ADLIFE WHITE PAPER

Digital Transformation and Empowerment

KEY SUCCESS FACTORS FOR ACCELERATING DIGITAL HEALTH INNOVATION

Developed in collaboration with

iHD The European Institute for Innovation through Health Data

The ADLIFE Project has received funding from the European Union under the Horizon 2020 Programme, grant reference number 875209

Table of contents

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Introduction

Digital health transformation needs powerful acceleration to outpace the growing demands on health systems, rising expectations of healthcare quality and equity from patients and the public, and the pressures on healthcare expenditure.

This White Paper identifies key success factors for accelerating digital health innovation, based on insights from the ADLIFE project, a large-scale European Commission pilot on the adoption of digital health innovations. The ADLIFE insights are complemented by lessons from other European projects and multi-stakeholder consultations.

These findings were consolidated at a European conference on equitable, integrative, and value-driven digital health transformation held in Bilbao, Spain, in November 2024.

This White Paper distils the success factors for digital health transformation that is patient empowering and democratic across the population, to scale up the delivery of more personalised, evidence-based, better co-ordinated and patient-engaging care in a cost-efficient way. The success of transformation depends upon the greater use of digital health technologies.

What is digital health?

The European Commission defines digital health as the tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health-related issues and to monitor and manage lifestyle habits that impact health[1].

The design, preparation for and implementation of digital health transformation is not, and should not be, a simple technology adoption process. It has to be approached as an organisational change process and a change in the way people (especially healthcare professionals) deliver care, interact with each other and interact meaningfully with each patient, that is facilitated by the capabilities provided through digital technologies and their connectivity. It is digitally-enabled healthcare.

Digital health transformation, the adaptation of models of care delivery to leverage digital health tools (DHT), is rapidly progressing across all health systems, certainly in every European Member State. Many digital health solutions also engage the patient, often in self-monitoring, self-management and lifestyle guidance that prevents disease, stabilises disease, intercepts potential escalations and reduces the risk of complications. The benefits to patients and to health systems of stronger engagement and empowerment[2] are interwoven with the broader success factors for digital health. However, the pace of change is not fast enough.

[1] The European Commission https://health.ec.europa.eu/ehealth-digital-health-and-care/overview_en

[2] Patient empowerment is understood here as “a process through which people gain greater control over decisions and actions affecting their health” (WHO, 1998).

Why digital transformation and patient empowerment are vital

The urgency of digital transformation

Health systems sustainability is now the pan-European, and indeed global, concern of health ministries and health purchasing/ commissioning authorities, due to the imbalance between growing demand, spiralling healthcare costs and the limitations on healthcare funding, especially post-COVID when public funding reserves are low, and healthcare backlogs are high.

There is a recognised need for **greater health systems resilience** to face contingencies and have better or alternative healthcare delivery systems in place that could respond rapidly to new health threats such as a new virus, pollutant or terrorist destabilisation of countries and world regions. This includes a lower reliance, or at least a lower dependency, upon face-to-face models of care.

Across Europe there is a **growing healthcare burden of long-term conditions**, made more challenging and expensive because of the increased proportion of the population with multiple long-term conditions. This rising multi-morbidity requires greater care team coordination and complex multi-disease management care plans, including the societally beneficial but expensive implications of innovative therapies such as gene therapies.

Society is placing increased **pressure on health systems** to demonstrate efficiency, including better care co-ordination and less wastage through avoidable costs and the usage of low-value or no-value care interventions.

This is linked to the demand for health systems to focus efforts on **demonstrating value**, which includes ensuring that the systems have the capability to accumulate an evidence base of health outcomes and can prove the value of the care they deliver. There is growing public expectation of **quality without disparities or inequity**, known as Universal Health Coverage, including public transparency on geographical variations in the quality of care and health outcomes. Especially since the COVID-19 pandemic, every health system in Europe has experienced an escalation in the **shortages of skilled healthcare professionals** and other vital staff such as health ICT, increasing the workload and stress pressures on existing staff and increasing the consequent risk of staff burnout.

Looking more widely, health systems are also beginning to look critically at the **environmental impact of healthcare delivery**, including the impact of patients travelling to healthcare facilities.

Today's limitations of healthcare services that require transformation

Healthcare is currently designed to be reactive and episodic, not proactive and preventive. For example health systems observe high numbers of hospital admissions for conditions such as diabetes mellitus type 2 that could be improved by better health promotion and self-management. This means that whilst it struggles to address the tide of rising demand, it has little capability, capacity or skills to reduce that demand.

Healthcare struggles with its fragmentation, which has hidden inefficiencies and disparities, because it has failed to adequately address the increasingly multi-disciplinary and multi-organisational nature of healthcare delivery that is inherent within care pathways, the interdependency of every care activity upon the well-informed and coordinated actions of other healthcare professionals, especially in the face of multi-morbidity. It has failed to properly recognise – through budget allocation and prioritisation - that healthcare is an information-intensive industry.

Healthcare procedures and treatments are often informed by evidence, such as clinical trial evidence, which focuses on relatively short-term **clinically meaningful** endpoints. The health outcomes **experienced by patients** are still largely unknown. **This is paradoxical because the health experience of patients drives demand but does not drive the delivery of the service or its feedback loops.** Core outcome sets need to

be developed that include the voice and perspectives of patients[3].

Health systems have been designed and are still largely delivered without leveraging digital tools or the online interaction with patients. Indeed, there is still a reluctance to trust information not captured through direct patient contact within the physical building of the healthcare organisation. Almost no other sector retains that archaic mentality.

The customers (i.e. the patients) are regarded as passive objects and not active co-contributors to their health and health care. Again, almost every other sector regards its customers differently.

The opportunities to accelerate digital health transformation

The rich functionality, affordability, usability and capability for integration of digital health tools, make digital health an important lever for health systems transformation.

Facilitating factors

- The diversity and sophistication convenience of digital health technologies
- The prospect of many quality-labelled and interoperable digital health apps
- Innovations emerging from AI
- The lowering cost of digital health technologies
- The lowering costs of adopting interoperability standards
- The rise of EHR systems that can incorporate care planning tools and remote connectivity from digital technologies
- The body of evidence that digital health tools can augment clinician care and improve outcomes at lower cost
- Strong drivers for patient empowerment and the readiness of more and more patients to engage
- The pressure to deliver healthcare more seamlessly with people's lives
- Greater digital maturity of digitally connected homes
- Greater (though patchy) health and digital literacy
- The momentum in Europe of the European Health Data Space

[3] PLoS One. 2021;16(3):e0247522. https://doi.org/10.1371/journal.pone.0247522

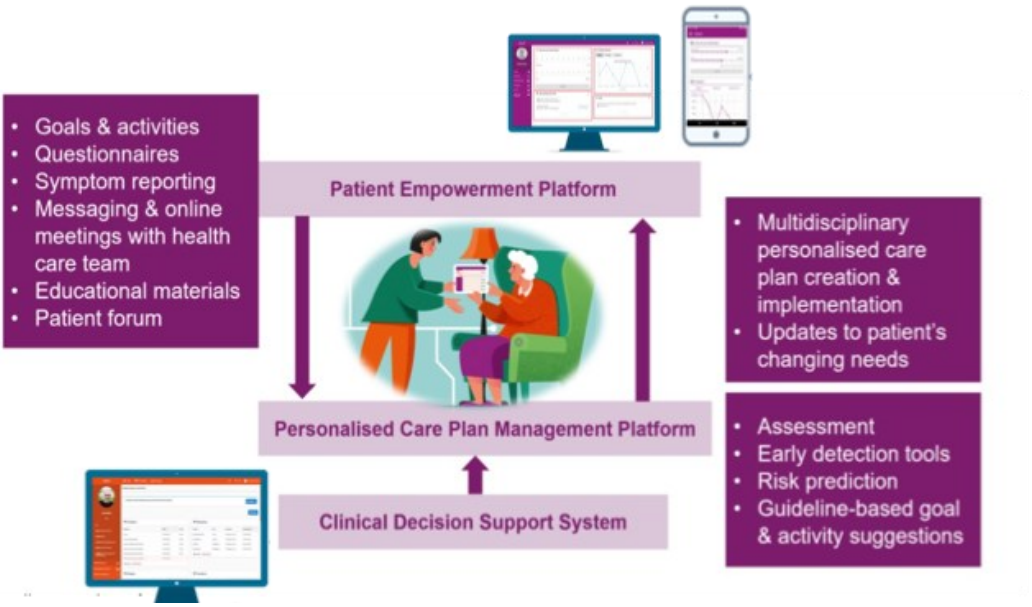
Executive summary of ADLIFE

Many of the findings and success factors reported in this White Paper have arisen from the innovation and pilot testing undertaken by the ADLIFE project.
https://adlifeproject.com

ADLIFE is an EU Horizon 2020-funded project that has developed digital health innovations to improve the quality of life and independence of elderly patients with advanced (severe) chronic conditions through digitally-supported interventions. It has developed an innovative and intelligent ADLIFE digital health toolbox to leverage integrated and personalised care, based on multidisciplinary collaboration and patient empowerment. It has been implemented and demonstrated in two prevalent advanced chronic conditions, Chronic Obstructive Pulmonary Disease and Heart Failure, to enable:

- care teams in different care settings to create integrated care plans, implementing intelligent tools for clinical decision support by automating evidence-based guideline suggestions, and optimising multidisciplinary coordination;
- a more active role of patients and informal caregivers in managing their own health during daily life and encouraging shared decision making about their care plan;
- better health systems efficiency, effectiveness and sustainability by promoting multidisciplinary collaboration, patient empowerment and AI-supported automated services.

To achieve this, ADLIFE has adapted published clinical guidelines in both clinical conditions to make them algorithmic and suitable for computerised decision support, and then performed reconciliation with added guidelines for the most prevalent comorbidities (diabetes, renal failure, cognitive impairment, etc.). These are presented on a clinical desktop to enable clinicians and patients to jointly personalise the care plan. With clinician and patient involvement ADLIFE has inserted patient self-management steps that can be undertaken using a patient empowerment platform (PEP) that is served both as a web portal and as a mobile application that can be integrated with wearable monitoring devices.



This ADLIFE personalised care model has been deployed and replicated in six healthcare settings in four European countries.

The ADLIFE evaluation findings

The ADLIFE digital health technologies and patient-empowering integrated care model have been quantitatively and qualitatively evaluated in the four largest pilot sites, in Spain, Denmark, the UK and Israel[4].

The evaluation approach of the ADLIFE study focuses on three complementary evaluation approaches:

- effectiveness;
- implementation process, which combines technology acceptance and adoption assessment and contextual factors for further exploitation to later scaling-up assessment;
- socio-economic impact analysis.

EVALUATION APPROACH	METHODOLOGY	
Effectiveness and healthcare related outcomes	Quantitative	Qualitative
Implementation	Quantitative	Qualitative
Socio - economic impact	Quantitative	

Major findings/outcomes

Clinical teams including hospital consultants, GPs and specialist nurses reported:

- they experienced greater professional confidence in the quality and evidence basis of their management of the two health conditions.
- they were always able to practice to the latest guidelines.
- they anticipated (but the data was insufficient to prove) a reduction in clinical errors.
- they could easily personalise care plans to the patients' needs and preferences, and engage better with each patient.
- ADLIFE provided better support to clinical teamwork, shifting workload and working patterns between care team members.
- New roles and organizational changes aimed at improving healthcare integration (care coordination nursing, call centres, etc.) played the most relevant roles in the success of ADLIFE implementation.
- Both integrated care and personalised care plans enhanced the quality of care by ensuring that patients' needs are met.

[4] García-Lorenzo, B., Gorostiza, A., González, N., Larrañaga, I., Mateo-Abad, M., Ortega-Gil, A., ... & de Manuel Keenoy, E. (2023). Assessment of the effectiveness, socio-economic impact and implementation of a digital solution for patients with advanced chronic diseases: the ADLIFE study protocol. International journal of environmental research and public health, 20(4), 3152.

Patients and caregivers reported:

- greater disease knowledge and understanding;
- encouraged self-care and self-management;
- greater confidence through the frequent monitoring;
- greater sense of self-control over their disease;
- a more informed relationship with clinicians, greater trust, co-responsibility;
- they experienced better care co-ordination between team members.

Quantitative evaluation showed that **healthcare organisations** experienced:

- reduced emergency department first attendance;
- reduced overall face-to-face consultation rate, especially for general practice;
- improved clinician engagement with their patients;
- The economic impact assessment suggested a potential significant reduction in disease burden due to ADLIFE.

More detailed evaluation findings can be found at www.adlifeproject.com/deliverables

Challenges to conducting large-scale pilots of digital health innovations

The ADLIFE experience

ADLIFE originally sought to establish live large-scale pilots in seven countries, at a mixture of hospital and primary care settings. In the end, not all of these sites were able to establish large-scale patient use, even though they originally hoped to and had sufficient budget. The practical issues that were faced are summarised here, as important learnings from the project that the partners have also correlated with other European digital health pilots.

Pre-requisite organisational readiness to pilot and evaluate digital health innovations

- Organisational acceptance and internal policies for permitting the use of, and integration of, third-party ICT products that are developed but still being enhanced, or upscaling existing systems with new and additional functions that have been demonstrated as useful.
- Organisational acceptance and internal policies for permitting the piloting of digital health tools that are medical devices but are being tested prior to seeking Medical Device Regulation approval.
- Efficient and quick organisational processes for the various required committee and officer approvals.
- Sufficient ICT capacity and expertise to integrate a third-party digital solution, including clinician-facing and patient-facing components.
- Ability and permissions to support developers with real, or close to real (anonymised) data.
- Capacity to provide dedicated (project grant-funded) personnel to support patients to use the novel solution, to support the pilot study and to perform the evaluations.

Informatics challenges to developing and deploying digital health innovations

- The absence of many computable guidelines in other disease areas, requiring a similar effort to ADLIFE: clinician expertise to formalise as rules, informatics expertise to formalise as algorithms and multi-professional expertise to adapt for even the common patterns of multi-morbidity;
- The lack of patient-empowered pathway steps in clinical guidelines;
- Integration with EHRs
  - heterogeneous information architectures and interfaces to EHR systems
  - limited adoption of interoperability standards
  - difficult integration of external platforms, even for those meeting international interoperability standards;
- Requirements, obstacles, costs imposed by EHR systems developers to enable the data flows;
- Bidirectional mapping requirements between the EHR and the digital health solution;
- The need for bidirectional exchange with the patient's EHR for personalisation (as implemented by ADLIFE)
  - pre-population of the innovation with relevant patient demographics and clinical details;
  - provision back to the EHR of the care plan created and patient self-management data;
- Reliance upon high-quality structured and coded EHR data for AI development and validation.

Driving digital transformation through policy

Localised digital health adoption and innovation pilots can occur without policy level support. However, successfully scaling up digital health transformation to make health systems more sustainable and resilient requires top-down policy guidance. Those policies must define the priorities of digital transformation, set health systems targets linked to financial allocation and accountability. For example, changes to financing and reimbursement models could incentivise innovative digital healthcare services. Financial levers could be used to accelerate value-based care, with outcomes targets standardized at a national level.

It is essential to embed digital health transformation policies into a comprehensive digital health strategy, which should be developed with input from multiple stakeholders.

This strategy must affect the enablers to enhance access to and sharing of high-quality interoperable health data. Structural support, incentives and procurement guidance are needed to direct the market towards better collaboration and alignment between EHR system developers, app and wearables developers, guideline developers, AI developers and other actors. This should ensure reliable integration of digital innovations with existing IT systems such as demographics services, authentication services and EHRs.

It is crucial to balance the benefits of enhanced data sharing with potential risks, while respecting public/private sectoral and population interests. This involves reducing unnecessary barriers to inter-organisational and cross-border data flows, along with investing in developing data-related skills, infrastructure, and standards adoption.

The strategy must strengthen the procurement of interoperable systems. For example payers could conditionally reimburse healthcare providers for ICT capital expenditures, such as EHR systems, only if they meet national interoperability standards. It must mandate conformance to a European and national standards portfolio for EHR data, specify and mandate standards for algorithmic clinical guidelines with EHR-aligned semantics, and proactively prevent vendor lock-in.

Reinforcing trust and empowering users through proactive stakeholder engagement in developing and implementing the strategy is crucial to facilitate data sharing and maximize the value of data reuse. This must enable greater data integration across the health system and enable future care models to be more representative and effective.

The strategy also needs to provide clarity on multi-disciplinary and inter-agency responsibility for sharing care and patient empowerment. It may be necessary to standardise inter-organisational agreements for data sharing and collaborative outcomes, implement changes to the professional accountability paradigm for patient empowerment and establish legal and ethical frameworks for the responsible use of data and new technologies such as AI.

Allocating resources and setting targets for improving digital skills among professionals and the public is crucial. Resources should also be provided for education to support patient self-care. Future healthcare professionals' education should include specific training in multi-professional collaboration, patient engagement, health outcomes and value-based care.

The uptake (including piloting) of novel digital health innovations – to stimulate the market – needs specific incentivisation and guidance. National level support is needed for healthcare organisations to participate in digital health evaluation pilots, including support to address GDPR, consent compliance issues and the challenges of Medical Device Regulation (MDR) for pilot investigations.

Key adoption success factors for digital health transformation

This section of the White Paper consolidates the success factors that were found to be valuable or found to be a challenge when working with the ADLIFE pilot sites in seven European countries, presented here as recommendations. These have been merged with success factors identified and recommendations arising from other European projects as they have implemented and deployed digital health transformative solutions across teams and organisations. These include H2O[5], Gravitate-Health[6], xShare[7], Label2Enable[8], ASSESS-DHT[9]. Almost all of these involve patients and caregivers through digital health tools that capture their health status, empower them in self-management of their health conditions, enrich the clinician-patient relationship through better informed joint decision-making, or quality assure those solutions. These projects all have a common transformative ambition to deliver more personalised, evidence-based, co-ordinated and patient-engaging care in a cost-efficient way, through the greater use of digital health technologies.

Driving transformation at the health systems level

As directed by policy, data and new technologies must be actively used to address society's major challenges. Commitment of leadership and management is key to success. Integrated care requires new roles and a revision of existing roles. Providing supportive digital tools by itself will not make integrated care happen. Integrated care has to be designed as a set of re-defined care processes looking for suitable digital health tools and not the tools trying to push the change processes.

Healthcare organisational readiness for digital transformation

There are many organisational barriers to achieving integrated and person-centred care. Support from the board, convinced of the value of a transformative agenda, is always vital. Strong change management leadership skills will be required and must be identified at the outset. The board's attitude towards prioritising health outcomes and value-based care is critical, alongside its ability to absorb and/or influence the consequent reimbursement implications, and to retain the potential benefit of projected cost savings.

Organisations and clinical teams must have an appetite for (positively) disruptive innovation, and be prepared to commit to the cognitive and time impacts of introducing change, even if it ultimately leads to workload and time efficiencies. The ICT department also must support the introduction and integration of novel digital health solutions. The organisation must show the willingness, culture and capacity to change clinical workflows.

The impacts of change depend on the pre-existing co-ordination and collaboration patterns between care teams within and between organisations. The current experience with integrated care pathways will also influence the extent of teamwork changes needed: it may matter less whether these pathways are on paper or electronic, well-integrated with EHRs, already incorporating reminders and alerts, but more on the extent of pre-existing multi-professional collaboration and experience of working with common care pathways.

It should not be overlooked that digitally enabled healthcare, if introduced well, can improve the working conditions and career attractiveness for healthcare professionals.

An existing culture, or a willingness to introduce a culture, of shared decision making with patients is essential, as is a positivity backed by organisational policies regarding patient self-monitoring and the inclusion of home monitoring data in EHRs.

[5] https://health-outcomes-observatory.eu
[6] https://www.gravitatehealth.eu
[7] https://xshare-project.eu
[8] https://label2enable.eu
[9] https://assess-dht.eu

Ensuring digital health empowerment and equity

Digital health tools and digitally transformed services must be designed to avoid a digital divide that would deepen inequity of access to healthcare. All parties involved must understand the existing inequalities and disparities in the service being transformed, especially for under-served communities, and strive to correct these so that digitisation actually improves equity. It is first necessary to focus on patients' (unmet) needs, to engage them early in the design process and then to tailor solutions to diverse populations and conditions. Assess and correct for sampling biases in data and in survey respondents.

The use of digital tools does not automatically empower patients but can support empowerment if they are used to strengthen, not replace, the patient-professional relationship, and to embed patient empowerment in care processes. Ensure digital health enriches traditional healthcare options: offer hybrid models combining in-person and digital services to accommodate patient preferences.

When designing patient empowerment solutions, include shared decision-making steps in care plans, communicate how patient data is used, stored, and protected and co-create data governance frameworks with patients. Invest in health, digital and data literacy.

It may be helpful to establish a large online testing pool of diverse patients. Use feedback loops from patients to continuously refine tools and services. Develop suitable outcome measures, collect these routinely and use the data to improve the service, to target disparities and to correct for underserved patient groups.

EHR systems must be more interoperable and interconnected

It is important for health systems to better prioritise interoperability, using policy to gradually remove the perverse incentives for closed silo systems and vendor lock in. Increase the market pull to build a well-connected health ICT landscape through interoperable products and services. Integrated care requires not only EHR data interoperability but care plan and clinical workflow interoperability enabling referrals, lab orders and appointments. ISO standards exist for all of these.

Many healthcare organisations struggle to recruit sufficient skills in interoperability standards such as HL7 FHIR and SNOMED. Prioritise early wins by leveraging the European cohesion around the International Patient Summary as a catalyst for interoperability and data sharing.

Improving health data quality

Focus on improving the capture and use of high-quality health data at organisational, people and technology levels. Provide data quality education e.g. workshops for all levels within healthcare provider organisations, embed data quality assessment into routine quality management processes, and provide feedback loops to clinical staff on the quality of the data they generate. Busy clinical staff need to recognise that high-quality data capture is important, not only for themselves but for multiple downstream uses of the data.

High-quality data is only appreciated if the data is used to deliver value. This starts by delivering value to the people who enter the data, such as through the rich use of clinical decision support and care pathway workflow tools and giving them clinically useful analysis reports of their activity and outcomes. This value includes fellow clinicians caring for the same patient, people analysing the data for various quality, safety and resource utilisation analyses, for population health and health systems learning and for clinical research.

Creating a vibrant ecosystem for the secondary uses of health data.

Such ecosystem is an important stimulus and feedback loop for healthcare provider organisations to promote (and maybe financially support) better data quality. These secondary uses, which often span public-private stakeholders, include reusing the data for evidence-based population health insights, real-time public health surveillance, and uses of real-world data to accelerate research and innovation.

Design and safety considerations

Some digital health success factors lie primarily with developers of digital solutions and with the clinical teams that adopt them. The design of the solutions needs to orchestrate co-ordinated continuity of care, usually through algorithmically implemented computable multi-organisational integrated care pathways, capable of personalisation and involving patients and caregivers as joint decision makers. Clinicians must advise on this, until computable, algorithmic, patient-inclusive guidelines become the publishing standard for national guidelines.

Clinician applications and patient empowerment tools must be formally risk-assessed for patient safety, especially if they involve AI components, and have robust failure modes in case of inadequate patient data. The design of the innovation must take into account potential limitations and failures in digital technologies as well.

User-friendly interface design

Clinician/patient-friendly interface design is key to scaling up use, especially beyond enthusiasts and early adopters. Comply with usability standards, embed each digital innovation in the EHR system as seamlessly as possible, incorporate single sign-on and seamless patient identification, avoid duplicate data entry and ensure a light cognitive load for learning and use. The digital health strategy must require digital health developers and approval agencies to ensure the use of universal accessibility features and equity impact assessments.

Adoption support

Involvement and commitment of senior decision-makers and healthcare professionals are key to transformation. Organisations must allocate protected time for training and for workflow changes, especially during the transition when old and new care processes will run in parallel. Ensuring the right healthcare professional skill mix to deliver transformed services, and provide necessary training and technical support. Consider the capacity and skills of healthcare personnel to train patients and caregivers. Adopt value-based payment models more widely across health systems.

Learning Health Communities

It may prove helpful at regional and national levels to establish Learning Health Communities, networks of healthcare provider organisations and professions that are engaged in various forms of digital health transformation, and share experiences and good practices even if they are working in different clinical domains and with different patient groups.

Conclusions

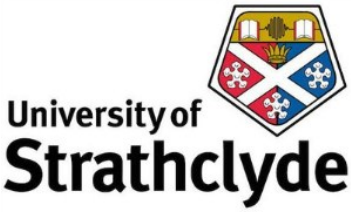
For digital health innovations to scale beyond pilots, even large-scale pilots such as ADLIFE, top-down **policy level prioritisation** of health system transformation is essential. This includes creating the enabling conditions for the adoption of digital health innovation, including targeted financial conditions.

Innovations cannot scale up exclusively through a bottom-up market push. There has to be a **market pull**.

Whilst digital health transformation is a crucial success factor for the sustainability and resilience of health systems, promising increased efficiency and cost savings, **investment is necessary to pump prime the changes**. This will usually require an increase in spending before cost savings can be accrued.

The European Health Data Space and other European regulations contribute to a favourable environment also at national level, not only to foster digital health adoption but to strengthen the digital health market that can be both national and European, by **aligning with European standards and cross border strategies.**

ADLIFE Consortium Members



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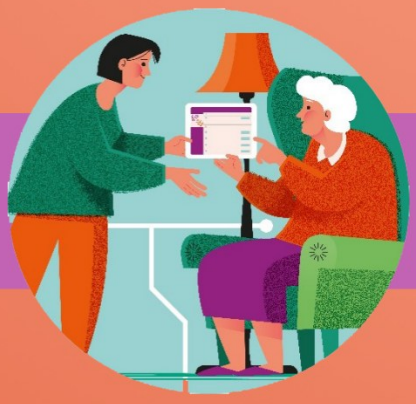

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