## Suggestions for European, national, and regional policymakers

### Governance



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- 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. 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 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 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.
- **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 partially 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.
- 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 [5] 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 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 digital technologies that support citizens and care providers in addressing health and social needs.
- 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, also to the general public. 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.
- 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.
- **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.
- At all levels **coordination and communication systems** for more resilient and for better integrated services should be improved.



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### ***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.
- **“Third sector” organisations** (e.g., social enterprises, cooperatives, charities, 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.
- An increasing part of public funding should be geared towards **preventive care, and to care delivered in community settings**, 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.
- Lessons should be learned from **existing good practices and knowledge** and information exchange should be encouraged at all levels.
- Strategies and tools for successful **collaboration** and allowing for the comparison and exchange of results, should be further developed.
- 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.
- 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.
- **Access** to own digital health records needs to be easy with low access barriers, but secure and controlled by the concerned individual or the person of trust. Transparent and open-source structures through public-private 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.



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- 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.
- Service providers should invest in the development of **multidisciplinary and interdisciplinary aspects of integrated care**, fostering teamwork.
- 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 professionals, researchers, policymakers, and end-user representatives.

### **Service Delivery**

- Like health services, similarly social care and support services should refer to better defined **quality frameworks and procedures**. Such frameworks should be outcome oriented and foresee intervention monitoring procedures.
- 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.
- Any introduction of person-centred technology in integrated care should be accompanied by **training programmes for staff and end-users**.
- 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 **care recipients** involved in pilot schemes **are respected and valued** with continued access after the pilot ends to technologies that have shown to be beneficial for them.
- The development of (technical) **standards for innovative products and services** should be a priority for research and development supporting bodies.
- Considering the domain and the type of data treated, the high risks 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.
- **Increased collaboration** between research institutions, technology companies and care practitioners should be encouraged to drive innovation and better meet the needs of care recipients.

### **References**

- [1] WHO (2015). WHO global strategy on people-centred and integrated health services: Interim Report. Geneva: WHO Publications. (WHO/HIS/SDS/2015.6).



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- [2] 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.
- [3] The European Council (2022). Council recommendation on access to affordable high-quality long-term care. 25 November 2022. Ref. 13948/22. Interinstitutional File: 2022/0264(NLE).
- [4] WHO (2021). Framework for countries to achieve an integrated continuum of long-term care.
- [5] European Commission (2022). Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the European Health Data Space. COM (2022) 197 final.

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