



integrated
care alliance

Multi-Stakeholder Digital Health Roadmap



to support
Integrated Care

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I. Executive Summary

Integrated Care consists of multi-agency and multi-disciplinary collaboration, focused on meeting the medical, social and practical needs of each individual in a coordinated way.

Integrated Care is enabled by Digital Care Technologies, which may include risk stratification, needs assessment, decision support, care planning, information sharing and care team collaboration tools, as well as online services to help citizens participate fully in their care plan (Population Health Management).

The Triple Aim of Integrated Care, as identified by the Institute for Healthcare Improvement, are to measurably (1) improve the patient experience and quality of care, (2) improve the health populations, and (3) reduce the per capita cost of health care.

The Integrated Care Alliance¹ is a dedicated group of multi-stakeholders' experts working together to provide direction, advice, and guidance for integrated care schemes. The goal is to strengthen and expand integrated, sustainable health and care services across the EU Member States.

Building on ICA first publication "United towards Integrated Care^{2"} in 2016, the ICA partners join forces again to elaborate a Multi-Stakeholder Roadmap to support integrated care.

The objective of this Roadmap is to support better health care coordination and to define specific activities in support of Integrated Care.

The Roadmap identifies specific sections (policy, new models of care, skills, training & education, data protection, and digital care technology & interoperability) which are the drivers of the Integrated Care.

Each of these sections are analysed in terms of objectives by 2021, and recommended measures for the implementation. The recommendations address various levels (European, national, and regional levels), and those stakeholders that ICA Partners cover. It is also an invitation for other stakeholder organisations implied in the integrated care value chain to join the initiative.

POLICY

Objective by 2021:

Develop sustained political, investment, clinical and professional leadership

Recommended measures:

1. **Secure** political leadership and develop national, regional and local (community) roadmaps;
2. **Invest** to scale up successful integrated care projects;
3. **Support** the implementation through regulations enabling digital transformation (including secure identification practices);
4. **Build** strategies and frameworks, in a trusted environment, at all levels to empower and involve patients, carers and citizens;
5. **Develop** strategic partnerships with research and academic centres to reflect on innovation in healthcare in Europe (including measuring and improving of hospital performance);
6. **Support** transition from research to widespread uptake of innovative projects on Integrated Care;
7. **Empower** informal carers in terms of e.g. access to labour market, financial security, health prevention, social inclusion;
8. **Offer** training to informal carers to build their capacities and competencies;

1. Please visit ICA website: www.integratedcarealliance.org

2. Call for Action United Towards Integrated Care

9. **Adopt** and **Encourage** Member States to implement the EU Directive on Work/life Balance as a minimum requirement and further develop national strategies including status of informal carers;
10. **Leverage** the level of local studies by encouraging cooperation between policy, knowledge centres, care sector and industry;
11. **Untap** the potential of Big Data, Artificial Intelligence and Internet of Things, that can be used for instance to pre-diagnose or diagnose a disease;
12. **Support** proactive integration of Digital Care Solutions into Reimbursement and Procurement strategies across the EU Member States.

NEW MODELS OF CARE

Objective by 2021:

Develop innovative financing and population health management models

Recommended measures:

1. **Develop** new care and economic models for Integrated Care tailored to the regional and local context;
2. **Encourage** strategic partnerships across health & social ecosystem (including academia and research entities);
3. **Promote** the involvement of informal carers in care teams through targeted training for both professionals and informal carers;
4. **Leverage** on the contribution brought by informal carers and the positive effect their care can have on the patients they look after (e.g. better adherence to treatment, good nutrition, improve access to services);
5. **Provide** accessible ICT based solutions to facilitate sharing of information between users, health professionals and informal carers;
6. **Support** public-private partnerships in health care including initiatives to support and improve market access models.

SKILLS, TRAINING AND EDUCATION

Objective by 2021:

Develop competencies needed to organise, deliver and manage Integrated Care

Recommended measures:

1. **Educate** health & social care workforce to use Digital Care Technologies applied in daily practice;
2. **Offer** training to care professionals to support informal carers and include them in care teams (training to be developed in cooperation with carer and research organisations that are available to share their expertise and knowledge);
3. **Develop** target coaching programmes on self-management for patients;
4. **Train** health professionals to develop specific health preventative measures aimed at informal carers;
5. **Enable** citizens/patients to manage their own care through digital skills development and literacy;
6. **Enhance deployment of** health information exchange platforms, electronic health record systems, and population health management systems.

DIGITAL CARE TECHNOLOGIES

Objective by 2021:

Adopt innovative and interoperable digital care technologies, and harmonised sharing data plans, in daily routine practice

Recommended measures:

1. **Establish** a framework for the deployment of interoperable solutions;
2. **Change** terminology: Use the term of “Digital Care Technologies” instead of “Digital Health Technologies”;
3. **Adopt** digital care payment models, where the professional guidelines and practice standards are based on digital care technologies as opposed to analogue care technologies;
4. **Define**, implement, and deploy a shared data model (incl. account privacy and security issues) and interoperability standards for Digital Care at EU and International level, that expands the current standards and models when and where required;
5. **Incentivise** the care system to move towards an “industrial” approach on product development standards and methods, by developing digital care technologies that by design have the quality for multiple deployments in a repeatable and sustainable way;
6. **Establish** a network of regional expert centres for digital care technologies for integrated care;
7. **Define** pilot integrated care scenarios which can be established in the majority of the EU Member States’ health systems. Ensure the scenarios cover usual care situations. Do not focus on scenarios which are rare;
8. **Promote** and define interoperability profiles and standards to use for implementing the scenarios. Build upon the 27 EU recognised Integrated Healthcare Enterprise (IHE) profiles [IHE profiles](#) and extend as needed;
9. **Incentivise** Member States to adopt, pilot and deploy these scenarios;
10. **Harmonise** implementation of Data Protection Framework;
11. **Raise** awareness of the citizens on the principles of the General Data Protection Regulation;
12. **Develop** value assessment methodologies for Integrated Care Pathways (broaden HTA – health technology assessment, including impact on wellbeing).

II. Introduction

Traditional care practices in early medicine were first developed in an era when life expectancy was shorter, with acute events and infectious disease being predominant causes of mortality and morbidity. The burden of disease in the developed world is changing. We have moved on from merely addressing the acute health needs that first shaped healthcare services. We now need to design our systems of care to retain our acute services, effectively manage chronic diseases and maintain the patients' functions and well-being.

Various policy approaches to tackle these challenges exist and need to be deployed jointly, in a coordinated and integrated way, to maximise their effects. Integrated Care systems also engage the citizen, including provisions for education, prevention and early diagnosis, and ensure appropriate care is accessible outside the hospital.

The Integrated Care Alliance³ aims at accelerating the transition towards Integrated Care. This is why the ICA Partners developed this "Multi-Stakeholders" Roadmap, which builds on the Call for Action "United Together"⁴ to foster the development of sustainable health and social care systems that meet the holistic needs of citizens, patients and carers, especially those with complex and long-term health and social care needs.

The Roadmap calls for a cooperation model and proposes specific recommended measures where each stakeholder intervenes at optimal level: government provides overall support; the various care providers, users, enterprises, and knowledge centers perform management and analysis, and there is real free market process for industry innovation and growth. All ICA members see the added value of this collaboration, and our recommended measures take account of all generations, young and old.

³. Please visit the ICA Website

⁴. 2016 ICA Call for Action "United towards the Integrated Care"

III. Policy

Objective by 2021: Develop sustained political, investment, clinical and professional leadership

1. INTRODUCTION

Today, demographic developments in Europe lead to a growing incidence of age related diseases, a growing demand for care, and health care systems sustainability challenges.

Community-care has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also supporting widespread preferences among people for being cared for in their own home⁵. In most countries, a large part of care is provided by informal carers who, alone, represent over 80 % of all care⁶.

However, despite these developments, informal carers⁷ across the EU still lack the visibility, recognition, and support.

Notably, considering the fact that people are likely to work longer, and that more women are working, the conciliation between work and care is becoming challenging. Working carers tend to be put under considerable stress, putting under threat their inclusion on the labour market. The Work/life Balance Proposal tabled by the European Commission, providing certain rights to informal carers, is being discussed by the European Parliament and the European Council. If adopted, it would constitute an important breakthrough towards the recognition of informal carers.

The future health care systems will need health and social care providers to use Digital Care Technologies, and to collaborate and share person data, knowledge and insights in the context of day-to-day operations. To enable the critical transition from small-scale, context specific and research-based activities of limited impact into more widespread uptake, there is a need for strong commitment of multi-disciplinary teams to support transformation, service innovation, technology adoption, and deployment of new business models and tools. This can be done through legal instruments, incentives and guidance on how to implement change in complex settings, investment in service innovation and research on integrated care implementation whilst boosting the deployment and scaling-up transformations through more replication and widespread adoption.

The journey of transformation of health care systems towards better coordination is just at the beginning. The underlying Digital Care Technologies that will support integrated care need to reach market maturity. Reimbursement and procurement strategies will also need to be revisited to effectively integrate digital solutions into clinical daily practice and population health management.

The shift towards integrated care that meets peoples' need will only happen if political, clinical and professional leadership is secured, building on national and regional evidence-based scientific research and practices addressing specific needs of local populations. This requires the development of long-term political and scientific commitment supported by effective and shared leadership that both help to build support for change but also creates the partnerships necessary to drive the change forward.

Yet, cultural, legal and financial challenges hinder greater coordination across the care pathways, which will be further described in this –policy – section.

5. European Union. 2012: Long-term care for the elderly –provisions and providers in 33 European countries. Luxembourg: Publications Office of the European Union. Retrieved from <https://publications.europa.eu/en/publication-detail/-/publication/6f79fa54-1199-45e0-bbf3-2619c21b299a/language-en/format-PDF/source-70687636>

6. Informal Carers: Who Takes Care of Them? F. Hoffmann and R. Rodrigues, European Centre for social welfare policy and research, 2010. <https://www.euro.centre.org/publications/detail/387>

7. Defined as a person who provides unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.

2. OPPORTUNITIES

Integrated Care and its supporting digital care technologies cannot be seen separately from the organisational context. The human aspect of this transformation must be carefully addressed. It is critical to take into account change management and new medical practices and tools in this transition. To further support the transformation towards Integrated Care, there is a need to incentivise health and social care providers and develop regulations providing a strong positive patient identification, that enable informed diagnostic using reliable patient data. There is a need to develop specific guidelines and/or regulations to incentivise and encourage Healthcare providers to digitally input and access the data, digitally sign their prescription, their reports, etc., without which the digital transformation of healthcare would be incomplete.

In addition, any transition towards Integrated Care should be embedded in a wider 'carer-friendly' ecosystem in which the role of informal carers is valued and supported, and carers are empowered in the various aspects of their life: access to the labour market, financial security, health prevention, inclusion in society. Such a recognition of the role of informal cares in the society would in turn trigger a cultural shift in the health care sector towards integrated care centred around the user and the person.

3. CHALLENGES

There is a lack of sustainable health, social and long-term care models in the European Union. European health and social systems were designed for a different era, different demographics, different epidemiology and different lifestyles. They are now struggling to meet the challenges posed by the demographic transition to an ageing society and the increasing burden of chronic diseases. Many health systems have pre-existing divisions in financing, management structure, and care provisions, which hinder the transition towards better coordinated health and care provision. Of these demographic and socio-economic challenges, as well as the increasing demand for care, the result is a growing pressure on informal carers who find themselves having to deliver more and more sophisticated levels of care, with very little training and minimal support (including lack of accessibility to dedicated services in rural areas). Informal care entails substantial opportunity cost in terms of employment, productivity and the impact on carers' health status itself. The recognition of patients and informal carers as partners in the process of better coordinated care is necessary, otherwise the shift towards the Integrated Care schemes would not be complete

Finally, and in order to unlock the power of digitalisation of health and care, trust needs to be ensured. As long as the users may not have a complete trust in Digital Care Technologies and Services they will not reach their full potential.

4. RECOMMENDED MEASURES

1. **Secure** political leadership and develop national and regional roadmaps;
2. **Invest** to scale up successful integrated care projects;
3. **Support** the implementation through regulations enabling digital transformation (including secure identification practices);
4. **Build** strategies and frameworks, in a trusted environment, at all levels to empower and involve patients, carers and citizens;
5. **Develop** strategic partnerships with research and academia centres to reflect on innovation in healthcare in Europe (including measuring and improving of hospital performance);
6. **Support** transition from research to widespread uptake of innovative projects on Integrated Care;
7. **Empower** informal carers in terms of e.g. access to labour market, financial security, health prevention & social inclusion;
8. **Offer** training to informal carers to build their capacities and competences;
9. **Adopt** and **Encourage** Member States to implement the EU Directive on Work/life Balance as a minimum requirement and further develop national strategies including status of informal carers;

10. Leverage the level of local studies by encouraging cooperation between policy, knowledge centres, care sector and industry;
11. Untap the potential of Big Data, Artificial Intelligence and Internet of Things, that can be used for instance to pre-diagnose or diagnose a disease and ensure cybersecurity is properly addressed;
12. Support proactive integration of Digital Care Solutions into Reimbursement and Procurement strategies across the EU Member States.



IV. New Models of Care, including organisations and financing models

Objective by 2021: Develop innovative financing and population health management models

1. INTRODUCTION

The increasing number of patients with comorbidities is already placing substantial financial and operational burdens on health and social care systems. As highlighted by the Call for Action of the Integrated Care Alliance, this shift in population health requires, better coordination between health and social care systems and interdisciplinary teams, including patients and citizens, policy makers, care providers, and industry.

We need to develop care pathways, incorporating Clinical Decision support systems and guidelines, to cope with the range of medical and social conditions and to support health and care providers to work together in new ways, and better adapt to ever-changing clinical and social contexts to enable Integrated Care.

2. OPPORTUNITIES

It is feasible to create dynamic care models for Integrated Care, multidisciplinary teams that respond to clinical and management changes, optimise the sequence and timing of required actions across organisational boundaries, and allow information sharing between all stakeholders in the care pathway.

Building dynamic care models that take into consideration all stakeholders' objectives can:

1. Help patients and care providers work as coordinated team
2. Accelerate Clinical Decision Making and Decision Support System
3. Support Personalised and Integrated health and social care
4. Increase care quality and manage costs more effectively

Given the level of information and resources involved, developing shared and dynamic workflows for Integrated Care teams, needs Digital Care Technologies support. Combining all medical, operational, social and financial aspects is far too complex task to be managed otherwise. Sharing patients' clinical and social data and dynamic workflows rely on a ICT systems to provide all stakeholders with accurate information on the status of the distributed and coordinated activities across multiple organisations.

As already mentioned, Digital Care Technologies support the shift towards Integrated Care by offering Decision Making and Support systems. Processing massive amounts of data (Big Data) can uncover hidden patterns and create insights, complementing approaches of clinical research. Business Intelligence software is increasingly used to process financial and operational data. However, the greatest value of systems for diagnostic and therapeutic activities will only be realised when operational, financial and clinical data are linked and processed jointly.

Furthermore, the emergence and deployment of new technologies will eventually lead to job creation in the health and care sectors. Physicians cannot (and often do not want to) handle everything by themselves, therefore they (will) need help, that is new healthcare professionals whom they will work with for the full use of new technologies at all levels (continuity of care, privacy, shift from paper work to computer work – filling forms, questionnaires, data templates, etc.).

Provided the value of informal carers' contribution is recognised, that they are supported and trained, and that they are integrated in the caring team, informal carers can be a key component of community-based health delivery

centred on the user. Indeed, in addition to helping the person they care for in his/her daily tasks, they are likely to play a key role with regard to the efficiency of the treatment, and the quality of life of the patient they look after (e.g. adherence to treatment, managing side effects, maintaining of the quality of life, high quality of service) ⁸.

3. CHALLENGES

- The health sector is organised in order to address the individual needs of a person affected by a disease, not to engage with his/ her relatives;
- Cultural, legal and financial challenges hinder data sharing and greater coordination across the care pathway;
- The lack of health literacy and lack of support towards health & social care providers need to be addressed to better co-ordinate management and organisational models;
- Decision support system and support for, clinical pathways fail because they are insufficiently context-aware and person-specific. Comorbidity is a typical example of where the system should adapt and create a new pathway based on existing medical knowledge;
- The lack of health data governance frameworks and infrastructures enabling all stakeholders to share common processes;
- Limits of regional and national Digital Care infrastructures managing shared and dynamic workflows across multiple organisations;
- Informal carers remain mainly invisible, their role is most often overlooked in the health sector as well as in society in general;
- The lack of informal carers' self-awareness regarding their role which may explain the difficulty to engage with health professionals, getting the information and support needed in order to take care of their relative.

4. RECOMMENDED MEASURES

1. **Develop** new care and economic models for Integrated Care tailored to the regional and local context;
2. **Encourage** strategic partnerships across health & social ecosystem (including research and academia entities);
3. **Promote** the involvement of informal carers in care teams through targeted training for both professionals and informal carers;
4. **Leverage** the contribution brought by informal carers and the positive effect their care can have on the patients they look after (e.g. better adherence to treatment, good nutrition, improve access to services);
5. **Provide** accessible ICT based solutions to facilitate sharing of information between users, health professionals and informal carers; Support public-private partnerships in health care including initiatives to support and improve market access models.

8. See: ECPC, Eurocarers, 2017: *White Paper on Informal Carers of People with Cancer* & Eurocarers, 2017: *Eurocarers toolkit for people caring for a person affected by cancer (to be published in April 2018)*

V. Skills, training and education

Objective by 2021: Develop competencies needed to organise, deliver and manage Integrated Care

1. INTRODUCTION

Integrated Care is a multi-disciplinary collaboration that aims at managing and delivering health and care services in a coordinated way, with ultimate purpose of better patient safety culture, care and public health outcomes.

Developing the patient safety culture, might require changing the attitudes of health and care providers, developing multi-disciplinary teams skills⁹, translating research evidence into practice, and addressing people's needs towards better citizens involvement and their recognition as a partner the health and care process. Safety culture starts with recognising the possibility of error and ensuring continuous learning¹⁰ and improvement processes are in place.¹¹

Along with other elements, professional education and eSkills are identified as crucial for the implementation of integrated care in a recent report by the Expert Group on Health Systems Performance Assessment¹².

Demographic ageing in Europe leads to a growing incidence of age-related diseases, a growing demand for care, and a serious sustainability challenge for our social and health care systems. Against this backdrop, community care has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also seconding widespread preferences for being cared for at home.

In order to materialise such a transition, there is a need to enhance digital health literacy, communication skills, develop multi-disciplinary teams training and eSkills¹³ for patients, carers and citizens (including the use of existing solutions to keep track of the health condition) to deliver integrated care.

Specific coaching on self-management for patients, through the use of existing technology solutions, is required. Also, there is a necessity to develop specific training for health professionals to ensure the integration of informal carers in the caring teams, given a large part of long term care for older people is currently provided by informal carers¹⁴ in most European countries.

2. OPPORTUNITIES

Although there are lot of examples and many collections of best practices, relating to different aspects of integrated care, the difficulty lies in upscaling and deploying those examples/practices. There is a need to better understand the needs and abilities of the care providers and institutions such as hospitals, in terms of using innovative digital care technologies in daily practice.

9. For an example of positive effects of interprofessional collaboration see: *Ann Pharmacother.* 2007 Feb;41(2):319-24. Epub 2007 Jan 23; <https://www.ncbi.nlm.nih.gov/pubmed/17244644>

10. A study was commissioned to map and review continuous professional development and life-long learning for certain healthcare professions: study concerning the review and mapping of continuous professional development and lifelong learning for health professionals in the EU; https://ec.europa.eu/health/workforce/key_documents/continuous_professional_development_en

11. Sammer CE1, Lykens K, Singh KP, Mains DA, Lackan NA. What is patient safety culture? A review of the literature. *J Nurs Scholarsh.* 2010

12. https://ec.europa.eu/health/sites/health/files/systems_performance_assessment/docs/2017_blocks_en_0.pdf

13. http://ec.europa.eu/information_society/newsroom/cf/dae/document.cfm?action=display&doc_id=8061

14. The number of informal carers in Europe is estimated to be at least twice as big as the formal care workforce. According to recent EU-funded research, informal carers across the EU provide over 80% of all care, with women providing approximately two thirds of care mainly as daughters (in law) and wives/partners.

For patients and citizens, Health literacy is an aspect of empowerment (see EMPATHiE study, 2014) and a critical strategy for people to cope with the overwhelming amount of information often available online, and to navigate an often-confusing healthcare environment. An integrated care environment will take this burden off patients and citizens as the healthcare system, often described as a maze, will be much easier to navigate and more person-centred.

Next to the knowledge of navigating the healthcare system, health literacy also entails the knowledge, motivation and competencies needed to access, understand, appraise, and apply health-related information in daily life. Skills and education for patients, health and care providers and citizens should be focused on such common issues, especially in the context of integrated care.

Effective communication between the members of the healthcare team as well as between healthcare staff and patients is an important issue that needs to be addressed. Patients facing communication barriers are more exposed to errors but also to “silent misdiagnoses”¹⁵. Patients often perceive a gap in understanding when trying to make sense of medical jargon; and quite concretely patients and professionals sometimes speak a different language, especially in cross-border healthcare and multi-cultural contexts. Centring health care delivery around the user and integrating the informal carers into care teams is likely to develop trust between the citizens and care providers, hence contributing to better working conditions of health professionals, and quality integrated care.

Furthermore, practical opportunities to give feedback using digital care technologies, for example via supporting services at the hospital or helplines, are very important in improving integrated care facilities. Patient feedback should be systematically collected and not only focus on negative feedback but also on what is positive.

3. CHALLENGES

Fragmentation translates as lack of continuity and co-ordination in health & care delivery. Multiple services providers and settings contribute to treat chronic as well as post-acute conditions. Currently patients and citizens must navigate through disconnected health and social care system that fail to meet their needs of continuity, comprehensive, coordinated, holistic care. Health systems are struggling to bring down the barriers between the health and social sectors, shift processes from old to new, adapt the structures of care to a people centric model, aligning (safety) culture and attitudes, and fully embrace Digital Care technologies.

Health professionals are still not appropriately trained to work in multi-disciplinary teams, and in partnership with patients and citizens, although the content of education is evolving. In principle communication skills, for example, are included in most types of professional training, but there are still too many gaps that hinder Person-centred Integrated Care. This raises the question of how effective the training provided is, and to what extent (organisational) culture might be undermining what graduates had learned during their education. In addition, professionals often fear blame and litigation as a result of errors, which makes them reluctant to speak out. Feedback is not currently embedded into the system, and the “blame culture” needs to be opened up.

There is a need to develop target training to further educate health and care providers to ensure that they develop the competencies required to manage and deliver Integrated Care, whilst understanding the benefits of digital care technologies and anticipating effects on organisations, and processes.

The role of informal carers is worth emphasising, given that involving them in care is beneficial for the quality of care of the patient, and yet their role and contribution is often under-recognised. Informal carers often face difficulties to engage in a dialogue with the health professionals, get information they need on the health needs and treatment of the person they care for, and a how to best care for him/her.

¹⁵ The silent misdiagnosis refers to the fact that patients' preferences are often not taken into account in treatment decisions. Whilst medical misdiagnosis is a recognised safety issue, preference misdiagnosis is not. “Patients preferences matter. Stop the silent mis-diagnosis” by Al Mulley, Chris Trimble and Glyn Elwyn, *The King's Fund*, 2012.

In the meantime, informal carers are at higher risk of having health problems themselves, due to the negative impact of their caring duties on their own physical and mental health (tendency to neglect one's own needs, overtiredness, isolation, stress, ...), which in turn can impact negatively on their caring activities and on their capacity to engage with health professionals.

Overall, the health and care sectors do not sufficiently respect, inform, engage and support informal carers, hence failing to implement the [WHO plan around integrated care](#) calling the "delivery of health care in partnership with people", "where people families and communities are respected, informed, engaged and supported".

Valuing and supporting informal carers also has an important preventative effect, as it contributes to maintain the well-being and mental health of carers themselves.

4. RECOMMENDED MEASURES

1. **Educate** health & social care workforce to use Digital Care Technologies applied in daily practice;
2. **Offer** training to health professionals to support informal carers and include them in care teams (training to be developed in cooperation with carers' and research organisations that are available to share their expertise and knowledge);
3. **Develop** targeted coaching programmes on self-management for patients;
4. **Train** Health Professional to develop specific health preventative measures aimed at informal carers;
5. **Enable** citizens/patients to manage their own health through digital skills development and literacy;
6. **Enhance deployment of** health information exchange platforms, electronic health records systems, and population health management systems.

VI. Digital care technologies

Objective by 2021: Adopt innovative and interoperable digital care technologies, and harmonised sharing data plans in daily routine practice

1. INTRODUCTION

The move to integrated care is happening within the European Union and beyond, and where the first wave was about system redesign and system integration, it is becoming very clear that to sustain and extend the system redesign, support of Digital Care Technologies is a pre-requisite. Digital Care Technologies can support the care workforce with powerful workflow, decision, administrative and business tools and help the care workforce to address the immense challenge ahead of us with the demographic change and change in demand / expectations from the citizens in the EU.

At the same time, the move towards integrated care, supported by Digital Care Technologies, will require a harmonised implementation of the new EU data protection legislative framework across the EU to ensure patient safety and data privacy, while avoiding the need to address different market conditions in the 28 countries. Data sharing has to be trusted and has to happen in way that protects patient safety and data privacy, which is the ultimate objective of the General Data Protection Regulation. It will have to provide favourable legislative environment for digital innovation, in order to develop ethical ways of patient data transfer for integrated care.

But, any transformation towards integrated care and data sharing is a journey deeply grounded in local health and care needs. Sustainable approaches that can improve people's health and wellbeing, and reduce reliance on institutional care, will not be achieved unless effective strategies, at the health, social care and the third sector (e.g. NGOs, charities, etc.) levels, are developed, to empower and engage people to become active and equal partners in their own care.

This section offers a high-level overview of a **potential – technical - roadmap** to support a shift to integrated care, which builds on 6 genuine phases as identified and illustrated below.

Phase 1: **NORMALISED PERSON-CENTRIC DATA CAPTURE**

During this phase, the focus for all stakeholders in the care continuum is to capture all necessary data. Currently, a substantial proportion of resources are being spent on collecting health and care data. However, this data is usually stored in different information silos rather than generating a comprehensive knowledge base for the patient's care. Therefore, the overarching goal of this phase should be to ensure that all relevant clinical and operational events are properly captured in reusable formats.

Phase 2: **AGGREGATING AND SHARING DATA IN A LONGITUDINAL PATIENT RECORD**

The objective of phase 2 is to enable all stakeholders in the care continuum - including the patient - to share, aggregate and visualise meaningful data on a daily basis. There will need to be health data governance mechanisms in place to allow for data use and sharing. These should organise and provide access to health data while safeguarding patients' privacy and data protection rights.

Phase 3: **CARE TEAM COLLABORATION**

Based on the sharing of data and person centric care plans, Phase 3 focusses on achieving widespread care team collaboration, involving the patient and informal caregivers as well as health and social care professionals. During this phase, it is important that case and care managers (or other professionals with a coordinating role) have the tools to effectively manage the processes of the care team, that will include the patient/citizen and caregivers, according to the different roles identified.

Phase 4: **CARE COORDINATION AND INTEGRATED CARE**

Genuine health management at individual person level can begin in Phase 4, based on the collaborative tools and sharing data and care plans. This can begin within one sector and evolve into all-encompassing care coordination,

including health, wellness, social care and support for independent living. A key focus during this phase will be in empowering and encouraging people to manage their own care and wellbeing and improving health literacy.

Phase 5: SMART APPLICATIONS LEVERAGING ANALYTICS AND COGNITIVE REASONING

During this phase, cognitive computing and Artificial Intelligence will take off in the form of decision support systems integrated into dynamic and person-specific workflows. This will be based on the shared, multi-modal and enriched (big) data established during the previous phases. Caregivers and patients will routinely look to smart applications for support, taking into account the constantly changing medical, social and operational context.

Phase 6: POPULATION HEALTH MANAGEMENT

The acquired experience and insights will trickle down to health care experts and health policy makers. This will close the loop at society level, improving health care systems. This phase will require re-structuring reimbursement and health financing systems to substantiate the efficiency gains at system level and to provide proper incentives for all stakeholders to fully support the changes.

PHASES	1	2	3	4	5	6
	CAPTURE	AGGREGATE & SHARE	COLLABORATE	COORDINATE	SMART CARE	POPULATION HEALTH
FUNCTIONS	All stakeholders in the care continuum capture all necessary data	All stakeholders in the care continuum may access, share, aggregate and visualise meaningful data on a daily basis	Multidisciplinary teams, including the patient, formal and informal caregivers and processes for collaboration are set-up	Delivery of integrated care may begin, based on agreed care pathways across health and care settings, covering first medical care but evolving to wellness and social care	Smart applications routinely support caregivers and patients, taking into account the changing medical, social and operational context. Quality management processes are in place	The acquired experience and insights trickles down to health care experts and health policy makers, enabling them to further focus on outcomes and adopt a VBHC approach
	POLICY		INCENTIVES		SKILLS	

TECHNOLOGIES	INTEROPERABILITY	DATA PROTECTION	HEALTH TECHNOLOGY ASSESSMENT
	<ol style="list-style-type: none"> Usability of EMRs, data capture and navigation tools Non-traditional data capture: medical devices, wearables, social media, -omics, Patient Reported Outcomes Cloud and Mobile-ready tools 	<ol style="list-style-type: none"> Semantic Interoperability for data and workflows Standards Natural Language Processing Identity management and patient consent Visual integration of external data sources Data sharing platforms 	<ol style="list-style-type: none"> IT support for the establishment of teams and collaboration between team members Bi-directional instantaneous communication between team members
	<ol style="list-style-type: none"> Big Data Lakes (from diverse data sources) Deep Machine Learning (bottom up) Rule based decision support (top down) Knowledge sharing platforms Big data analytics, including risk stratification tools Impact assessment tools 		

Source: COCIR Digital Health Roadmap to support Integrated Care [Here](#)

2. OPPORTUNITIES

Digital Care Technologies support the transition to better care coordination. The scope of care technologies provides a more generic approach than Digital Health technologies and covers both health & social care.

Many of the integration processes for establishing integrated care will be virtual: instead of being merged, the involved parties will form alliances and networks to exchange the data supporting the delivery of seamless, continuity of care, provided interoperability, the prerequisite for the efficient and effective delivery of Integrated Care, is successfully implemented.

This section offers an overview of the opportunities each of the 6 phases of the Integrated Care provides, and also how technology can support the shift towards better health and social care coordination.

Phase 1: CAPTURE

From a technological perspective, this phase offers the following opportunities:

Enabling data capture, input and navigation through cloud and mobile-ready tools.

Kick-starting the normalisation process by capturing person-centric data in a standardised format, with parallel processes in structured data entry and Natural Language Processing-enabled data capture. Professionals should also be able to use Natural Language Processing (NLP) tools for auto-coding purposes, enabling quick and user-friendly structured data entry. The data collected should be stored in systems that are built with person-centric, rather than administrative-centric, approaches: this means collected data are consistently linked to the person and follow the individual rather than stay in the administration.

Facilitating both the inclusion of clinical data and of data generated through non-traditional health and care information sources. These include vital signs sensors, -omics, mHealth apps, social media and patient-generated data. The person is both a key stakeholder, actively engaged in their own care, as well as a primary source of data. Therefore, an effective IT system must allow patients to contribute their own care data, via a variety of channels including forms, questionnaires and methods appropriated;

Addressing usability. One of the keys to successfully deploying any new IT infrastructure is to address user design and usability early in the design process. There needs to be both smart and kind (user-friendly) applications in all the phases of the Roadmap. This is particularly relevant for IT systems supporting integrated care, as the solutions deployed need to suit both health and care professionals as well as the non-professional users such as citizens, patients, family members and carers.

Phase 2: AGGREGATE AND SHARE

From a technological perspective, this phase should focus on the following aspects:

Enabling technical visual integration of the systems that the stakeholders in the care continuum will use routinely. This means fully integrating the shared data into existing IT infrastructures and applications, thus allowing health and care professionals to use the available data and tools in their daily practice. This will require data-sharing and interoperability between existing IT infrastructures as well as the development of new standards. The data will need to be accessible in multiple formats and via multiple platforms to meet differing user needs (admin, clinical, patient, carers, etc.). Appropriate governance frameworks will need to be developed to enable beneficial and ethical use and transfer of personal health data for the delivery of integrated care.

Allowing a common visualisation of assigned care plans and care teams. Although many institutions have already adopted care pathways, there is no common widely used standard, making them difficult to share. Agreeing on a common care plan and sharing it as a document, even in pdf format, would already be a productive start and will begin to pave the way for collaboration.

Adhering to care data interchange standards along with richer semantic standards. Many of the current standards are formalising concepts such as diagnoses but not the relationships between these and the context in which they were captured. In addition, as the goal of a single standard seems unreachable, there should be greater emphasis placed on ensuring interoperability between the various standards in use.

Implementing healthcare communication standards (HL7, DICOM, FHIR), IHE profiles and other guidelines, e.g. the Continua guidelines, for exchanging health information and integrating the various information silos.

Using semantic technologies and NLP to extract meaningful information from non-structured data. In Phase 1, we suggested using NLP to capture new data; during this Phase, we recommend using it to exchange the huge amount of existing non-structured data.

Deploying a global identity management solution to ensure that all stakeholders involved (patients, carers, health and care professionals) have a unique identifier that will allow on the one hand to ensure proper linkage between data and patient and on the other to ensure secure and controlled access to data.

Rolling-out within regional or national care systems patient consent management systems, allowing patients to grant consent for sharing their personal data outside the institutions where it was originally collected.

Providing information on data provenance. It is extremely important to always know exactly where shared data is coming from and who has entered it.

Phase 3: COLLABORATION

From a technological perspective, this phase should focus on the following aspects:

Deploying well integrated tools for team collaboration, both technical and visual, across the care continuum settings based on social media and collaborative principles.

Enabling bi-directional and instantaneous communications between all stakeholders, including healthcare, social, long-term-care settings and home. This will make information timely available across the care continuum without information gaps or duplications.

Assessing teams' efficiency, tracking outcomes and use of resources and pursuing clinically proven best practices.

Phase 4: COORDINATE

From a technological perspective, the focus should be on the following aspects:

Enabling virtual sharing of care plans among all care team members. The care plan should be holistic, describing both clinical and non-clinical needs and services, including both home and community-based care. As a bare minimum, the available IT solution should allow team members to electronically view information directly relevant to their role, easily identify roles and responsibilities within the team and to update other members on developments. The care plan itself will be an agreed set of tasks, which can be assigned to - and by - care team members, including the patient and care givers.

Deploying IT systems that support dynamic, distributed, person-specific and integrated (clinical + social + informal) care workflows.

Using gamification or other social engineering tools and apps to help patients and care givers increase treatment adherence through behavioural change therapies and other psychological motivational elements, improving long-term outcomes.

Phase 5: SMART CARE

From a technological perspective, the focus should be on the following aspects:

Advancing deep machine learning, imaging analytics, formalising and sharing of medical knowledge, statistical evidence and mathematical models.

Sharing algorithms and high-level clinical decision and workflow generation ICT-services via service ecosystems that go beyond mere data-access services.

Providing smart alert services based on integrating clinical decision support in treatment and preventive settings, striking a correct balance between over and under-alerting to prevent alert fatigue.

Developing self-adapting and contextual user-specific user interfaces.

Enabling controlled access to ‘data lakes’ of relevant clinical data that comply with an agreed legal framework and with proper pseudonymisation of sensitive data.

Addressing the clinical, social and technical challenges linked to the coverage of multiple diseases. This involves dynamically generated care plans to deal with the complexity of co-morbidities.

Personalising care delivery by analysing large amounts of data (including -omics data);

Phase 6: POPULATION HEALTH

From a technological perspective, the focus should be on the following aspects:

Deploying analytics systems for performing population risk stratification. This will enable targeted prevention interventions that address the specific risks facing specific population groups, for example high-need patients at risk of hospitalisation;

Enabling large scale access and analysis of large amounts of multi modal data. This will allow to extract population-wide epidemiological trends to measure the efficiency and value of health policy measures and new technologies;

Disseminating and sharing, in a computer-readable and human readable way, the findings and evidence from statistical analysis of big data;

Develop value-based reporting models, where agreed targets are the driver for all stakeholders;

3. CHALLENGES

There are huge differences how health systems, and especially the delivery of integrated care, work in the various EU member states. Many fragmented projects exist, which come up with their own interoperability concepts, with no clear path for establishing an EU wide robust set of profiles and standards. There are limited incentives for the EU Member States to follow EU wide interoperability strategies.

More specifically, there are significant barriers for scaling up Digital Care Technologies for Integrated Care. These barriers are grouped into three major families (technical, organisational, objective) developed below:

TECHNICAL CHALLENGES: Lack of interoperability standards between social and health care, greatly limits the exchange of data between agencies. Lack of interoperability between home health devices and care systems such as EMR's, is a great impediment for remote monitoring and prevention. The definition of EU wide interoperability standards on the basis of available international profiles and standards for exchanging health data are needed in order to establish the new models of care, so that a sufficiently large market drives their opinion in a wide portfolio of interoperable solutions. Lack of shared data model between social and health care, makes the development of holistic tools for Artificial Intelligence and Clinical/ Care Analytics more complex and slows the distribution of the output of these tools. At the same time, the implementation of data protection rules should ensure safety and data privacy to facilitate data transfer to and should not hamper innovation, notably with regards to the prospects of the digital health economy.

ORGANISATIONAL CHALLENGES: Digital Care is still seen as something that is either in the hands of innovators or early adaptors. Care should move to a “digital first” approach, if you are not using digital tools you should motivate why not, and potential have a different reimbursement scheme applied. Many organisations today still follow the old paradigm of developing something first, then test the impact, and only in a second step investigate what is commercially available. This re-inventing of the wheel creates a slowdown of scaling up and overall much higher spending on R&D. There is a need to leap-frog the different evolutionary steps.

When designing Digital Care Technologies programmes for Integrated Care, the objectives of the users, which explicitly includes the workforce and people affected by the programme, are often not included. We need to move to a co-design of objectives while industrializing the implementation of technologies.

4. RECOMMENDED MEASURES

1. **Establish** a framework for the deployment of interoperable solutions;
2. **Change** terminology: Use the term of “Digital Care Technologies” instead of “Digital Health Technologies”;
3. **Adopt** digital care payment models, where the professional guidelines and practice standards are based on digital care technologies as opposed to analog care technologies;
4. **Define**, implement, and deploy a shared data model (incl. account privacy and security issues) and interoperability standards for Digital Care at EU and International level, that expands the current standards and models when and where required;
5. **Incentivise** the care system to move towards “industrial” approach on product development standards and methods, by developing digital care technologies that by design have the quality for multiple deployments in a repeatable and sustainable way;
6. **Establish** a connected network of regional expert centres for digital care technologies for integrated care;
7. **Define** pilot integrated care scenarios which can be established in the majority of the EU Member States health systems. Ensure the scenarios cover usual care situations. Do not focus on scenarios which are rare;
8. **Promote** and define interoperability profiles and standards to use for implementing the scenarios. Build upon the 27 EU recognised Integrated Healthcare Enterprise (IHE) profiles [IHE profiles](#) and extend as needed;
9. **Incentivise** Member States to adopt, pilot and deploy these scenarios;
10. **Harmonise** implementation of Data Protection Framework;
11. **Raise** awareness of the citizens on the principles of the General Data Protection Regulation;
12. **Develop** value assessment methodologies for Integrated Care Pathways.

Notes

A large area of the page is filled with horizontal dotted lines, serving as a template for taking notes.

About the Partners:



European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients. Our mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU. www.eu-patient.eu



Voka Health Community is a partnership between entrepreneurs, patient organisations, knowledge centres and health care providers. It is hosted by Voka, the association of the Flemish chambers of commerce. The communities' mission is to breakdown the wall between profit and non-profit, to speed up the implementation of innovation, and to foster the white economy in Flanders. Actually 150 members are active in networking, information exchange and creating new business opportunities. www.healthcommunity.be



Eurocarers brings together carers' organisations as well as relevant R&D organisations from across Europe. Eurocarers works for a future in which caring is recognised and valued, and in which unpaid carers do not face poverty, social exclusion or discrimination. The role of carers is more crucial than ever due to demographic changes and challenges to formal health and social care services throughout Europe. The aim of Eurocarers is to raise awareness of the significant contribution made by carers to health and social care systems and the economy as a whole, and to ensure that EU and national policies take account of carers. www.eurocarers.org



Arsenà.IT - Veneto's Research Centre for eHealth is a voluntary consortium among the 23 Local Health Authorities and Hospital Trusts of the Veneto Region (Italy). It aims at enhancing the quality of the clinical processes and assistance offered to citizens with an inter-enterprises view. Arsenà.IT provides the guidelines for the use of ICT standards, promoting homogeneity and the adaptation of the existing systems to new laws and monitoring their application, thanks to the debates at international level. www.consortioarsenal.it



European Society for Radiotherapy & Oncology (ESTRO) Founded in 1980, ESTRO is a non-profit and scientific organisation that fosters the role of Radiation Oncology in order to improve patients' care in the multimodality treatment of cancer. ESTRO supports all the Radiation Oncology professionals in their daily practice: Radiation Oncologists, Medical Physicists, Radiobiologists and RTTs (Radiation Therapists) and the wider oncology community. ESTRO's mission is to promote innovation, research, and dissemination of science through its congresses, special meetings, educational courses and publications. www.estro.org



European Union of Private Hospitals (UEHP) The purpose of the UEHP is to defend and represent the independent hospitals in Europe, to generate the political and economic conditions aiming to improve the independent initiative in the health field. Moreover, UEHP studies and creates better conditions for the smooth management of independent hospitals. The priority of the UEHP is to promote high quality healthcare focused on the patient. www.uehp.eu



COCIR is the European Trade Association representing the medical imaging, radiotherapy, health ICT and electromedical industries. Founded in 1959, COCIR is a non-profit association headquartered in Brussels (Belgium) with a China Desk based in Beijing since 2007.

COCIR is unique as it brings together the healthcare, IT and telecommunications industries. COCIR is leading the Digital Health Industry voice and is working with other organisations to advance integrated and patient – centric models. www.cocir.org

