



# Health and Care Ecosystems as Drivers for Transforming European Welfare in the 2020s

A European Encounter organised by the AAL Programme, University of Vaasa, University of Tampere, German Health Regions, ScanBalt Regional Network and the Health Valley

Executive Summary



This paper reflects discussions of the online seminar held on May 31, 2021 under the aegis of the AAL Programme with the cooperation of German Health Regions, Health Valley Netherlands, the University of Vaasa/IRWIN project and the Tampere University from Finland and the ScanBalt BIO Network.

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This executive summary report has been written by Tom Kennis, MakeShiftPublishing.

The document aims to complement the rich discussions and select direct quotes (yellow boxes) of the seminar, with definitions-in-the-making gleaned from the discussions and from outside sources (grey boxes); where attributable we have included sources, but just as often they are paraphrased reflections of an ongoing process rather than clear-cut definitions. For the sake of brevity, we could not detail every example project that was mentioned or that the participants are currently involved in, but we have highlighted a few (in green). Finally, we draw attention to a preliminary set of proposed actions to move this exciting field forward (in blue).

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## Introduction

Europe is faced with a tremendous health and care challenge. Ageing populations and tighter budgets are creating a gap between growing demand for health and care services and a decreasing supply of resources. The shock of the COVID-19 pandemic has accelerated these trends and brought into sharper relief overall shortcomings of European health systems. As it is with many crises, the current inflection point is also an opportunity.

This opportunity comes in the form of health and care ecosystems emerging everywhere. Broadly speaking, health and care ecosystems can be seen as integrated networks spanning across sectors, including multiple if not all the stakeholders that are involved in creating health outcomes: healthcare providers, formal and informal caregivers, insurers, governments; regional, national and cross-border networks, academia, technology companies, and – most importantly – the citizens and patients themselves. Health is and remains, by definition, a *public good*.

Crucially, these ecosystems are not designed or decided upon from the top down. They emerge naturally and collaboratively. Their goal is not solely to treat disease, but also to prevent it, and to promote health and wellbeing in a holistic way.

The AAL Programme with its partners has brought together a broad range of stakeholders engaged in such ecosystems to discuss the implications of the emergence of health and care ecosystems, opportunities and pitfalls based on concrete examples from the daily practice. Much work lies ahead, many questions need answers, which have been put forward during the event:

How can we increase awareness of health and care ecosystems?

How do we ‘manage’ them, from a governance perspective and practically?

How do we engage and activate ourselves in them?

How, in short, do we design more resilient health & care systems, beyond the pandemic?

The needed system transformation is aimed simultaneously at the micro-meso- and macro- levels. Health & care eco-systems connect these different levels, providing new roles and opportunities first and foremost on the demand side; citizens, customers and patients that are actively engaged in improving their own well-being and in caring for others. Organisational processes and structures on the supply side need to follow these evolving needs.

Organisational processes require structural change at the organisational level of health and care suppliers (policies, practices, resource flows), relational change (connections, power dynamics), and finally transformative change of mental models.

*“The Water of Systems Change: Action Learning Exercise”, John Kania, David Garfunkel, Hayling Price*

## Exploring complexity – The European Welfare System House is on fire

*The following section reflects a panel discussion with Riina Sikkut, Dr. Oliver Gröne, and Professor Eve Mitleton-Kelly, led by Klaus Niederländer, AAL Programme, and Petri Uusikyla, University of Vaasa.*



*Top left: Klaus Niederländer, AAL Program, Petri Uusikylä, University of Vaasa, Riina Sikkut, MP, former Minister of health, Estonia  
Bottom left: Dr. Oliver Gröne, Co-Chairman of OptiMedis, Germany, Prof. Eve Mitleton-Kelly, Cambridge University, UK*

Through greater awareness and understanding, through methodology and rigour but above all through personal and organisational experience, eco-systems can become drivers for systemic change & transformation. But first, how can we better understand complex systems? How do we navigate complex systems? How do we integrate ourselves in them, and become co-creators?

### Clinical micro-systems – Complexity calls for integration

Exploring complexity begins with analysing a system at the smallest unit level. The **clinical**

**micro-system** thinking, a term coined by Professor Nelson at Dartmouth, illustrates this micro-level approach. The clinical micro-system is the building block of every healthcare system. It's the place where patients, families, and care teams meet. It's the frontline care, which encompasses a small group consisting of support staff, technology, processes, and recurring patterns of

Successful clinical micro-systems have five things in common.

1. They are **focused on the patient**, and work very closely together.
2. They are also **focused on the staff**. The staff feel important and that their work is valued, regardless of their place in the hierarchy or seniority.
3. They require excellent **leadership**. Anyone can be a leader, be it a nurse, a doctor, or an administrator.
4. They **emphasise providing good care**; both in processes and outcomes. There is a continuous effort to improve results, i.e. the health benefit to the patients.
5. They make use of innovative, standardised, and user-friendly **information technology**, as well as **effective communication**.

*Eugene Nelson, D.Sc., Dartmouth Medicine, Summer 2006  
[https://dartmed.dartmouth.edu/summer06/html/what\\_system\\_05.php](https://dartmed.dartmouth.edu/summer06/html/what_system_05.php)*

information and behaviour and results. The patient who is central to every clinical microsystem.

Complexity arises where, for instance in cancer care, a recurring loop of 15 to 20 micro-systems are found working together in the **care-pathway** of the patient: screening, oncology, surgery, pathology lab, education, shared decision-making, etc. The challenge lies in managing the complexity of this clinical micro-system chain, their inter-connectivity and mutual influence or co-evolution. The huge complexities at the micro level are indicative of even greater challenges at the macro level.

**In practice:** One way of changing the mindset is to look at the problem in a broader way. We need to establish **integrator units**. These are teams whose task it is to harmonise systems. We assume that just passing along information between units will do the trick. However, people need to actively manage these linkages, beyond simple data transfer. Integrator units should be given the responsibility to harmonise the system's various components.

### ***Fear of failure?***

At the organisational level there exists a fear of failure, which keeps health professionals and policy makers from experimenting. This applies to the clinical setting, all the way up to the ministries. Changing established methods requires analysing a problem at its core, without looking at existing solutions, to experiment with an open mind. Convincing people to do this takes leadership.

Estonia came up with **innovation teams** that work across silos. The starting point was 'solving complex

*"A look at decades-long patient safety statistics reveals that on average 10% of all hospital admissions lead to some form of harm. At the system-level, we see that resources are limited, yet studies indicate that 20 to 30% of what is being produced in the health & care system is waste. Failure to look at the whole results in expensive fragmentation, duplication and inefficiency. Germany has excellent professionals, yet linkages between clinical micro-systems are still weak."*

Dr. Oliver Gröne, Co-Chairman of OptiMedis, Germany

*"Innovation and experimentation are fundamental. We need to continuously explore the space of possibilities."*

Prof. Eve Mitleton-Kelly, Cambridge University

***Organisational sustainability does not mean sustaining the status quo.***

It is an ongoing dynamic process of co-evolution and learning within a changing environment. New structures and ways of working are developed to – continually – adjust to a changing set of conditions.

*"People who co-create in the health & care system need to have an open mind, but also a common starting point: patient welfare and data confidentiality are paramount to name a few. A balance must be struck between the freedom to experiment, the right to fail, and a basic shared framework."*

Riina Sikkut, MP, former minister of health, Estonia

problems', tackling for instance improving the cancer care pathway, or increasing traffic safety. Looking at resources or the need to change the legal framework derived from this starting point. This way they were able to engage the problem with fresh eyes. It's much easier to rally stakeholders, in this case coalition and opposition parties, around a solution that has been shown, empirically, to work. One challenge is that many people have great ideas but have little experience in collaborating or actively advocating for their ideas.

Leadership and the creation of an enabling environment for change are necessary but not sufficient. The idea of '**continuous change**' needs to be embedded within the organisational culture, through a different way of working, relating and thinking. Leadership is key to fostering learning in organisations, as well as co-creating enabling environments that facilitate learning.

Prof. Eve Mitleton-Kelly of Cambridge University developed an innovation process, the principle and methodology of which has been used at different scales, from a team to an entire organisation, from fixing healthcare to global issues like deforestation or overfishing. It consists of three main steps:

1. **Understand the problem in depth.**  
Making assumptions and jumping to solutions is an all too human reflex, which leads to repeating mistakes of the past. Complex problems exist in multiple dimensions: political, technical, cultural, financial, social, etc. How does change in one dimension impact another?
2. **Co-evolution\***: We get overwhelmed and paralyzed by the sheer volume of problems. To overcome this, we zoom in on inter-connected clusters, and analyse what happens when we introduce change in one aspect. One or two clusters can serve as the starting point for decision making. Because everything is interconnected, you end up addressing a lot of other issues at the same time.
3. **Complex problems don't have simple solutions**, but can be addressed effectively by co-creating an Enabling Environment which includes an enabling infrastructure. What are the skills, resources, etc. that are needed to address a problem, today and tomorrow?

*"Before you disturb the system in any way, watch how it behaves."*  
Donella Meadows

\*Co-evolution is reciprocal influence which changes the behaviour of the interacting entities.

**In practice:** you bring together a small representative team, which means looking at a cross-section of an organisation. Multiple viewpoints are crucial. Then you ask straightforward questions, trying to

*"Every system is perfectly designed to get the results it gets."*  
W. Edwards Deming

*"We cannot assume a linear system. We need to provide space to adapt systems to a local context. You have to **pilot every time** in every new context where innovation is implemented. The human touch remains critical. This way, change will be embedded, not just be the icing on the cake."*

Dr. Oliver Gröne, Co-Chairman of OptiMedis, Germany

understand how each team member perceives the problem to be. One key question is: What happens when we change this or that? What would it take to do things differently? It's a very practical approach towards inviting people to think in a different way.

## Estonia's recipe for success

Estonia has been comparably lucky. Upon the country's independence in 1991 few legacy systems existed. Today, citizens have a lot of **trust** in the state and towards digital solutions and data collection.

Challenges remain: While a lot of data is collected, not enough of it is used to inform decision-making. Digital solutions are geared toward reducing paperwork, improving efficiency, but there isn't enough attention to what happens in other parts of the system. Inter-connectedness is underappreciated.

Reimbursements of prescription medication in Estonia have been fully digitised. People no longer have to keep track of their spending or apply for reimbursements. Benefits kick in automatically at the pharmacy when the 300 Euro spending threshold is reached. Unexpectedly, in addition to simplifying people's lives, the number of people spending more than 300 Euro on medication dropped from 17.000 to 120, substantially lowering people's out-of-pocket spending burden.

## One-day clinic

In the U.K. the first point of contact of a patient is their general practitioner (GP). The GP might send the patient to a specialist; tests follow, and the patient returns to the GP to discuss the results. They often go back and forth for weeks, sometimes months, until the patient is diagnosed and a treatment started.

One hospital executive decided to cut the Gordian knot, creating the one-day-clinic. The patient enters in the morning. By the end of the day, all the tests are done, resulting in a diagnosis. To achieve this, everyone involved had to radically adapt their thinking. A lot of this process came from experimenting. Solutions arose spontaneously, often unexpectedly.

Pursuing change in a community is about tactics, **coalition-building**, and **advocacy**. One needs to think through the implications of proposed changes on other parts of the system. Every organisational change implies winners and losers who need to be convinced of new ways of doing things.

**Creating** space for reflection and coalition-building is equally crucial. High workloads too often make it impossible to sit down and think about systems.

*"Leadership is not just people at the top. Allow for distributed leadership to develop. An enabling environment lets leaders emerge for particular tasks. The system benefits from their particular viewpoint."*

Prof. Eve Mitleton-Kelly, Cambridge University

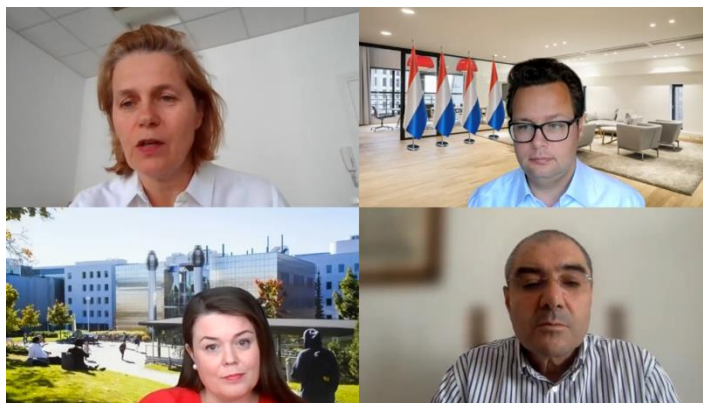
Recommended reading: <https://www.oecd.org/health/health-at-a-glance-europe/>



## Designing & framing more sustainable welfare systems

*The following section reflects a panel discussion with Ulriika Leponiemi, Herko Coomans, and Prof. Pietro Siciliano, led by Sophie Schmitt-Crespel.*

Notwithstanding differences among national welfare systems, European healthcare policies share similar objectives such as the need to promote healthier environments, to better respond to patient needs, to advance equal access to services and at the same time to ensure financial sustainability of the system.



*Top left: Mrs. Sophie Schmitt-Crespel, Seniosphere Conseil, France  
Bottom left: Ulriika Leponiemi, Tampere University, Finland  
Top right: Herko Coomans, Ministry of Health, Netherlands  
Bottom right: Prof. Pietro Siciliano, IMM-CNR and National Cluster SMILE, Italy*

The recent COVID-19 crisis has brought into sharp focus the fact that European healthcare systems share the same limits and weaknesses, in particular linked with an ageing population and digitalisation.

A new approach is needed. Different models, applied at different scales; cities, regions, countries, and Europe, can lead the way. The challenge for the future is to find sustainable institutional, organisational and technological policy frameworks that can generate better health and well-being for all. In other words, the objective is to design more effective and sustainable welfare systems without compromising quality or efficiency.

What can we learn from novel governing models aimed at harnessing this complexity, challenges and opportunities, that have been applied in different countries?

### The Netherlands: an emerging inclusive governance approach

The Netherlands have created a good but complex system. It's a decentralised model, with a key role for private organisations, funded through mandatory health insurance. Given that in 2011 parliament prohibited the establishment of a national health governance system, an alternative **national health information council** came into being. This is a governance board that includes patients, payers, healthcare providers, professionals, and government. 20 different stakeholders represent their own interests yet working towards

#### Listening to patients

Patients /users/citizens should be included at every level. At the local implementation level this is easier than at the policy level.

In the Netherlands a **CEO – Chief Experience Officer Council** – was created where patient advocates are given access to training, emerging policy proposals before they are sent to parliament, let alone voted into law. Taking patients seriously is taken seriously.

common goals. It has worked on interoperability and making sure data is at the right place and available to those who need it. The council gave rise to what is called **blended services**: providing care where it is needed – less often exclusively inside hospitals, and increasingly at home. Another objective was to give patients access to the data to improve their own health decisions.

The governance board is not based on a law. It does not have a mandate, consisting solely of ‘meetings’ on all aspects of healthcare, including elderly care, clinical care, primary care, and mental health care. The intrinsic motivation of the different stakeholders makes it sustainable. The government is involved as a partner rather than top-down. The board’s actions and results garnered trust and authority, attracting more stakeholders. The structure that emerged has now become an ‘authority’ that guides or allocates about 1 billion Euros in health and care investments. In all this, trust and collaboration, and the realisation that a bottom-up approach yielded better results than a top-down approach was key.

#### → EUROPEAN LEVEL

Everyone is evaluating their national health systems. The Netherlands looks to Europe for guidance and boundaries. The European digital single market approach to data entails a variety of new legislations, on AI, data governance, the operation of large platforms, or the secondary use of health data. Connected to the European health data space is the European recovery and resilience fund. A part of its 800 billion Euros pertains to health as a way of building resilience. AAL could provide guidance as to what happens with these funds.

#### Italy: regional assistance technology clusters within national super-cluster

Italy has been a forerunner in clusters: a public-private aggregation of companies, research centres, universities, and other stakeholders. The clusters, set up under the aegis of the ministry of education but also supported by the regions, are meant to function as engines for the sustainable development of healthcare services. They currently have over 200 members. Clusters are not just about collaborating between different stakeholders, but also supporting the government in certain initiatives, to create synergies between the public and private sectors, and attracting additional resources for user-driven innovation.

*“Think big - we share challenges and solutions. Act small - make it relevant for the user. Start today - don’t wait until you have all the answers. Experiment!”*

Herko Coomans, Ministry of Health,  
Netherlands

#### Challenges

The COVID-19 pandemic has shown that health systems need a bottom-up redesign to better respond to citizens’ needs. Increased pandemic-preparedness is just the start. Globalisation facilitated the lightning-fast spread of the pandemic, pointing to the need of more centralised management of health and care, as opposed to the current large autonomy of the regions in Italy. To this end, the national government envisions among other things the creation of

*“Enough research has been done. It’s time to deliver. Time for large-scale deployment of technology, digitalisation, and integrated care.”*

Prof. Pietro Siciliano, IMM-CNR and National

national health & care hubs to create in-home monitoring of older adults living alone. The aim is to improve their quality of life and independence by detecting early signs of illness, functional decline, or emergencies, using non-intrusive, privacy-preserving smart sensor systems.

### Finland: Linking local healthcare with regional and national levels

Like most European countries, Finland is confronted with an ageing population. As an added challenge, the country is extremely sparsely populated. Its 310 municipalities are responsible for organising healthcare and social welfare services, alone or in joint municipal authorities. In addition to the public sector, services are also available from the private sector. Third sector organisations play a major role in the provision of services supplementing public services.

In a bid to improve efficiency, the government plans to move health and care from the municipalities to 21 regional governments (counties). This reform comes on the heels of attempts at reorganising health and care. The first reform attempt; the National Health Project, started in 2001. Each subsequent government has since tried to implement its own reform.

While decision-making at the national level drags on, some actors on the ground are waiting for solutions to their problems. Others, like the Tampere region, are taking action. Whereas Finnish municipalities are very different, historically, culturally, topographically, and socio-economically, in Tampere conditions are favourable for quicker decision-making: education levels are high, and the population is small: proximity enables easier decision-making.

While the need for services increases, there is a limit to how much can be done. Digital tools can bridge the gap. For instance, the KEHYS-project pilots the deployment of a digital tool for two service chains: substance abuse and diabetes. Patients are divided into four different groups based on symptoms, coping mechanisms, and other factors. Services are tailored to these groups' different needs: **One size does not fit all.**

#### Why do we need innovative ecosystems?

- Close the gap between needs and resources
- Improve productivity and cost-efficiency
- Facilitate new business models, RDIs, partnerships, customer-centric approach
- Accommodate and harness disruptive innovations

*"Local actors have lots of expertise and knowledge. They need to be heard."*

Ulrika Leponiemi, Tampere University,  
Finland

#### KEHYS. Kehitämme yhdessä project

*An effective RDI environment for the social and health care sector.*

The aim of this project is to build a model for an active RDI ecosystem in social and health care to promote customer-oriented, integrated and digital services in the Tampere region. The aim is to facilitate the integration of stakeholders; clients/patients, companies, start-ups, researchers, decision-makers into the ecosystem.



## Eco-system Learning Journey – achieving greater collaboration

*The following section reflects a panel discussion with Marit Tanke, VGZ Health Insurance, NL, Jelle van der Weijde, Regional Development Authority Utrecht, Netherlands, Nico de Fauw, In4Care, Belgium, Malek Bouhaouala, Ageing Well eco-system Grenoble, France, Antonio Lindo da Cunha, Instituto Pedro Nunes, Portugal, led by Victor Haze, Health Valley, Netherlands.*

### Understanding & defining healthcare ecosystems

A digital healthcare ecosystem is an infrastructure that supports the shift from an organization-centric to a patient-centric model of delivering healthcare services using digital platforms. The primary goal of this system is to encourage cross-organizational, multidisciplinary, and collaborative healthcare delivery.

*“Eco-systems have a hidden strength to transform individual capacity into collective capacity. The whole is more than the sum of its parts.”*

Antonio Lindo da Cunha, Instituto Pedro Nunes, Portugal

*“Collaboration is the new innovation. No one can do it by himself.”*

Jelle van der Weijde, Regional Development Authority Utrecht, NL

*“Some activities are too complex for companies alone to produce desired outcomes.”*

Malek Bouhaouala, Ageing Well eco-system Grenoble, France

*“An ecosystem is a community working towards a common goal. It’s about connecting people more than connecting organisations.”*

Nico de Fauw, In4Care, Belgium

### Health hub Utrecht

The health care sector in the Netherlands suffers from high costs, a shortage of qualified personnel, among other issues. To address these complex issues an ecosystem on health and well-being consisting of all health-care providers in the province, health insurers, 25 health organisations, and advisory boards was set up. By providing innovative solutions to have the right care at the right place by the right people, the goal is to make Utrecht the happiest and the healthiest region in the Netherlands by 2030.

## Experimentation

How can we bring people together to overcome societal challenges, and at the same time enabling the emergence of new business models?

Experimenting or learning – together – by doing can be a powerful catalyst for robust change. Coming up with interesting ideas is only the first step. The real challenge is implementing them. This is where the ecosystem comes in. Innovation hinges on multiple stakeholders agreeing to a course of action. One party cannot do it alone.

Crucially, a balance must be struck between innovation and preserving what works. For providers, innovation is interesting, but a patient just wants a treatment that works. An ecosystem is not oriented exclusively toward innovation. Developing new products comes second to creating better outcomes for patients.

### Bringing in start-ups

Most health start-ups bring an individual perspective to the table. They don't see the benefit of being part of an eco-system. To engage them, we need to bring early adopters. For instance, some care-givers are eager to adopt new technologies. Such divergent stakeholders can be connected among other things through conferences to promote products.

## Distributed leadership

Leadership is crucial, but we need to move beyond the classical hierarchical notion of leadership. Leaders, people who identify issues and advocate for their resolution, can be found at every level and in any sector. In a true ecosystem, different organisations can contribute to 'leadership' on specific topics, striving towards a common goal.

Inside a network, different organisations are at different levels of innovation. Some are leaders, most are not. To cater to these divergent groups, connecting leaders is crucial.

Leadership is closely related to inspiration. Leaders can inspire others to 'jump the fence' toward adopting new technologies and practices, to innovate, and establish connections.

### Rapid changes versus long-term thinking

An ecosystem is per definition something that transcends projects or programmes. But long-term road-maps need to be broken down into shorter, manageable bits.

Change seems to be accelerating. Some established healthcare providers almost function like a start-up. Some things do stay the same, but new things are introduced continuously. A tension exists between staying flexible but also building something that is future-proof.

### A slow regulatory environment can be a spoiler.

*"We have to publish our plan first, before we start implementing. Meanwhile the world has already changed. So how do you catch up with that?"*

Marit Tanke, VGZ Health Insurance, NL

## Trust

While the technical conditions for the emergence of health and care ecosystems are relatively easy to set up, cultivating an atmosphere of trust is a much more challenging endeavour. Among critical trust-building traits are transparency, reliability, relations between citizens and health and care providers, competency, leadership, and fairness, to name but a few aspects. Building trust is everything, and it is an absolute prerequisite to establishing long-term partnerships. Where trust is established, synergies follow.

In order to maintain **trust in the processing of personal data**, individuals must:

- be able to monitor the processing in real time;
- stay informed on the phase and scope of the processing of their data;
- be given an opportunity to withdraw their consent in real time;
- have a guarantee that their data is protected by default, meaning that the control over data is as easy as possible;
- have the authority to control who, why and for what purpose their data is used.

## Spreading use cases & best practices

Best practice resources need to be actively promoted. Simply building databases and focusing on explicit knowledge is not sufficient. Databases relate to examples and people, but it is through people that deep knowledge is transferred. To advance the spread of use cases, best practices, and tools that have been shown to work, connections inside and among ecosystems can be a powerful tool. 'Hubs' can play a role in this, but also the 'brand' or reputation of particular ecosystems and networks. When it comes to start-ups who don't have a track record to inform potential partners of success stories, ecosystems can be instrumental to opening doors.

## Role of government

Transforming healthcare toward more prevention means, among other things, that some stakeholders will grow, while others shrink. Government can play a role in facilitating this difficult process, not just by providing extra external funding, but by establishing necessary frameworks, for instance to guide the setting up of ecosystems across national borders, but just as often, by stepping out of the way. Regulation needs to catch up with vast technological and cultural changes underway in the sector. This comes on top of the classical role that government plays in healthcare in terms of education, capital investment, etc...

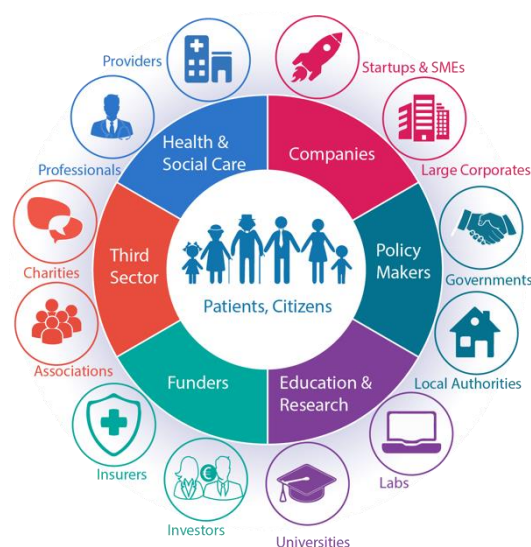


## Health & Care data ecosystems

*The following section reflects a panel discussion with Martina Thelen, Gesundheitsregion Koeln/Bonn, Germany, Henrike Gappa, Fraunhofer-Institut, Germany, Erik Gehl, HAKISA, France, Conchita Kleijweg, ehealth competence center, Netherlands, Rauno Mäekivi, Ministry of Social Affairs, Estonia, led by Dr. Alexia Zurkuhlen, Gesundheitsregion Koeln/Bonn, Germany.*

In Europe a growing realisation kicks in that the digital transformation is crucial for bridging the gap between increased demand for health and care services and scarce funding, and overall to providing better, more patient-centric care. Moreover, the global COVID-19 pandemic has undermined traditional face-to-face healthcare delivery models in most non-emergency situations, leading to an accelerated adoption of digital solutions like virtual consultations and remote patient monitoring.

At different levels numerous policies to help drive the adoption of digital solutions have been initiated. Within and between countries, progress has varied, hampered by different standards, privacy issues, or a failure to fully harness exploding amounts of data.



Source: Digital Health Malta Ecosystem Gathering, 2018 – ECH Alliance eco-system graph

As regards the adoption of digital health technologies by health professionals and patients alike, trust is key, as is inclusiveness. No one should be excluded. As a next step, leaders across the health system will need to agree on how innovation is funded, and which technologies and standards are most effective. A robust ICT infrastructure should provide secure and equitable access to both the technology and the generated data.

So far, experience indicates that ICT solutions are best tailored at and to the needs of the regional level, cognizant of the diverse needs of healthcare, social and home care recipients and providers. At the same time, true interoperability between data systems will enable the establishment of connections, infrastructure-agnostic flexibility, the exchange of ideas, and the harnessing of data for research purposes. Ultimately, every level needs to formulate an appropriate response, fitting the right technology to the

Citizens are no longer prepared to be passive recipients of care but expect health and care services to be available when and where they are needed. While people increasingly use technologies to access services and monitor their own health, many also want to own their own data and decide who to share it with. However, existing divides in digital health literacy risk exacerbating health inequalities

*“Technology will play a substantial role in making healthcare truly predictive, preventive, personalised and participatory.”*

Alexia Zurkuhlen, Gesundheitsregion Koeln/Bonn, Germany

appropriate domain, be it AI and machine learning in diagnostics, or cloud solutions for organising human resources or patient data.

10 years ago, a first attempt by the **Netherlands** to set up a national health-record system floundered in the courts due to a large extent to privacy issues.

In a second phase, alternative, bottom-up initiatives started emerging, connecting providers, companies, public-private coalitions. So far, none of them have been able to scale up.

In the current third phase, the government is trying to introduce interoperability, a unity of language and technology, overseen by certified bodies, forcing health and care providers to use a digital exchange of health data for designated use cases. The infrastructure will be designed to be open to all kinds of exchanges, taking into account international standards.

## Building trust

How is data flowing through the system? Is it coming from one or more applications? Is it limited to a single sector? Who owns and/or controls it?

To enable the sharing of data among hospitals, elderly care organisations, GPs, and the patients themselves, HIMMS Netherlands started working with suppliers, innovators, universities, policy makers, regional organisations, insurance companies, to identify the main obstacles. A national programme, from the ministry and insurance companies, set out to entice hospitals to implement standards. The

The **FHIR**® (Fast Healthcare Interoperability Resources) standard specifies how health and care information can be exchanged between different computer systems irrespective of how the data is stored in those systems. The system, developed from 2012 onwards by the standards development organization **HL7**® (Health Level Seven®3) using a collaborative approach, allows healthcare information, including clinical and administrative data, to be available securely to those who have a need to access it, and to those who have the right to do so for the benefit of the patient.

### Infrastructure-agnostic

The realisation has grown that data infrastructure needs to be separate from the applications and from the provided services. In this model, the applications need to use open API's to exchange – mainly cloud-based – data. Competition will take place in functionality and services.

An additional aim of this model is to stimulate regional cooperation and a market for start-ups and enterprises, where they can innovate and diversify, and to have a healthcare system that produces optimal outcomes for patients.

### HIMMS

The Healthcare Information and Management Systems Society is an American not-for-profit organisation dedicated to improving health care in terms of quality, safety, cost-effectiveness and access using information technology and management systems.

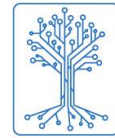
*“What are the building blocks that we can reuse again and again? Could we envisage the government supplying them for free?”*

Conchita Kleijweg, e-health competence centre, Netherlands chair of HIMMS

suppliers of the ICT systems are to build in the standards, learning from daily practice, and improving incrementally.

### Inter-generational platform

Hakisa.com was founded as an inter-generational mediation platform to help bridge the digital divide. This Community Engagement Management (CEM) platform aims to protect digital communities that are fragile and close the divide between the ‘classical’ digital world and newer platforms like the Internet of Things, or AI applications. In all this, data protection is paramount. Hakisa mediates between these concrete needs and sensitivities, which in the end are not about the technology, but about organisation, local ecosystems, and connecting humans and technology.



**GAIA-X**

The **GAIA-X** project aims to create a secure and transparent European data infrastructure. In this digital ecosystem, data and services can be made available, collated and shared.

The underlying goal is to entrench European values, including the idea of an open and federated ecosystem of cooperation and collaboration in contrast with the Chinese model of heavy government control of domestic markets and buildup of national champions, and the US model of uncontrolled corporate domination.

*“Amazon has won retail. Let’s not give them health care as well. We can do it if we do it right.”*

Mr. Eric Gehl, Hakisa, France

### Three layers of data

A successful solution should encompass the wider community, not merely be aimed at seniors. Social and home care arenas are very diverse. For this reason, frameworks or platforms, including those aimed at incubating and attracting durable business models, should adopt a regional hub philosophy, incorporating three layers of data:

1. healthcare data
2. real-life data, collected by home nurse for instance.
3. social data and social networks; everyone’s on social media, even the seniors.

### Trust

In order to set up a successful platform you need to understand who are the informal helpers, who are the health and care professionals, who is healthcare-driven, who holds which data, and who plays which role. Home care is a sensitive environment that has taken decades to emerge. Convincing people to engage with a digital platform requires above all trust.



## E-health, usability and accessibility, a work in progress

### Home care

Currently, not much data is available concerning home care, or on which interventions are suitable to preserve home care, or prevent worsening of the home care situation.

Home care consulting visits are already a part of the German care system, but data is not always gathered in a standardised way or made easily available to all concerned. With a digital tool, nurses can easily follow up on what's working, and what is not.

#### Accessibility

Many people **'just Google it'** when searching for information about health issues, leisure, certain products, etc.

For many people, however, the Internet is not so easily accessible. They cannot find their way around a Web site, or the assistive technology they need to access Internet-based information experiences technical hiccups. This is particularly true for older and handicapped people.

Applying the methods and techniques of barrier-free Web design can change this. This includes for example the removal of unnecessary features to simplify the number of levels and options and reduce the load of navigation using what is called shallow hierarchies.

#### INGE – integrate4care

INGE is a digital service platform to support informal caregivers and to safeguard the quality of home care. It has among other things set up home care counselling visits. Professional nurses assess the health situation of the person in need of care and the resources available for care-giving, and recommend improvements: ex. suitable medical aid or a fall prevention programme. The secondary aim is to reduce the burden on informal caregivers, enabling longer at-home care, taking into account the needs of all the people involved.

The platform for care-giving relatives, patients and health care providers facilitates access to available documents as needed. An assessment app for nurses:

- monitors care history, suggests interventions
- enables continuous care planning
- summarises counselling visit for other health care providers to facilitate cross-sector cooperation to help prevent faulty diagnoses, misguided therapies or double prescriptions.

*INGE is also FHIR®-compliant*

*"When linking data and people, standards like FHIR are key, but the reality is always more complicated."*

Henrike Gappa, Fraunhofer-Institut, Germany

### From disaster to opportunity

A tool to aid elderly, locked down at home during the COVID-19 crisis, and alleviate isolation, grew into a regional healthcare / homecare platform, integrating social data, real life data, fragility indicators and other 'dashboard'-like information collected by formal and informal helpers, featuring nutrition alerts and social depression alerts – all of the above interoperable and co-developed with the regional healthcare platform.

### Electronic health records in Estonia

Estonia established its first electronic health records in 2008. This happened in three phases:

1. The first phase was strongly government-led and administered. ICT enthusiasts and companies took over. Getting the providers to connect was a challenge.
2. Trend towards a more user (medical staff) - centric model.
3. Grown into a naturally evolving ecosystem, transcending classical management models, encompassing health practitioners, the social sector, patients, researchers, local and international entrepreneurs.

#### First mover advantage / disadvantage

Estonia is seen as an early innovator. Currently, healthcare providers can make use of a well-established national database. Its success – over a thousand suppliers are connected – at the same time makes it difficult for instance to implement upgrades. What was avant-garde ten years ago is considered a legacy system today. As many ecosystems are converging on the FIHR interoperability standard, Estonia is taking first steps towards FIHR while still working with its predecessor CDA.

### Integrated services and GDPR

Establishing data interoperability has been a challenge for many years: integrating services, and hence, merging social care data, health data, social data, etc. remains out of reach. Fundamental questions arise: Who needs to see what data?

*"GDPR is seen as a constraint, but it's also a useful framework. The principle is solid: the person owns the data."*

Rauno Mäekivi, Ministry of Social Affairs,  
Estonia

The only way to navigate GDPR is by looking at data at the granular level: **Selectively sharing is caring**. Obtaining consent to connect third party applications into the national data stream represents a challenge. To resolve this, Estonia is working on an application to automatically send compliance requests to individuals on a pinpoint basis along the patient pathway.

### From gathering data to figuring out what to do with data

On the collection side, improvements can be made, for instance by implementing speech and natural language text input. But once we find ourselves confronted with exponential amounts of data in proliferating databases – cloud-based or otherwise – the question arises: what to

do with all this data? How can we leverage this data to create better outcomes for citizens? How can a GP sift through 5 years' worth of patient data? Processes need to be developed to automatically summarise data. Most likely these solutions, like patient risk stratification based on data and statistics, will be AI-based.

### Cooperation at the regional level works

Gesundheitsregion ('health region') KölnBonn e. V. is one of six regional health industry cluster organisations in the German state of North Rhine-Westphalia. Founded in 2009, the association links 130 companies, institutions and organisations across sectors aimed at jointly exploiting the opportunities of an innovative healthcare industry and improving the quality of care in the region.

The 'health region' sees itself as a door opener or innovation scout, providing a space, in the form of working groups or events, to think about health and data ecosystems, linking the public sector with the private sector.

*"The only way to innovation is by testing things in the real world. This is easier done on the regional level, when you know the people."*

Martina Thelen, Gesundheitsregion  
Koeln/Bonn, Germany

### Hub-philosophy

While building a health & care ecosystem, social factors are more important than technical issues. The focus in Health Region KölnBonn is on building agile, open, trusted, disciplined, and innovative communities. The Hub-philosophy points the way forward: bottom-up initiatives in the region drive the process of tackling shortcomings in the organisation.



## Integrated Health (Social) Care

*The following section reflects a panel discussion with Hien Nguyen, Novartis, Germany, Dr. Eduard Maron, DocuMental, Estonia, Niclas Forling, Vaesterbotten Region, Sweden, Bengt Andersson, Nordic Welfare Center, Sweden, and Miriam Jern-Matintupa, Vaasa Hospital District, Finland, led by Oliver Stenzel, ScanBalt, Germany.*

### Integrated welfare regions in Finland

The Aster Bothnia project in the Vaasa hospital district aims to achieve more common processes in health and social care. To support this, a joint client patient information system (CPIS) is implemented, together with 3 other regions in Finland.

*“Integrated care is about creating care and services and flow of information seamlessly around the patient/client so that their needs are met as a whole, along a unified health and care path, and not as separate pieces.”*  
Mirjam Jern-Matintupa, Vaasa Hospital District, Finland, organisational change manager

The aim is to create more possibilities for clients to take part in their own care by digital means. The CPIS tool is adaptable and configurable. The provider is an international provider, able to infuse the project with a bird's eye view and a means to compare progress with other regions. What are the commonalities that can be copy-pasted, and what is specific to one region requiring tailor-made solutions?

#### Under the same roof

As part of an ongoing Finish health care reform, preparations are being made to set up the **Ostrobothnia** welfare region. All of the region's social and health care services will be brought under one roof. The focus is on creating a service that is modern, client-centric, sustainable, and leads with knowledge.

#### Structured subjects

At the beginning of the **Aster Bothnia** project a plan was drawn up, focusing on making including clients/citizens. The plan will be used as a control as the project is implemented. One tool to achieve this consists of 'structured subjects'. The question is not: what do you want from healthcare? Rather, it's focused around a specific topic. How would you like to contact your healthcare provider?

#### A common European understanding of integrated healthcare emerges:

- patient-centric
- patients are empowered
- integration with social care
- demographic evolution seen as a common threat
- connection with climate and sustainability
- distinguish between commonalities and transplantable tools across regions and countries and area-specific circumstances that require investment in tailor-made solutions.

By looking for commonalities across subjects, more automatization can be introduced. There is high involvement of a cross-section of the professionals themselves: nurses, physicians, specialist, administrators, secretaries, etc. to boost representativeness.

### Health and care at a distance

The 'Healthcare and Care Through Distance-Spanning Solutions, 2018-2021' -project aims to improve the Nordic population's accessibility to good healthcare and social care, regardless of where they live. It creates the conditions for development and growth in rural areas as well as around major cities. ([www.healthcareatdistance.com](http://www.healthcareatdistance.com))

Much of this experience is transferrable to other regions of Europe. What works in the Nordic countries with relatively low complexity levels, can definitely work in cities across Europe.

*"There are too many silos: secondary care, primary care, social care, home care, psychological care. We need to whittle it down to integrated health care. We have to do it because it's better for the patient and because it's more efficient. The coming demographic challenge makes it imperative."*

Bengt Andersson, Nordic Welfare Centre

#### Hospital -> Home

A recurring trend in Europe is moving healthcare into people's own homes. This way, less health infrastructure is needed. This is particularly useful in sparsely populated areas, but can be implemented everywhere. The impact on the climate-footprint of hospitals is substantial.

#### Infrastructure

In sparsely populated areas infrastructure is critical. You cannot move healthcare into the home if the home is not connected. Conversely, a constant connection is not needed if nearby or temporary hotspots are available. Ultimately, culture and leadership are more important than infrastructure.

#### An implementation ecosystem integrates:

- investment support
- Implementation process support
- Service innovation and implementation
- Leadership
- Training of staff and citizens (Welfare technology – ABC)
- Informal and formal networks, exchange of knowledge
- Structured follow up, analysis and recommendations for wider implementation.

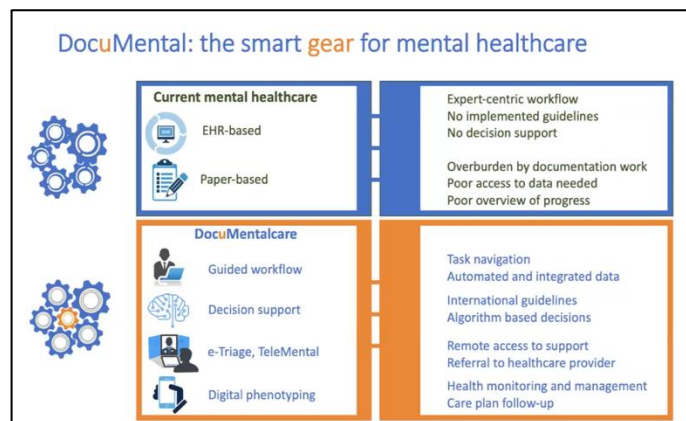
*"It's crucial to include the informal care givers, indeed to include the entire family."*

Niclas Forling, Vaesterbotten Region, Sweden

### Patient-centric mental healthcare in Estonia

Looking at the statistics on mental health, one is tempted, in the wake of the COVID-19 crisis, to speak of a mental health pandemic. Despite advances in digitising Estonia's general health

and care system, the mental healthcare space is still largely paper-based, and lagging in other areas. Psychiatric care is heavily expert-centric, hampered by long waiting lists and poor follow-up. GP and primary care is are hampered by low diagnostic accuracy and poor data access. Psychological care is poorly integrated, and lacks data access, while private clinics are overly expensive and inaccessible to most people. So-called mental health self-management apps raise privacy concerns, and are disconnected from healthcare providers.



## Thuringia on target

The aim of this project is to jointly improve outcomes for patients with ST-elevation myocardial infarction (STEMI), and to improve secondary prevention for people with high cardiovascular risk.

**DocuMental**, a company set up by Dr. Eduard Maron, is a clinical Digital Support System (DSS), purposefully designed for diagnosis, treatment and management of mental disorders.

Cardiovascular disease concerns 13,7% of total health expenses in Germany. 18,3% of people who have suffered a myocardial infarction will suffer another within a year. Focusing on this group can diminish morbidity as well as costs.

### Moving from patient-centric to patient-driven mental health care requires:

- access to and control over own health info
- active involvement in clinical assessment and care plans
- adherence with mobile applications
- co-designing sustainable journey
- 'destigmatisation'

The key to reducing the risk of a second infarction is LDL-cholesterol- reducing medication. One of the challenges in increasing adoption of this medication is the initial increased cost, borne by one set of stakeholders, which is recuperated further down the line, representing savings for other stakeholders. Addressing this divergence in interests requires a sustained effort to get stakeholders to look in the same direction.

Most treatment deficits, however, are easily addressable by increasing communication between all care givers and patients, albeit from a patient-centric perspective.

*"Integrated care is cross-sectional interdisciplinary cooperation with a strong focus on patient-centric thinking."*  
Hien Nguyen, Novartis, Germany

*"People travel to get care across borders, for instance between Estonia and Finland. What happens elsewhere is a blind spot. How can we integrate these systems?"*  
Dr. Eduard Maron, DocuMental, Estonia (psychiatrist)

## Co-creating in the Transformation Space

*The following section reflects a final discussion, bringing together thoughts and preliminary conclusions from the different break-out sessions, guided by Klaus Niederlander, AAL Programme, and Petri Uusikyla, University of Vaasa.*

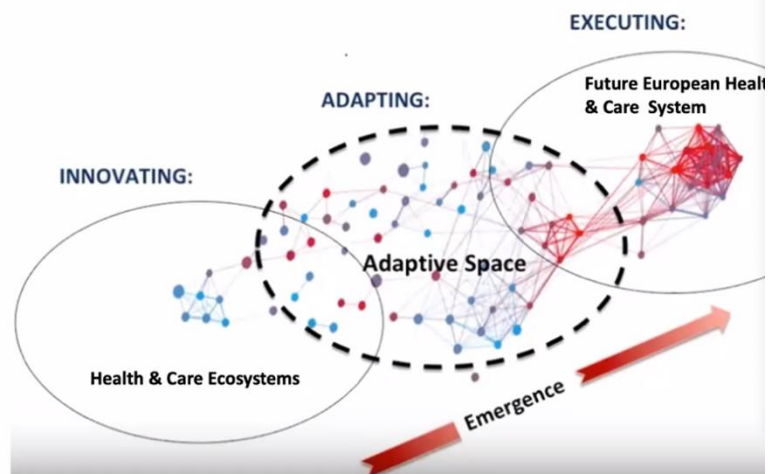
### Adaptive space

A tension exists between relatively flexible local and regional levels, and more traditional hierarchical governance and financial structures on the national and European level.

This tension is not negative per se. Competition between competing visions drives progress. Complexity leadership can identify and pursue a consensus that is then scaled up and implemented; unlike the classical model of copy-pasting best-practices from one region to another.

However, a balance must be struck between too much tension, which imbalances a system, and a lack of dynamism, which is equally detrimental. Seen from this perspective, a health and care ecosystem can be seen as an enabling environment; an open policy space where distributed leadership, emerging spontaneously on all levels to solve pinpoint issues and enabled by trust, can make real progress.

### Adaptive European Health & Care Space



*Modified from: Prof. Mary Uhl-Bien, Complexity Leadership in Organizations*

*"Change is often very personal and led at a very small level, yet when you introduce technology, that really needs scale. It's in the adaptive space that these two levels come together, catalysed by brave leaders with vision, cognizant of the fact that there is no definite answer."*

George MacGinnis, UK Research and Innovation,  
(audience)

#### **Actions:**

It's important to redesign service systems so that they take into account the patient's perspective, integrated care and care pathways, but also by bolstering citizen involvement leading to the interests of patients being taken into account at all levels.

New technologies should be harnessed, like increased use of big data, to integrate care from a system perspective.

Finally, action is needed at every level to integrate policies, integrate regional and local knowledge, and share experiences through, for instance, the AAL Platform.



## The patient comes first

What emerges is an inclusive governance approach, which includes patients /users/citizens at every level. The idea of a CEO (Chief Experience Officer) Council embodies this notion, providing patient advocates access with training, and access to emerging policy proposals at the earliest stage to reinforce their voice in the decision-making progress.

## Crucial role of regions

Regional and local governance level play a pivotal role in developing policies to enhance wellbeing, along with private, public and third sector stakeholders; a bottom-up approach toward national reforms and an emerging European coordination framework.

*“Local interventions or regional ecosystems can be used to stimulate changes at the national level.”*  
Ulriika Leponiemi, Tampere University,  
Finland

## Common threads

*Leadership is key to make ecosystems work.* People connect less based on classical hierarchical patterns, but more on energy and chemistry. You need to find the right people to get things moving. Who will inspire you to action?

*“Ecosystems are more about connecting people than connecting organisations.”*  
Nico de Fauw, In4Care, Belgium

*Tension between innovation and keeping things that work.* “This is my first time,” is not something a patient going in for a knee surgery wants to hear from his surgeon.

*“Long-term roadmaps for transformational change are best broken into incremental steps to keep things manageable.”*  
Jelle van der Weijde, Regional  
Development Authority Utrecht, NL

*Key actors or ‘hubs’ are needed to make a health and care ecosystem work.* A central node is essential to bring older and newer players together. These are different for every context, ex. the EIT Health Network or the AAL Programme & Project Community.

*Technology plays a crucial role in the health and care of the future.* While an increasing number of technology-enabled systems and services are used by healthcare providers, the scale of adoption and the types and capabilities differ widely across Europe. Citizens are seen less as passive recipients of care, accessing healthcare services when and where needed, monitoring their own health, owning their own data and deciding who to

Building successful health & care data eco-systems requires:

- establish and manage interoperable standards
- build regional frameworks/think in regional terms
- hub-thinking, trust, data sovereignty
- not just harvest data, but use it

share it with. However, a divide in digital health literacy risks exacerbating health inequalities.

### Integrated Care

Nordic countries use distance-based solutions to offer integrated care to extremely remote rural areas. Germany faces a different kind of access issue: in addition to silos between different sectors that create far from perfect outcomes, in the eastern states there is a scarcity of medical care providers that could be alleviated with distance-based care. As for Estonia, it is far ahead regarding digital solutions, but not in mental health care, which is an obstacle to integrated care.

Regardless of these different contexts, a common view emerges: People essentially face the same problems everywhere: a demographic challenge, shrinking financial means, and the looming threat of climate change.

### Micro -> meso -> macro

The needed system transformation is aimed simultaneously at the micro- meso- and macro- levels. Health and care eco-systems connect those different levels, providing new roles and opportunities for citizens, customers and patients, actively engaged in improving their own well-being and in caring for others.

### Culture of change

It's not just health and care governance systems that are lagging, but the overall mental models. In order to bridge the gap, the idea of '*continuous change*' needs to be embedded within the organisational culture. Change management; introducing different ways of working, relating and thinking is key to fostering learning in organisations, as well as co-creating an enabling environment – built on trust – that facilitates learning. A culture of change aims to nurture what emerges out of these interactions in an environment; a mix of formal and informal networks, that connects people rather than organisations, integrating the whole of society.

Europeans no longer accept different quality health care systems. We all look at Estonia regarding digital health and care, Denmark is an example for hospital reform, while Finland is ahead on the use of research data. National and regional disparities have the advantage of allowing for ***experimentation and emergence*** of successful models that can serve as examples to others.

*"Our governance systems and mental models are lagging a world that's changing at a rapid clip. Europe needs leadership and adaptive regulatory systems to catch up."*

Petri Uusikyla, University of Vaasa

### Actions:

- Long-term integrated care plans are needed to overcome silos.
- More cross-country integrated care concepts are needed as border regions of different countries often have a lot in common in terms of health needs and challenges.
- Mental health has to be integrated in integrated health and care concepts.
- Stakeholders matter: everyone has to be brought on board. Patients are the most crucial among stakeholders.
- Integrating climate in integrated care thinking: better integration means less infrastructure is needed, shrinking the overall carbon footprint.

Organisational processes and structures need to follow these evolving needs and aspirations.

The aim of the AAL Programme is, together with its current and future partners, to continue the discussion, shaping a European agenda on transforming European welfare. We need to crack the hard nuts of governance and regulations, investment, funding, but in the end it's about people sharing experiences, networking, dealing with culture, organisational differences, and bringing in collaborative leadership. A system produces exactly the outcomes it's designed for, so let's design a system to improve the quality of life for all people.

*"Ecosystems are not about beginnings or finish lines, they are open-ended."*

Klaus Niederländer

This seminar and paper are part of an ongoing eco-system learning journey that will be followed up by the European Week of Active and Healthy Ageing organised by the AAL programme in partnership with the JIP MYBL in October 2021, an international session on health & care eco-systems by the AAL Programme and Health Valley at the latter's annual event in Nijmegen, the Netherlands in March 2022 and during the European week of Active and Healthy Ageing by the AAL programme and partners in Gdansk, Poland in October 2022.



