

A SHARED AGENDA ON SUSTAINABLE HEALTH INSPIRED BY LEADING
DECISION MAKERS ACROSS THE NORDIC REGION

N O R D I C H E A L T H 2 0 3 0



TOWARDS PREVENTIVE HEALTH

CONTENTS: The New Reality of Health in the Nordics | The 5/5 Aspiration | Self-Cultivation of Health | Transformative Resilience | You Are the Key to Preventive Health | Interview: Spotlight on Finland | Nordic Data Cohesion | Interview with Charles Alessi: The Nordic Window to the World | The Nordic Health 2030 Movement | Interview with Paula Lehtomäki, Secretary General of the Nordic Council of Ministers: 2030 Vision for Nordic Cooperation | Nordic Innovation & NordForsk | What's Happening Beyond the Nordics? | The Drivers of the Transition | Personalised Health 2050 | The Rise of the Eco Individual



*We can only
eliminate
short-termism
by investing
in the future*

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H E A L T H
2 0 3 0

*Authored by The Copenhagen Institute for Futures Studies
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Nordic Health 2030 Workshop Participants, Contributors, & Reviewers

A A R H U S U N I V E R S I T Y

Carsten Obel, Professor of Children's Mental Health

B U S I N E S S F I N L A N D

Minna Hendolin, Senior Director, Health and Wellbeing

C A M B I O

Jan E. Larsson, Senior Vice President, Sales & Management

D N V G L

Bobbie Ray-Sannerud, Programme Director, Precision Medicine
Stephen McAdam, Global Healthcare Director

F R E D E R I K S B E R G H O S P I T A L ,
P A R K E R I N S T I T U T E

Tanja Schjødt Jørgensen, Senior Research Scientist and Chairman

I K T N O R G E

Nard Schreurs, Director eHealth and Smart Living

I N N O V A T I O N F U N D D E N M A R K

Peter Høngaard Andersen, Former CEO
Charlotte Videbæk, Health Consultant

N O R D I C I N N O V A T I O N

Svein Berg, Director
Mona Truelsen, Senior Innovation Adviser

N O R D I C I N T E R O P E R A B I L I T Y P R O J E C T

Anders Tunold-Hanssen, CEO and Project Manager

N O R W E G I A N C E N T R E F O R
E - H E A L T H R E S E A R C H

Line Linstad, Department Manager

N O V O N O R D I S K

Ib Groth Clausen, Principal Scientist
Martijn van de Bunt, Head of Bioinformatics and Data Mining

S C I L I F E L A B

Valtteri Wirta, Director, Clinical Genomics Facility

S E C T R A

Petter Østbye, General Manager

S I T R A

Jaana Sinipuro, Project Director, IHAN

S U N D H E D . D K

Jakob Uffelmann, Director of Innovation

T H E R E S E A R C H C O U N C I L O F N O R W A Y

Ina Kathrine Dahlsveen, Senior Adviser

T R Y G

Kathrine Bjerga Tøraasen, Head of Innovation

T H E D A N I S H C O M M I T T E E F O R H E A L T H
E D U C A T I O N

Charan Nelander, Director
Lars Münter, Head of International Project Unit

T H E D A N I S H M I N I S T R Y O F B U S I N E S S ,
I N D U S T R Y A N D F I N A N C I A L A F F A I R S

Rune Scharff Andreasen, Special Advisor

T H E R E G I O N O F S K Å N E

Tobias Schölin, Development Manager, Life Science and Health

T H E S W E D I S H E - H E A L T H A G E N C Y

Carl Jarnling, Head of Unit, Residential Services

T H E S W E D I S H R E S E A R C H C O U N C I L

Malin Eklund, Senior Research Officer

U N I V E R S I T Y O F C O P E N H A G E N

Jeanette Knox, Associate Professor, Health Services Research

U N I V E R S I T Y O F O U L U , C E N T E R F O R
H E A L T H A N D T E C H N O L O G Y

Maritta Perälä-Heape, Director and Professor
Kalevi Virta, International Network Coordinator

V I N N O V A

Elisabet Nielsen, Programme Manager, Health Division

E D I T O R I A L T E A M

Rasmus Rask, Senior Advisor
Nicklas Larsen, Senior Advisor
Patrik Henry Gallen, Research Assistant
Aron Szpisjak, Research Assistant
Manya Lind, Advisor
Bogi Eliasen, Associated Partner

C R E A T I V E T E A M

Anne Sofie Bendtson, Art Director
Melina Paulli, Art Director Assistant
Cover photo: Juuso Westerlund
Photos, page 11 & 73: Kevin Faingnaert
Photo series, page 24-33: Peter Helles Eriksen
Photo series, page 40-52: Markku Lahdesmaki
Photo, page 62: Frederique Peckelsen
Photo, page 70: Kristian Septimius Krogh / norden.org
Photos, page 78 & 91: Viktor Gårdsäter
Photos, page 88 & 96: Joakim Blomquist
Photo, page 103: Tamara Eckhardt

EDITORIAL In February 2019, thirty Nordic healthcare experts from the public and private sectors were gathered in Copenhagen to take part in the Nordic Health 2030 process, a workshop series that aimed to address how to best shape the future of health in the Nordics. From the beginning, there was broad agreement among the group that our healthcare system is sick, and the prognosis is clear: There is an urgent need for change in health that will shift the balance from reactive and costly sick care towards proactive, sustainable, and preventive care. But when asked how this transition should be made and who should drive it, silence fell on the group. This was the ‘eureka’ moment of the workshop series. It suddenly became clear that these were not only the questions the Nordic Health 2030 process should strive to answer, but also the questions that have the power to spark a movement to improve health in the Nordics and beyond. From that moment on, the remainder of the process was committed to laying the foundation for the much-needed transition to a genuinely preventive *healthcare* system.

The aim of this publication is to illustrate how we can build on that foundation and propose a vision for healthcare that will ensure a set of robust, sustainable, and resilient life conditions for future generations. The Copenhagen Institute for Futures Studies’ collaborative exploration of the topic has led to some bold conclusions about what is needed to improve the state of health in the Nordics towards 2030, as well as the identification of what could be the best catalysts for a preventive health revolution. These catalysts — a focus on fostering resilience in individuals and communities and the development of new health data models — receive particular attention in the following pages given the Nordic countries’ unique advantages and potential to contribute in these areas.

As we work towards realising these efforts, it is essential to acknowledge that we may not derive all of the benefits ourselves. Just as the builders who, centuries ago, were among the first generations to lay the foundations of the grand cathedrals that cover our continent would never know how they would look when completed, we know that we will not see the end results of our hard work in our lifetime, but hope that our children and grandchildren will. This form of ‘cathedral thinking’ — embodied by the Nordic Health 2030 Movement that was inspired by the outcomes of the workshop series — is not only needed to motivate long-term efforts to reform our healthcare systems, but also drive the cultivation of skills to manage and prosper in natural and social environments that are undergoing drastic change.

Most importantly, a push by the founders of the Nordic Health 2030 Movement to spread the visionary ideas they have helped develop as widely as possible will ensure that everyone in the Nordics can play a role in making the shift from sick care to preventive health. With a sustained commitment to a movement and a purpose that goes beyond self-interest, the Nordics can shape the future of health and act as a beacon for the rest of the world.

We can no longer wait for the future to begin. It is time to deliver.

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Part I

WHY DO WE NEED A NEW WAY OF THINKING?

Understanding the tectonic plates of the emerging health landscape.

A need for a radical redesign of how we deliver, practice, and think about healthcare is emerging across the Nordics. Changing demographics and new demands from citizens, private actors, and public institutions indicate that a shift towards preventive and proactive care is crucial. We must ensure that healthcare systems in the Nordics continue to provide excellent care and position the Nordics as leaders for the rest of the world as we draw closer to an uncertain future.

THE NEW REALITY OF HEALTH IN THE NORDICS



If we are to believe what the rest of the world tells us in a regular cycle of reports, then the Nordic people are among the best-educated, happiest, and healthiest to be found on the planet. The consistently high achievement of each Nordic nation when measured against certain social, economic, and health indicators would suggest that we are doing something right. There are many within our region who attribute this success to the Nordic welfare model, which is founded upon principles of trust, equality, fairness, and redistribution. The welfare model has helped establish a sense of social cohesion and security, while ensuring that all citizens have access to quality public services and institutions.

Nothing illustrates this better than a trusted universal healthcare system that provides comprehensive care from the cradle to the grave. Healthcare is perhaps the one thing that everyone in the Nordics has in common, as we all share a dependency upon it. Yet, this is also a system under strain, confronted by a perfect storm of challenges. How we address these challenges together – in partnership as a region rather than as separate nations – could prove to be the true test of our highly admired welfare model.

DEMOGRAPHIC SQUEEZE

The healthcare system, as well as the welfare model that underpins it are subject to significant pressure on a number of fronts. This pressure has been created in part by a combination of increasingly uncertain demographic conditions:

First, the population is ageing, with life expectancy now above 80 years of age across the Nordics and an ever-growing proportion of the population aged over 65 (already over 20% of the population of the Nordic countries today). Paradoxically, longevity and quality of life can be attributed to the very system now under pressure, as treatment, education, and prevention have served to reduce many incidences of communicable diseases.

Second, a longer average lifespan, nonetheless, can equate to increased susceptibility to non-communicable diseases as the population ages. Indeed, the rise in non-communicable diseases has been notable in the Nordic countries, accounting for around 90% of disability-adjusted life years (DALYs) in 2016, according to the World Health Organization (WHO).

Third, the number of people working and contributing taxes that feed the welfare system has shrunk. This can be attributed not only to retirement, but also to health factors like long-term illness and premature deaths, as well as to people working fewer hours than in the past and spending more time in formal education and training.

Fourth, birth rates in the Nordic nations either have stagnated or fallen, which will have long-term implications for the tax-dependent redistribution systems that are favoured in the region.

Each of these in turn highlights the lack of financial viability for the current welfare model and healthcare system. Fundamental reforms are necessary that can both accommodate these developments and mitigate their effects.

SYSTEMIC PRESSURE

Demographic considerations are just one of many complex and interacting factors that have coalesced into a substantial wicked problem confronting the health sector. Long-term health conditions, for example, place immense pressure on the healthcare system. Statistics collected on DALYs illustrate the life-span disease burden: taxes are no longer contributed to the system by those in need of care, while money is constantly extracted from it to cover the cost of their care. Historically, healthcare spending has been increased in order to keep up with citizen demand, but this is no longer sustainable. OECD projections indicate that, by 2060, the cost of long-term care will have doubled across the Nordics. Yet, as we have seen, the proportion of people contributing taxes towards the system will have reduced during the same period.

Notably, technological innovation in healthcare can both alleviate and exert pressure on the system. The aspiration of technological innovation is to improve the long-term health of citizens and the quality of care they receive, making advances in diagnosis, treatment, and prevention. An additional aim is to improve efficiency and effectiveness, reducing bureaucracy and administrative costs wherever possible. Healthcare professionals are themselves facing their own set of challenges: Burnout is increasingly prevalent, exacerbated by a shortage of qualified healthcare professionals and the requirement to undertake administrative and managerial tasks in addition to frontline patient care. Technology has the potential to automate some tasks, freeing healthcare workers to interact directly with patients. However, the price of technological innovation – covering research and development, procurement, implementation, and associated training – has proven to be prohibitively expensive. Recent WHO studies indicate that 50-75%

of the increase in healthcare costs can be attributed to technological progress and increased service levels.

In the Nordics, approximately 20% of health expenditure is allocated to long-term care, tending to the chronically ill, disabled, and elderly, among whom cardiovascular diseases and cancers are common. OECD data also illustrate that long-term care expenditure has steadily increased over the past two decades, with this trend set to continue and accelerate over the coming years. Substance abuse and mental disorders also carry direct costs, as a result of medication and treatment, as well as indirect costs, through lower employment rates, loss of productivity, and the knock-on effects on loved

ones who have to take on care responsibilities. The OECD estimates that across the Nordics approximately 5% of GDP is spent on these combined costs.

The convergence of these disparate but interconnected factors creates a sense of urgency. The current healthcare system is subject to so much pressure that, without a radical change in focus, it is likely to collapse. The majority of healthcare expenditure in the Nordics remains directed towards curative and rehabilitative care, even though there is clear evidence of the need for more funding to address

long-term-care, preventive health, mental health, and the treatment of other non-communicable diseases. The escalating trend in DALY figures, the surging costs of long-term care, the spike in mental disorders, and the professional challenges confronting the healthcare workforce are all early signs of a failing system. How do we treat these symptoms? What needs to change in healthcare? How can we redesign the system to ensure both its effectiveness and its sustainability?

TECTONIC SHIFTS

The Earth's crust is formed of multiple tectonic plates. These can be forces for change when they collide with one another, altering the topography of the landscape. To be sure, these collisions are not always disastrous – they can also be subtle reminders that our world is not static. Nor are these collisions exclusively destructive. They also create new features that change how the landscape looks and the way we navigate through it. In the health sector, there are several forces in play that can have a similarly powerful effect when they clash together. Indeed, it could be argued that a number of plates have already begun colliding along the fault line on which the healthcare sector sits, raising new challenges but also shaping new opportunities.

LONG-TERM CARE

Long-term care (LTC) is defined as a range of services required by people with a reduced degree of functional physical or cognitive capacity, and who are subsequently dependent on help with basic tasks for an extended period of time. Long-term care expenditure represents a growing share of the GDP in many EU countries — it is not particular to the Nordics.



The entry of Big Tech into the health sector – in the shape of Google, Facebook, Amazon, and Apple in the West, and Alibaba, Tencent, Baidu, and Huawei in the East – represents one such force. By taking advantage of their already deep integration into consumers' daily lives and activities, tech giants have bypassed the hurdles faced by traditional healthcare providers and systems. They can connect with individuals in a much more intimate and direct way. Wearable technologies offer real-time diagnostics and health insights. Smartphone apps can expedite visits to the hospital or doctor's practice, as well as even incentivise healthy behaviours. More and more of our interactions with healthcare systems are mediated through technology, with big tech firms designing the healthcare experience, shifting it into the digital domain and away from real-world interactions with people and physical structures.

Another force is centred on a new understanding of health. The notion that our health is the sum of both nature and nurture rather than nature or nurture alone is gaining wide acceptance. Rapid advancements in genomics and related fields have been instrumental in this development, paving the way for a new understanding of systems biology. We now possess sequencing technologies that enable granular exploration of human and environmental health and how they interact. Access to health and behavioural data is making it possible to more accurately predict health outcomes, needs, and trajectories. Overall, we are beginning to see how deeply intertwined our own health is with that of our communities and the rest of the planet.

Individuals and their demands possibly constitute the most powerful force of all. The decreasing cost of advanced healthcare and communication technologies along with changing social norms have had a profound impact on how we think about and what we expect from the healthcare system. Immediacy and personalisation in nearly all of our interactions, both inside and outside the healthcare system, are the new standard. As noted, such expectations have been fed in part by the Big Tech companies. It is unsurprising, therefore, that there is a high demand for health services to conform to individual preferences, and to untether us from physical points of care.

Individual demands on healthcare systems can only be expected to grow as the technologies that enable them – from AI consultation platforms to blockchain and public digital ledgers – become more affordable. This is perhaps best illustrated by the plummeting cost

of genome sequencing that has managed to break Moore's Law. A process that once cost over \$2.7 billion and took 13 years to complete, involving intense collaboration between scientists from around the world, now costs less than \$1000 and can be completed in a single day. What might happen when the price falls to \$100?

These shifting tectonic plates add to the immense pressure already exerted from within the healthcare system. The perfect storm of internal and external pressures poses an existential threat to our healthcare systems in the medium-to-long term. There is an increasingly urgent need to accommodate preventive and personalised healthcare models. Failure to anticipate the significant demographic, economic, technological, and social changes that will affect virtually every facet of our healthcare experience can only generate more uncertainty. There will be a growing need to support and cooperate with new actors in the healthcare sector as the system is redesigned and evolves.

THE CASE FOR PREVENTION

To ensure the long-term good health of Nordic citizens and the sustainability of our healthcare system, any redesign requires a fundamental shift from

services centred on sick care to one that promotes preventive health. By investing in the latter, the potential for return on investment is substantial as costs for treatment should decrease in parallel with the reduced number of people requiring treatment. Yet, according to figures collected in 2017 across Denmark, Finland, Iceland, Norway, and Sweden, the total public expenditure on preventive health in the Nordics as a percentage of GDP was only 0.3%. This contrasted starkly with the 2017 figures for sick care, which amounted to 9.8% of GDP on average.

Today, we are witness to innovative forms of treatment and the construction of high-tech super hospitals designed for the effective treatment of diseases, but we see little innovation in terms of preventive services. Of course, this is not to say that the super hospital does not have a place in the healthcare system of the future, but it is symptomatic of the long-established tendency to invest in treatment rather than developing preventive health capabilities and awareness among institutions and citizens.

A transition towards preventive health can enable well-informed citizens, supported by access to tools, data, and relevant information, to remain healthy for longer. It will also equip them to recover more quickly and effectively from injury and illness, and to boost their overall resilience when coping with daily challenges

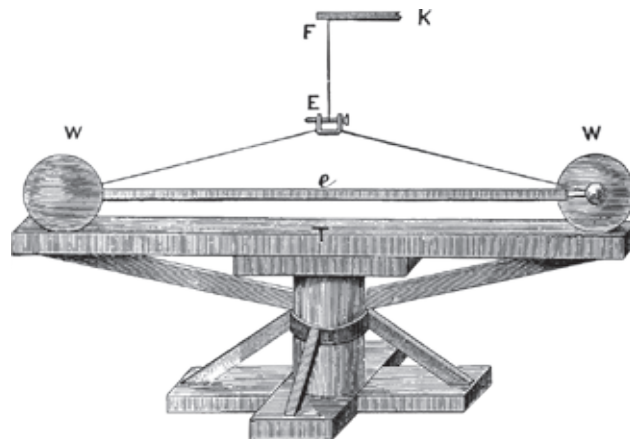
“To ensure the long-term ... sustainability of our healthcare system, any redesign requires a fundamental shift from a services centred on sick care to one that promotes preventive health”

MOORE'S LAW BROKEN

Moore's Law is in fact an observation made in 1965 by Gordon Moore, Co-Founder of Intel, which holds that the number of transistors on an integrated circuit chip doubles every two years. Genetic sequencing technology has broken Moore's Law, with sequencing times and costs falling at higher exponential rate since the first sequencing of the human genome in 2003.

THE 5/5 ASPIRATION

A sustainable approach to healthcare requires a fundamental shift from sick care to preventive health. By 2030 the Nordic countries should allocate 5% of the GDP to treatment and 5% of the GDP to prevention.



and significant life events, such as starting a family, moving, or the loss of a job or loved one. Collective responsibility for preventive health, moreover, will have the positive effect of ensuring that sick care can be delivered where it is most needed.

Preventive health is intended to support a healthy, productive, resourceful, and equitable society that enjoys improved quality of life. It depends on shifting the point of care closer to citizens and their communities.

A sustainable approach to healthcare, founded upon the Nordic principles of fairness and equality, could see a rebalancing of expenditure, with a renewed focus on preventive health. This is exemplified by the 5/5 aspiration, a solution promoted by the Nordic Health 2030 Movement that requires a slightly lower overall allocation of GDP to healthcare than in 2017. It assigns an equal proportion of 5% of GDP each to sick care and preventive health. In this way, everyone can benefit, with funding and resources allocated to treatment and prevention, and with additional room for expenditure on related public services.

“Preventive health is intended to support a healthy, productive, resourceful, and equitable society that enjoys improved quality of life”

WHAT WILL ENABLE THIS TRANSITION?

Data has been called the most valuable currency in the future, which is especially true in the case of health data. It has the potential to improve and democratise healthcare by providing a personalised and preventive approach that could inform all health-related activities. For individuals, data enables better decision-making based on credible information around them, while the system can provide better and more personalised care eventually moving the point of care closer to individuals and their communities. The application of the continuous stream of data around them in the form of biological, biological impact and quality of life data enables the earliest intervention possible to keep the individual's health trajectory stable and build resilience. The amount of personal health data available today, combined with the intervention capabilities of the health system, has the potential to bring the individuals and systems together while also providing service at the convenience of individuals. This ultimately allows for creating a synergy between individuals and the system, a synergy which is sustained and further developed by the application of data.

From the system's side, the synergy is enabled by better access to comprehensive health data from citizen registers managed by the public sector and enriching it with analytical insights from other

organisational partners or additional behavioural data offered by individuals. On the individual's side, the synergy would mean a transfer of resources and autonomy to healthcare professionals, communities, and citizens to ensure that health systems more accurately reflect the needs and goals of those they serve. Following such a model would not only enable greater cohesion between citizens, communities, care providers, and other stakeholders, but also ensure the long-term sustainability and prosperity of the Nordic welfare states overall.

It is imperative that alongside the shift from sick care to preventive health we also move from the quantified self to the qualified self. The quantified self is a movement that aims to collect as many datapoints on the individual as possible through self-tracking. However, if these data are not qualified for changing behaviours geared towards prevention, it is not creating value for individuals. Likewise for the system, collection of data in centralised silos that are not being utilised does not create value for neither individuals nor the system. Therefore, we need to move to a qualified self approach that is supported by a system that uses the data we already possess and creates value by

applying the data to encourage preventive behaviours. In the end, the joint capabilities of the individual and the system are what determine whether we become qualified or not by comparing different data sets, making better decisions based on solid data, and turning these into actions that have a positive impact on the health of the individual.

THE NORDIC OPPORTUNITY

The shift demands a consortium of stakeholders across the entire healthcare value chain. A consortium that is capable of both innovation as well as implementation in public health systems. The Nordics are in a favourable position to spearhead the needed shift from sick care to preventive health. Their healthcare systems are set up similarly and produce fairly similar outcomes. Nordic societies are one of the healthiest regions in the world which is both due to high quality care as well as a generally healthier lifestyle than most. They have also built a well-functioning universal healthcare system while also not shying away from modernisation and digitalisation. On top of this foundation is a reliable public data infrastructure that already allows for a high quantity of high quality data to be captured, as it is widely used by citizens. Throughout the Nordics, there is also a strong connection between

FOLK HIGH SCHOOLS

Today's cherished folk high schools and the concept of self-cultivation that drives their educational philosophy were introduced in the Nordics by N.F.S. Grundtvig, a Danish theologian, writer, philosopher, and educator. Grundtvig strove to democratise the enlightenment of the Danish population by reaching out to uneducated and poorer segments of the peasantry, helping people qualify themselves as active, engaged members of society.

the public and private sectors, which is highlighted by their long track-record in successful public-private partnerships (PPPs). PPPs are generally characterised as vehicles for innovation, as well as sharing risks between public and private sectors, all for the benefit of the citizens.

The potential for redesigning the healthcare system is built into Nordic culture as well. Trust among citizens and in governments is crucial for reinventing the way healthcare is carried out. The Nordics are also among the most innovative countries in the world, being active in many fields ranging from tech start-ups to cutting-edge pharmaceutical research. Moreover, citizens across the Nordics participate actively in society and democratic institutions, which is exemplified by consistently high voter turnout as well as through their long history of grassroots and local community initiatives. These values – trust, innovative thinking, and a commitment to democracy, mutual respect, and freedom of expression – are among the most cherished Nordic values that bind the countries in the region together, and can play a fundamental role in designing the healthcare systems that we need in the future.

But the shift to preventive health is not only dependent on the healthcare system. Citizens also need to take an active part in shaping how they interact with the system on their terms. Traditional healthcare systems are set up so that citizens have to conform to however the system wants to interact with them. With persistent efforts, citizens can demand that points of care instead be designed around them in the future. As the primary points of care, citizens can engage more effectively in the self-cultivation of preventive health. Though it is not always explicit, self-cultivation is a very familiar concept to most Nordic citizens. Spread throughout Nordic history culture by the folk high school movement and inspired by the German tradition of *Bildung*, self-cultivation has to do with achieving self-realisation by educating oneself, experiencing the world, and acting responsibly in the best interest of both oneself and society. Experience with self-cultivation is yet another reason the Nordics are highly suitable to adopt such a system.

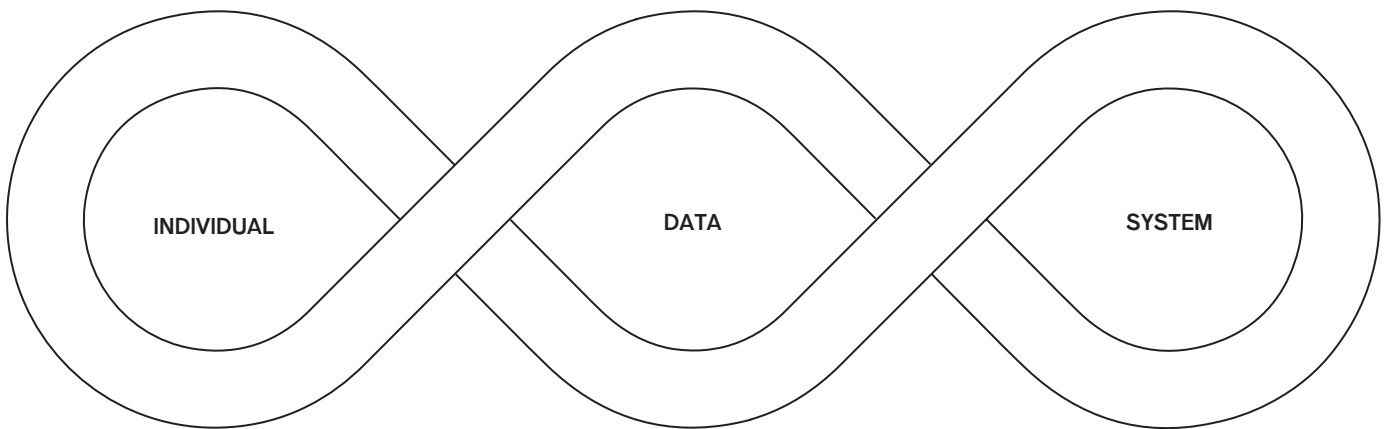
While the Nordics have much to offer, it is clear that there are areas in which they cannot and likely should not compete with

other large international players. A largely privatised market in the United States, for example, has allowed Big Tech firms to engage with individuals directly and innovate healthcare services rapidly, albeit at significant costs. Elsewhere, in China, a massive, state-controlled digital infrastructure and access to the data of over one billion citizens has enabled personalised health technologies to proliferate and research to be conducted with unprecedented speed.

What unique path can the Nordics take? By taking advantage of their unique capabilities, the Nordics have the potential to develop a more secure, equitable, and ethical alternative model for the future of healthcare. With strong local democratic institutions, well-equipped data infrastructures, experience with public-private partnerships, and a commitment to principles of equality and fairness, the Nordics already have the fundamental building blocks for a healthcare model that places citizens at the centre of all activities.

We can foster a truly sustainable Nordic Health movement that has preventive health at its core by leveraging the values and expertise that have already made the Nordics strong in facilitating public and private partnerships in concert with citizens. We have the opportunity to renew our understanding of Nordic solidarity and welfare if we manage to tame the perfect storm headed our way through the application of shared values, traditions, collaboration, and innovation. Not only that, but the Nordics could also serve as a guiding star in preventive health and become leaders in Europe and beyond, showing what the future of health could be. Just as the Nordics have set an example for the rest of the world in the areas of good governance and human-centric design, they now have the opportunity to set a new global standard for healthcare innovation. What might be the potential of integrating Nordic values into how we manage and deliver health care?

This magazine and the Nordic Health 2030 process that inspired it serve as the foundation for such a movement and are contributing to previous efforts to improve healthcare in the Nordics and place individuals at the centre of care activities and in control of their own health. The Nordic Health 2030 Movement aims to connect both new and existing bottom-up initiatives with top-down decisionmaking. ■



Sundhedsdan Terveysosaam Helsedannels Bildning i Hä Self-cultivat

Definition: A lifelong learning approach to cultivate preventive health behaviours and values rooted in an innate sense of responsibility to oneself and one's community.

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Part II

HOW CAN YOU BENEFIT FROM RESILIENCE?

The Nordic Health 2030 workshop series initiated a workstream with the aim of building resilience in individuals. To inform and inspire these efforts, the Copenhagen Institute for Futures Studies has explored resilience on the following pages.

Good health in the future will not only be dependent on well-designed healthcare systems — you will also have an important role in proactively ensuring your own health. The combination of adopting a healthy lifestyle and cultivating transformative resilience may be among the best responses to this challenge.

TRANSFORMATIVE RESILIENCE



There is little doubt that over the coming decades you will need to take more proactive action when it comes to your health and that of your loved ones.

It is increasingly difficult for the healthcare system to cope with a rising demand for services. The burden is worsened by the growth of the elderly population, as well as by higher rates of heart disease, cancer, diabetes, Alzheimer's, depression, and anxiety.

Western societies today discuss how we transfer some of the responsibility from the centralised healthcare system to local communities and even to individual citizens. Surely, for example, it is in everyone's interest to stay healthy for as long as possible without the need for healthcare services. Today's hospitals, moreover, do not play any significant role in preventing diseases from occurring.

So how do you prevent yourself from getting sick in the first place?

If you ask your doctor or search the internet, the most likely advice will relate to the adoption of a healthy lifestyle. Stop smoking, get your BMI into the safe zone (18-25), exercise for at least 30 minutes, and eat a minimum of five different fruits and vegetables daily. There is no doubt that a healthy lifestyle is vital for your health, yet only a tiny fraction of the population lives up to all these recommendations. Managing to establish and maintain a healthy lifestyle carries a lot of potential for you and your loved ones.

But what if there were something even more critical at play? An underlying condition that profoundly impacts all of us.

According to the Doomsday Clock, it's 2 minutes to midnight. You live in dangerous times. Threats like nuclear warfare and climate crisis are destabilising the world we live in. Add to that the increasing amount of information and interfaces you have to engage with each day. In today's world, you may feel overwhelmed more often by the pace of life, experiencing mounting pressure, pain, and even trauma.

No matter if you are conscious or not about the stress you are exposed to, you have to strengthen your overall ability to bounce back and thrive.

“Traditionally, resilience has described how we bounce back in response to difficulties, whereas newer interpretations cover how we thrive in the face of such challenges”

Such an ability is known as resilience. Traditionally, resilience has described how we bounce back in response to difficulties, whereas newer interpretations cover how we thrive in the face of such challenges. The latter relates to how you transform with difficult circumstances to become a better and more sustainable version of yourself. This has become known as transformative resilience.

The combination of a healthy lifestyle with the ability to achieve a positive transformation under stress is both an essential and natural way to boost your health and to avoid getting sick in the first place.

There is a vast amount of research on transformative resilience that provides guidance on this topic. It should be highlighted, however, that the advice in this article is by no means comprehensive. It is intended to inspire you and spark your curiosity. Transformative resilience is, after all, a very dynamic concept, open to different interpretations, and continuously leading to new insights.

You should think about transformative resilience as a fundamental balance in your life that you must identify, establish, and strive to maintain. This can take place through your own efforts, through the help of others, or most likely, through a combination of the two.

Transformative resilience includes *life wires*, *life skills*, and *life framing*.

Life wires help you to better connect with the context of your life. You can use life wires to establish a healthier relationship with the world around you:

RELATION TO FAMILY, FRIENDS, AND COMMUNITY

There is nothing more important than how you connect with your family and friends. This is where you find a safe harbour from all the stressors of modern life and where you connect with other people with whom you can share values, sympathy, trust, and forgiveness. Whereas experiences outside the inner circle can often be very individualised, a close relation is usually based on a

conscious or unconscious *agreement of belonging* that goes beyond the individual experience. This agreement is most robust if it can function across family, friends, and communities. The more fragile and uncertain family relations are in your life, the more critical friends and local communities become.

RELATION TO WORK, SCHOOL, AND LEISURE ACTIVITIES

This is where you as an individual gain a sense of your place in the world. It is a source of stability filling your every day with rituals and habits you can relate to and train yourself to master. Experiences at work or in school are based on a conscious or unconscious *agreement of solidarity*. The functions you perform together with colleagues or the things you learn along with your fellow students serve a higher purpose than anything you could achieve yourself. If this solidarity cannot be experienced at work or in school, it can be experienced through meaningful leisure interests or activities shared with other like-minded people.

RELATION TO NATURE, ART, AND HISTORY

This is where you experience that you are a tiny part of something much more significant than yourself. That everything that surrounds you, everything that went before you, and all that inspires you on a profound level have done so for millions of other people. You establish a conscious or unconscious *agreement of harmony* between you and the things that you can only begin to understand, even when these things seem threatening and impossible. You learn that you are not the centre of the universe and that you can live a more meaningful life outside the realm of your selfishness.

All 3 *life wires* have in common that they enable you to experience that life cannot be controlled from the inside, but instead must be inspired from the outside.

As the German poet Rainer Maria Rilke wrote:

*I live my life in widening circles
that reach out across the world.*

Life skills help you to optimise your *life wires* better.

“We all need both transformative resilience and a healthy lifestyle going forward. No one should be left behind. Everyone should contribute”

SELF-QUALIFICATION

This life skill is the ability to know yourself on a deeper level: How you see the patterns of your experiences; how feelings, thoughts, and behaviours are connecting to increase or reduce your overall vitality; and how you understand your place in the world better and accept your reality as the starting point of a meaningful journey. Self-qualification is ultimately about developing a more profound personal empathy for other people and outside circumstances that help you better respond to social interactions.

SELF-EXPERIMENTATION

This life skill is the ability to experiment with better ways of living your life: How you see the negative impact of your past experiences, shortcomings, and failures and respond to your sense of shame, blame, resentment, and heartbreaks with constructive actions; and how you use your creativity and imagination to improvise, innovate, and problem-solve with better daily rituals. Self-experimentation is ultimately about claiming personal agency over your life by trying new things that help you better take control over your life.

SELF-CULTIVATION

This life skill is the ability to identify what enables you to transform successfully over time: How you better listen to the lessons you learned in life, allowing you to reflect on the problems you enjoy having and the ones you enjoy solving; and how you learn to recognise what works and what does not work for you when you experiment with better ways of living and interacting with your surroundings. Self-cultivation is ultimately about building more trust in your personal behaviours and values to help you better respond to changing conditions.

All 3 *life skills* have in common that they enable you to qualify the things that matter most in your life.

Your *life framing* motivates you to build transformative resilience. Either by you forming an enhanced *life story* and/or by you being supported through *social facilitation*.

LIFE STORY

You are the architect of your life story. Your emotions are not hardwired in your brain. Emotions are best guesses that your brain constructs at the moment where millions of brain cells are working together. You have far more control over those guesses than you might think. It is not what happens in your life that upsets you, but rather how you interpret it. By constructing and documenting a life story of how you use your life skills to optimise your life wires, you can create a self-reinforcing, positive spiral – or, at a minimum, find better acceptance of the current state of your life. Everything from that point on can then be interpreted as something you can engage with much more constructively.

SOCIAL FACILITATION

Every human being has a specific starting point, a unique set of abilities and values, and a varying degree of available resources. Maybe you are dealing with addiction, long-standing illness, problems at home, poor mental health, or money problems. You might not be able to cope with these challenges. Remember that the sources of your transformative resilience go beyond what is within you. It relies just as much on what is between you and your world. If you cannot find the resources to boost your transformative resilience yourself, then make your expectations heard in your community. Ask for social facilitation through a programme, a structure, or a sense of direction that can open up the relational spaces you are looking for. Get activated in your community so you can experience the *supernormal* interactions that will enable you to contribute.

We all need both transformative resilience and a healthy lifestyle going forward. No one should be left behind. Everyone should contribute. That is the balance of the responsibility that we should all bear together. If you can't help yourself, you should have access to help from your family, friends, community, or society. If you can help others, you should proactively support the health of those around you. We transform better when we contribute to one another. Especially if you have children, you should act on their behalf so they can thrive into the future. ■

TRANSFORMATIVE RESILIENCE

The ability to thrive under difficult circumstances

“Transformative resilience describes a living system’s capacity to transform itself in response to changing conditions and disruptions”

- DANIEL CHRISTIAN WAHL

“The personal qualities that enable one to thrive in the face of adversity”

- CONNOR & DAVIDSON

“A dynamic process encompassing positive adaptation within the context of significant adversity”

- LUTHAR

“Resilience relates to the social structures, networks and interdependencies that make communities able to flourish in response to adversity”

- WORLD HEALTH ORGANIZATION (WHO)

“To develop a better balance between protective factors and risk factors”

- WERNER

“The capacity to adapt successfully to disturbances that threaten function, viability, or development”

- MASTEN

“Negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse”

- UNGAR

“An interactive concept that is concerned with the combination of serious risk experiences and a relatively positive psychological outcome despite those experiences”

- RUTTER

“Resilience incorporates the dynamic interplay of persistence, adaptability and transformability across multiple scales and multiple attractors in social-ecological systems”

- FOLKE

“Resilience offers a different way of understanding the world around us and of managing our natural resources. It explains why greater efficiency in itself cannot resolve our resource issues, and it offers a constructive alternative that creates options rather than limits them”

- WALKER

A VISUAL EXPLORATION OF RESILIENCE AMONG “SUPERNORMAL” PEOPLE SITUATED IN THEIR DAILY LIVES

*Individuals were selected based on their match with
an average demographic marker*

Page 26 *Average age of being under the influence of alcohol for the
first time: 14 years old*

Page 27 *Most common mental health issue: Anxiety disorders*

Page 28 *Average age to give birth for the first time: 29 years old*

Page 29 *Average age of getting married for men: 35 years old*

Page 30 *Average debt: 483,185 Danish Crowns*

Page 31 *Most common job: Social and healthcare helper*

Page 32 *Average height of men: 179 cm*

Page 33 *Average daily television consumption: 3 hours and 14 minutes*

Following pages:
SUPERNORMAL

Where:
DENMARK

Photographer:
**PETER HELLES
ERIKSEN**

















Part III

WHERE WILL DATA MATTER MOST?

The Nordic Health 2030 workshop series initiated a workstream to better utilise health data. To inform and inspire these efforts, the Copenhagen Institute for Futures Studies has explored future opportunities and obstacles for health data on the following pages.

Until recently, healthcare was associated almost exclusively with places you had to travel to, experts whose advice you sought when sick, and health professionals who did things for you when you weren't capable of doing them yourself. But this scenario is changing.

YOU ARE THE KEY TO PREVENTIVE HEALTH



An increasing quantity and quality of data derived from a wide range of sources both within and outside of the traditional boundaries of the healthcare system is creating a vastly different landscape for health. With improved knowledge about how to prevent disease before it occurs, manage disease, and recover most effectively, you can play a key role in reshaping the logic of the healthcare landscape from one of 'sick care' to preventive and personalised health. You have the potential to be at the centre of this new landscape because you are the primary source of the data that enables a more preventive and personalised approach to health.

HOW YOU DRIVE PREVENTIVE HEALTH

That you as an individual are the key to the shift towards preventive health is not as radical as it may sound at first. Overall, you are more equipped to act preventively than today's healthcare systems. You have a number of advantages when it comes to preventive health: At the most fundamental level, you have a natural preference for and ability to keep yourself healthy, whereas the healthcare system focuses on addressing problems after they arise. While you may not actively practice preventive health, you have the means to learn about the basic elements of a healthy lifestyle and you are well-positioned to achieve and realise them. Of course, healthcare systems can recommend and motivate certain courses of preventive action, but the power to take

preventive action lies with you. You also have a more fluid and holistic understanding of your health than that of today's healthcare systems. You are constantly aware of how you feel. Your perception of your health is on a gradient – it is not that you are just sick or healthy, but that you feel either more or less healthy given a wide range of factors that are related directly to your physical and mental condition as well as your environment and social interactions. Today's healthcare systems, on the other hand, are characterised by mostly incident-based, reactive care that operates on snapshots of your health and follows a black-and-white logic. In the context of the healthcare system, you are either healthy or sick.

While the healthcare system can provide detailed diagnostics on specific aspects of your health, less attention is paid to how your health status fluctuates and evolves over time. The diagnoses that lead to treatment often rely on a very granular understanding of health: a specific problem is sought in a specific part of your body, and there is no assessment of the sum of the internal and external factors that have an impact on your health. The data that you produce from your everyday experiences have a significant impact on how you can act preventively compared to the data that are collected periodically by the healthcare system.

DATA CAN ENABLE PREVENTIVE HEALTH FOR YOU AND HEALTHCARE SYSTEM

This is not to say, though, that healthcare systems are not needed in a world where preventive health is becoming the rule rather than the exception in health. On the contrary, an approach to health that emphasises prevention should aim to deepen the synergy between you and the healthcare system. You will inevitably be dependent on services that only the healthcare system can provide at certain points in your life. So, a system that can respond to problems after they occur is something you cannot do without and cannot separate yourself from.

To be sure, the biological and behavioural data that you constantly produce and that enable you to act preventively is also data that can improve the healthcare system's ability to support prevention. Take, for example, wearable technologies that monitor health data, such as your pulse, in real time. This data can be used to develop a more accurate picture of your cardiovascular health for both you and health professionals, allowing for more preventive action or personalised care in the event of a health emergency. Over time, a more open flow of data between you and the healthcare system can also help push the healthcare system to offer a wide array of more tailored services as the system manages to develop a better picture of your individual health needs.

This relationship not only works directly to your benefit, but also to the benefit of society. Your data, when further analysed

and qualified by the healthcare system, have the potential to contribute to population health data sets, which can in turn improve preventive care for you and others.

But all of this raises a crucial question – how can healthcare systems be redesigned to provide both the reactive care and improved preventive services you need as well as support the preventive behaviour for which you are naturally built?

YOU AS THE PRIMARY POINT OF CARE

The most fundamental aspects of this redesign may have to do with time and location. As things stand today, the clinical points of care are largely centralised, found in physical spaces such as hospitals, community health centres, and GP offices. When you make an appointment to see a healthcare professional, it is the system that decides when, where and with whom that will happen. This set of conditions is not sufficient in a health landscape that is making the shift towards prevention.

However, digital technologies and the data on which they depend challenge the idea that points of care can only be associated with physical locations and fixed times. A different way of thinking about this is emerging. Already by using a wide range of digital health services and technologies, you are drawing the point of care closer to where you are at any point in time. And, as you assume more autonomy in monitoring and acting on health information, you have the potential to become your own personalised point of care. This means that a redesign of the healthcare system to accommodate the shift towards preventive behaviours and services will be a redesign of the healthcare system around you.

This redesign makes sense because – just as you are better prepared than the healthcare system to drive a shift away from sick care – you are also more equipped than the healthcare system to be at the centre of data-intensive activities that make preventive and personalised health possible.

Think of the four categories of data-related activities that are central to preventive and personalised health – *generation, assembling, application, and sharing* – and how you play into them. Whereas the healthcare system can provide necessary insights into health problems you experience, you and your surroundings generate the data that make up the basis of preventive and personalised care.

Moreover, although the healthcare system may have the ability to assemble your data to create a meaningful picture of your health, it is your activities and health status over time that inform this assembly. How the health data that you generate are acted upon in both your own activities and those of the healthcare system is also directly dependent upon your motivations and preferences. Accordingly, how your data are shared should be based on consent and permissions that you provide to the healthcare system.

“The data that you produce from your everyday experiences have a significant impact on how you can act preventively compared to the data that are collected periodically by the healthcare system”

But just knowing that you are well-positioned for the transition to more personalised and preventive healthcare isn't enough. In order for you to act proactively in the interest of your own health and to contribute to the transformation of the health landscape, you may need an idea of what you are capable of – a concept that clearly shows how you and your data make up a personalised point of care.

A DATA CONCEPT FOR THE PERSONALISED POINT OF CARE

In response to this need, we propose a data concept that both highlights your potential in the emerging health landscape and identifies ways of more proactively engaging with your health. This concept is applicable to everyone, while at the same time unique to each individual, much like our fingerprints. Everyone has one, and at the same time yours is unique to you. This concept is also built around the notion that you as an individual have advantages over the healthcare system in driving a shift towards preventive and personalised health. We call this concept the Humanome.

“The term ‘Humanome’ is made up of two parts, ‘Human’ and the suffix ‘-ome’. The suffix ‘-ome’ refers to the totality of a subject. The subject here is the health of a human”

THE HUMANOME – A PERSONALISED POINT OF CARE DATA CONCEPT

The term ‘Humanome’ is made up of two parts, ‘Human’ and the suffix ‘-ome’. The suffix ‘-ome’ refers to the totality of a subject. The subject here is the health of a human. Therefore, a Humanome is a qualified data pattern that correlates a set of health-related data markers in real-time to constitute a personalised point of care. The personalised point of care is continuously utilised to develop knowledge, make informed decisions, and enable more conscious interactions around the holistic care of the individual.

As a visualised concept (see page 38), the Humanome is split into four rings where you and your data are in the two innermost rings as the primary source of data, the ecosystem and publicly- and privately-held data about you are in the third ring as the secondary source of data and the fourth, outermost ring features data requirements. Both data source layers are split into four categories of data. The vertical axis features more novel types of data on the top and more traditional types of data on the bottom. The horizontal axis features more static data on the left and more dynamic data on the right.

More specifically, the innermost rings feature data markers that are informed by data primarily generated by the individual. The centremost ring features individual preferences that are subjective and only you have the capacity to measure. The middle ring features biological data, novel biological data, behavioural data with biological impact, and novel behavioural data with biological impact.

The outermost ecosystem ring features data markers primarily generated by your surroundings. These data markers are still

related to you, but are secondary to the data within your body. It features static environmental factors, dynamic environmental factors, static public records, and dynamic public records.

The following list provides examples for each data marker. Note that the Humanome concept is not meant to be a complete list of existing types of data. It is meant to serve as an inspiration for what types of data that are already available to you either within your body or in your surroundings and that you can begin using today.

THE CENTRE OF THE MODEL

Individual preferences where you would ask yourself questions:

- Are there early signs of stress or depression in my life?
- How can I best self-cultivate values and behaviours around preventive health?
- Whom and what do I depend upon to preserve my health?

THE PRIMARY SOURCE OF DATA RING

- Biological data: blood tests, cardiovascular tests, and urine tests.
- New biological data: genomics, microbiome, and proteomics.
- Behavioural data with biological impact: dietary habits, exercise patterns, and sleep patterns.
- New behavioural data with biological impact: digital phenotypes, social media usage, and wearable data.

THE SECONDARY SOURCE OF DATA RING

- Static environmental factors: climate, geography, and rural/urban setting.
- Dynamic environmental factors: air quality, noise, and weather.
- Static public records: demographics, employment, and socioeconomic climate.
- Dynamic public records: citizens services, commercial services, and transport.

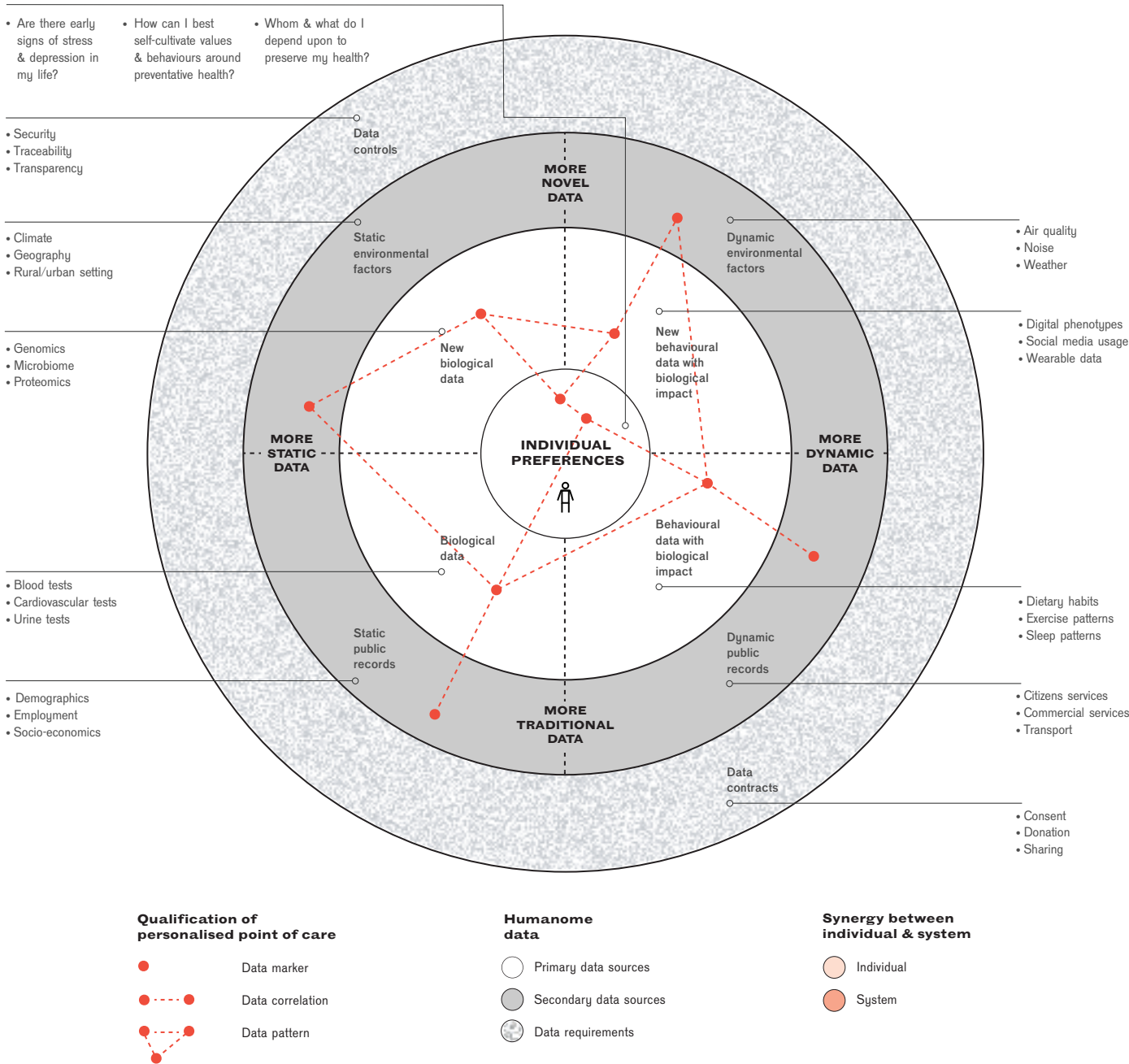
THE OUTER RING – DATA REQUIREMENTS

- Data controls: security, traceability, and transparency.
- Data contracts: data donation, data sharing, and data consent.

The Humanome concept at its best can be used to qualify your personalised point of care. Although there is already a quantified self movement thriving today, it is not enough to collect as many data points on yourself as possible. You need to go a step further by qualifying the separate data points through combination and correlation. The first level of data qualification is what the majority of the quantified self users tend to do, i.e., to collect a vast amount of data on themselves for the sake of collecting data. The Humanome concept proposes that these separate data markers be correlated and combined to form a data pattern that leads to deeper insights for you. The establishment of data patterns are the highest level of data qualification you can reach for your personalised point of care.

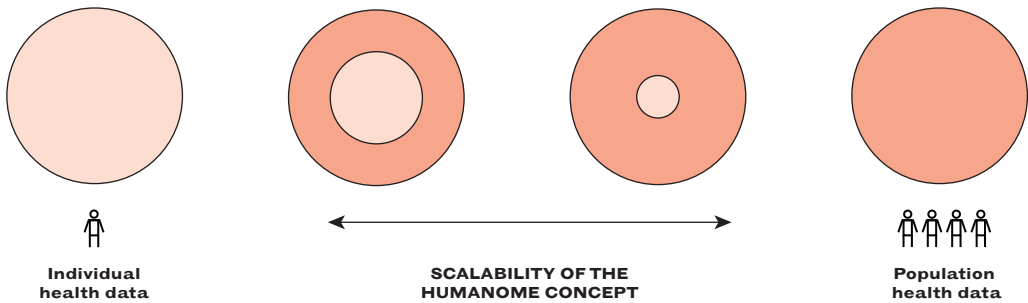
THE HUMANOME — A PERSONALISED POINT OF CARE DATA CONCEPT

The Humanome is a pattern of qualified data that correlates a set of health-related data markers in real-time to inform a personalised point of care. The personalised point of care is continuously utilised to develop knowledge, make informed decisions, and enable more conscious interactions around the holistic health of an individual.



Humanome Scenarios

These scenarios demonstrate how individuals can be placed in the centre of preventive care while being able to manage and apply their data to a varying degree.



HUMANOME SCENARIOS

The scenarios below are meant to be seen as snapshots in time. In reality, your interactions with the healthcare system are much more fluid and constantly shifting between the scenarios, hence the gradient logic. The scenarios demonstrate how individuals can be placed in the centre of preventive care while also managing and applying their data to varying degrees.

SCENARIO 1

INDIVIDUAL-DRIVEN PREVENTIVE HEALTH

In this scenario, you are the primary initiator of a lifestyle change towards more preventive behaviour for your health, and you are also the one who can take action on generating, assembling, applying and sharing your health-related data. You have all your data assembled in one easy-to-use interface, and you become your very own personalised point of care. You interact with the system on terms that are aligned with your needs and interests based on your real-time flow of data. For example, through digital health platforms, you can upload a wide range of clinical, genomic, digital, and quality-of-life data that can be analysed to produce a holistic picture of your health and highlight potential health risks.

“The cohesion created from opening up the health data value chain will enable both you and the healthcare system to get the most out of your personalised point of care”

SCENARIO 2

INDIVIDUAL-DRIVEN PREVENTIVE HEALTH MOTIVATING THE SYSTEM

In this scenario, you are still the primary initiator of preventive behaviour for your health, and the health system can therefore take action based on your preferences. By having your data assembled in one easy-to-use interface, you can clearly articulate your expectations towards the health system. You interact with the system when you want to, but it is the system that decides what treatment or intervention you need. You can already experience this scenario today through wearable technologies with blood pressure tracking apps that notify you of irregular readings. Then, in the event of an issue, you can go to your GP and tell them and make a decision about what to do together.

SCENARIO 3

SYSTEM-DRIVEN PREVENTIVE HEALTH MOTIVATING THE INDIVIDUAL

In this scenario, the health system is the primary initiator of preventive behaviour for your health, but you are the one that takes action. You have access to all of your assembled data in one interface and so does the system. The health system makes its preferences towards you heard by notifying you of changes you could make to live healthier. Through insights gained from your data, it can motivate you to take preventive action in exchange for an incentive. For example, the healthcare system can identify a risk for diabetes based on your genetic profile and recommend life-

style changes that could prevent its onset. The cost of the most effective lifestyle changes could be subsidised to motivate you to make them.

SCENARIO 4

SYSTEM-DRIVEN PREVENTIVE HEALTH

In this scenario, the health system is the primary initiator of preventive behaviour for your health and helps you to take action. You and the system have access to all of your assembled data, but you might not have the capabilities to take action, so the health system gives you support. A key difference between this

and the other scenarios is the question of awareness. In this scenario, the system might make health decisions on your behalf and implement them without you necessarily being made aware of them. You are both incentivised and rewarded for taking the actions the health system recommends. For example, every time you visit your GP, they could take a blood sample and automatically screen for an array of vitamin deficiencies. Afterwards, the health system could support you with advice, incentives, or rewards for dealing with

possible issues to prevent any further complications.

Each individual has a unique starting point in life and a set of resources for generating, assembling, applying and sharing data with others. This means that there will be people more capable of applying the Humanome concept starting today as well as people that don't have the capacity or the resources to apply it to the same extent in their own lives.

Therefore, the Humanome concept has to evolve over time into something that is more system-driven to take care of individuals who cannot necessarily start the transition themselves. In turn, the individuals who do start the transition today can relieve some of the pressure on the health system by living healthier and therefore use fewer services. This frees up the health system to concentrate more resources on those who are in need of more support. In addition, the Humanome concept could allow more resourceful individuals to better contribute to those less capable.

But how can the healthcare system drive the implementation of the Humanome concept and better support your preventive behaviours? It is clear that a redesign of the system is needed in order to work effectively with so many different types of data and ensure that your data can follow you.

Right now, the effort with the most potential impact is the development of a shared premise for data management and sharing across borders. The cohesion created from opening up the health data value chain will enable both you and the healthcare system to get the most out of your unique and personalised point of care. A more navigable data landscape will make for a more navigable healthcare system and a more navigable future for you. ■



SUOMI FINLAND

Finland holds the 2019 Presidency of the Council of the European Union. During its tenure, Finland has prioritised strengthening common values and the rule of law, making the EU more competitive and socially inclusive, highlighting the EU’s position as a global leader in climate action, and protecting the security of citizens. The Copenhagen Institute for Futures Studies interviewed three Finnish data experts who participated in the Nordic Health 2030 workshop series about their work and what health data means for people in the Nordics.

SPOTLIGHT ON FINLAND

A PROGRESSIVE NORDIC COUNTRY WITHIN HEALTH INNOVATION

Dr. Minna Hendolin, Senior Director for Health and Wellbeing at Business Finland and a member of the World Economic Forum Expert Network on the Future of Healthcare as an expert in healthcare and precision medicine.

Jaana Sinipuro, Project Director at Sitra, the Finnish Innovation Fund and Steering Group Member of MyData Global working to empower individuals by improving their right to self-determination regarding personal data.

Dr. Maritta Perälä-Heape, PhD., Director at Centre for Health and Technology, University of Oulu, and laid the foundations for the MyData movement through the Digital Health Revolution programme.

Q & A

What health data projects focusing on benefits for the individual are you currently working on?

MINNA: At Business Finland we are facilitating the creation of innovation and business ecosystems aiming for better health and business growth. Our focus areas are personalised medicine, digital health data and exponential technologies. Examples of some of our flagship projects include FinnGen, which combines genome information with digital health care data, and the CleverHealth Network, which is a health technology ecosystem in which companies and healthcare experts develop better treatment solutions for Finns and produce successful export products for companies.

JAANA: At Sitra we’re currently working with the IHAN® Human-driven data economy project which aims to build the foundation for a fair and functioning data economy. The main objectives are to create a method for data exchange and to set up European-level rules and guidelines for ethical use of data. We are creating a test ground for consent-based data sharing, which is needed to build new digital services based on trust and transparency. This benefits individuals and their health by making it easy for service providers to reuse and link health and wellbeing data in personalised health services.

“Finns are quite positive about the use of their data for scientific research, and new legislation will streamline research practices and ensure that it is used in a safe environment”

MARITTA: I was leading a large strategic research program called the Digital Health Revolution, which worked on defining the human-centred data management principles used in the MyData movement. It was also essential for creating the service scenarios for the P4 Medicine and Healthcare project, which emphasises predictive, preventive, personalised and participatory healthcare instead of reactive disease care. I am very proud of that since, at the time, nobody was talking about MyData-based service development. At the moment, I am working on a Horizon 2020 project called MIDAS, which is also inspired by the power of MyData in health policy making. I am in the process of preparing a co-innovation project with THL, the National Institute for Health and Welfare in Finland, called 'My data and my genomics to healthcare'.

What do the recent Finnish regulations in secondary use of health care data mean for individuals?

MARITTA: Good question! The new Act on the Secondary Use of Health and Social Data opens the use of social and health data from only research and statistics to also include management, development, innovation and education.

MINNA: Yes, this regulation establishes FinData, a one-stop shop for the secondary use of social and health data that starts operating at the beginning of 2020. It will create a stronger knowledge base that relies on data, and facilitates research and development for better social and healthcare services through smoother service pathways, new drugs, improved treatments and trust. The new regulation implements the GDPR (the EU's General Data Protection Regulation) in Finland. It is one of the first implementations of the GDPR for the secondary use of data in Europe.

JAANA: Finns are quite positive about the use of their data for scientific research, and new legislation will streamline research practices and ensure that it is used in a safe environment. Individuals

benefit from research in many ways – evidence-based care is one example. The health and social care service providers can measure outcomes much more precisely and therefore enhance service quality. Patients also receive better care through access to novel drugs, which perhaps can be brought to markets faster with the use of real-world evidence. Individuals will be assured greater transparency and security of their personal data, and society benefits when there are new methods of estimating effectiveness of new medicines.

How can we make sure that technology and data serve the purposes of individuals?

JAANA: I think this is both a concrete and philosophical question. By integrating lifestyle and wellbeing data into your health status, it is easier for individuals to take an active role for their own health. Still, for novel data like genetics, we need to be careful when returning data back to individuals. It is important that we do not cause unnecessary concerns about their health, and in that sense, the role of professionals as data interpreters is changing. On a more philosophical note, technology can be considered neutral, and responsibility for its appropriate use must be at the systemic level and based on common values. The system needs to ensure that less capable people also have access to the latest benefits from technology and data.

MINNA: I have two good Finnish examples for preventive and holistic approaches to health. Neosmart Health uses a wide range of scanning, mapping and measuring methods of the body's functions to gain a holistic view of health risks and opportunities. Through gathered data and artificial intelligence, their medical experts provide insights on how to optimise performance and reach one's full potential. Also, Buddy Healthcare reduces the administrative burden and improves patient experience and outcomes. It is a mobile care coordination platform that automates and digitises pre-and post-surgery care pathways and performs care-related education.

“The most likely way to organise all the interoperability needs in the society is through the personal databases, which are all controlled by the citizens through their personal data accounts”

MARITTA: I think we can ensure that technology and data serve the individual by creating MyData-based services and technical infrastructures to support dynamic consent management, as well as by making data actionable with tailor-made services for individuals. Interoperability of IT systems will be crucial in order to fulfil integration and coordination of health and social services. Planning and execution of integrated care models is not possible without access to health and social information as widely as each individual case requires. The most likely way to organise all the interoperability needs in the society is through the personal databases, which are all controlled by citizens through their personal data accounts. Publicly available information and comparisons are fundamental requirements for choice and competition. Without adequate and reliable information on quality, individuals are restricted in exercising their freedom-of-choice of treatment or provider.

JAANA: The IHAN project tries to build a self-regulated ecosystem focused on data sharing with transparent rules and consent-based data sharing controlled by individuals. We’re also investigating whether a “Fair Data Label” could be an option for those companies who want to be seen as fair and transparent. We are hoping to create an open ecosystem of companies that are respecting individual rights in their personal data usage – companies who are seeing the GDPR as an opportunity, not as a sanctioning tool.

In terms of dynamic consent, do you think we can give citizens control over how and when their data are used?

MARITTA: Yes, we absolutely should give citizens the possibility to decide where, for what and by whom their data is used.

MINNA: In most of the cases it will work, I think, but we need a dialogue on where to draw the line with regards to children, disabled people, or in emergencies or life-threatening situations.

JAANA: I agree, consent is a good tool for specific use cases, but especially in health, data needs to be available for emergencies in primary use and, when used for the public good in research, from the public registries in secondary use. Consent will become more usable when people start having more health data outside the public registries and official health care services. Novel service providers including Apple Health have more and more data about people. Here, dynamic consent is the best tool to grant access for both primary and secondary use of that data. We should be more precise on what regulated data is, its use cases, and how to use consent.

What ethical dilemmas will individuals face in the future concerning health data utilisation?

MINNA: The obvious one is data security – can my employer or insurance company get access to my sensitive data? Also, genetic data may cause concerns since it affects not only the individual, but also their relatives – do I have the right not to know? Then there is the power of social media and consumer data - will AI develop and be used such that it starts to affect my mindset and behaviour in a bad way?

JAANA: The ethical dilemmas are much debated, but I would highlight one that is usually less discussed. Will the benefits of health data and personalised services be available for everyone? Usually the discussion tends to lead to the possible misuse of data or data leakage risks, but the access to care will – in my opinion – become a bigger issue in the future. Companies that invest heavily in Big Data, AI, and genomics will need return for their investments. Will the access to personalised healthcare services be limited to the wealthy or people with occupational health insurance, or only people living in western societies? How do we ensure that innovations that require huge datasets, which can be considered a public good, will be able to be accessed in fair terms by everyone? Sustainable health management systems





“I believe Finland is in a good place to reach our goals with emphasis on facilitation of the public-private-people partnerships already present, such as the CleverHealth Network already mentioned”

need to have a broader and more systematic view on contributors of health – covering both professionals and citizens as agents for better health.

MARITTA: Some of my concerns are related to the fact that citizen-generated data is not taken into account in the treatment and/or health coaching, and that standardised care recommendations are only based on population-wide research. The personal data in the private cloud is not accessible in the large quantities needed for the evidence-based research. Personal intervention should be based on that research when evaluating individuals' risks of certain diseases.

How can we ensure that individuals experience the same quality of healthcare across borders with the best possible access to their own relevant data?

MARITTA: Healthcare systems are very different, as well as the quality of care being delivered. One could ask whether the access to one's relevant data is a guarantee for quality care in another country. I think that there must be changes in the health system before we can really see the benefits of our own data traveling across borders.

JAANA: I think this is a difficult question because it's always in relation to existing structures and their regulation and culture in different countries. As Maritta said, the existing structures are so different that a simple transfer of data across borders does not necessarily lead to quality care. However, we are trying to facilitate the move of a basic set of health records across countries and healthcare professionals with the consent of individuals.

MINNA: I agree there is a huge amount of work that needs to be done to ramp up infrastructure and update policies in many countries, while also ensuring harmonisation and standardisation. However, I believe that the Nordics could lead the way and set standards for that.

How do you in Finland work towards a citizen-centric personalised/preventive health care model, and how could it inspire Nordic health collaboration to become a European lighthouse?

MARITTA: Today, the documentation of patient data in the Finnish healthcare system is 100% digitalised. In public hospitals, electronic patient records (EPR) were widely adopted in 2007. In public primary healthcare centres the complete availability was reached in 2010, and even earlier than that among private health care service providers. The Finnish health and social care system has been a success story in many aspects, but there is still more work to be done.

JAANA: Indeed, we are in a strong position, but we are still hard at work on multiple fronts to achieve a citizen-centric health model. One important step has been to set up a comprehensive national health sector growth strategy for Finland in collaboration with all relevant stakeholders. It includes steps towards personalised healthcare, including the national data authority (FinData), the Genome Center Finland, biobanks, Neurocenter, etc. What we are trying to do in Finland is to use the current environment, plans, and national engagement to showcase how regulated data can be combined with data collected by individuals, which leads to the next phase for value creation and innovation. On that note, we are happy to invite bright-minded professionals, active public servants, and responsible companies to join this effort. We are open to participate in Nordic collaboration, as I believe it is crucial.

MINNA: I believe Finland is in a good place to reach our goals with emphasis on facilitation of the public-private-people partnerships already present, such as the CleverHealth Network already mentioned. Additionally, it is important to keep a high level of transparency in policymaking and preparation of legislation, as in the case of the Genome Act that is being discussed now. Sitra's work on IHAN is a good example as well.

“Let’s make this data work for our health and wellbeing and ensure that when it happens, it is based on trust and it enhances our sense of belonging in the society. Surely, Nordic values are the bedrock for sustainable care in the future”

JAANA: Sitra is currently working on the IHAN project to facilitate the sharing of personal data and pilots in healthcare. An example of a citizen-centric personalised health care initiative that IHAN’s “technical & business pilots” are focusing on is accessing national health registries. A specific case is My Travel Health, Tokyo 2020. It is a mobile health wallet for Tokyo 2020 Olympic visitors, which sets up the convenient and reliable use of health data recorded in Finland to help international travelers if they run into health-related problems away from home. Additionally, IHAN-projects can shed light on Nordic initiatives such as Case Alva. Case Alva is a project that is focused on consent-based, real-world health data collection from monitoring devices that can be brought directly to all relevant stakeholders for the benefit of a diabetic adolescent.

MARITTA: Finland has achieved a lot in national interoperability especially on patient health records through Kanta, which is the national online health platform. It has the potential to fulfil some of the information needs in service integration. Similar databases related to other sectors of life, especially related to lifestyle, must be made available and usable parallel to healthcare data in Kanta.

What do you hope to achieve from the Finnish EU Presidency in relation to health?

MARITTA: I hope to see the new Finnish Government agenda be promoted during the Finnish EU presidency, especially its statement on MyData principles: The right of citizens to their own digital information and privacy. Individuals are given the possibility to manage their personal data in public information systems and to give consent to data reuse in other services. I hope to see these principles promoted in both national and international regulation. The Finnish Government agenda should be aligned with the Digital Europe programme’s priority to establish EU-wide common data spaces for pooling and sharing of

data in sectors identified as priorities (including, but not limited to, health, climate, environmental, manufacturing, agriculture, energy, financial and mobility data). The large-scale actions may include the creation of data platforms enabling secure and compliant sharing and re-use of sensitive, confidential, proprietary and personal data, as well as large-scale experimentation based on AI and advanced analytics. These programmes, in my mind, are creating the foundation of MyData-based service development in health care.

MINNA: My hopes are that we can spread wider awareness of Smart Health throughout the EU. Smart Health solutions combine technological developments in mobile devices, mobile data connectivity, application development, sensor technology, big data analytics, and cloud computing, with groundbreaking ideas on health monitoring in remote communities, and prevention of unhealthy lifestyles. As such, Finland, by pushing the agenda further in Smart Health, has the potential to deeply transform the healthcare sector. This would also lead to data- and innovation-driven, sustainable health outcomes. Outside of health, Finland is working towards achieving an ‘economy of wellbeing’, i.e., a new approach to how people’s wellbeing enhances productivity as well as generates economic growth.

JAANA: I really hope that Finland’s pioneering legislative work on secondary use of sensitive data and terminology defined in legislation will be used as a blueprint for streamlining GDPR compliant data governance practices across the Nordics. Practical interpretations and guidelines are needed for the ethical and secure use of AI and other applications. Finland, together with the other Nordic countries, has a long history of digitalisation, and data storage is extensive. Let’s make this data work for our health and wellbeing and ensure that when it happens, it is based on trust and it enhances our sense of belonging in the society. Surely, Nordic values are the bedrock for sustainable care in the future. ■

SAUNANHOITAJA

SAUNAN-
HOITAJA
VALVOJA
KASSA
PAY OFFICE





The Nordic countries have invaluable health-related data that remain underutilised. If legal, ethical, and technological challenges are met, these vast datasets, in combination with data generated by individuals, present significant opportunities for radical innovation in research and the delivery of more sustainable health for the benefit of people across the Nordics.

NORDIC DATA COHESION



Denmark, Finland, Iceland, Norway, and Sweden, as well as the autonomous regions within the Nordics, all have the potential to harvest untapped value through health-related data. Such data could provide competitive advantages for the regional health and life science industry, leading to innovation of healthcare systems and services in addition to access to improved information. Access to a broad array of data will make it possible to act on early detection of disease and other health conditions, shifting the emphasis from sick care to prevention. By leveraging the strengths of universal equal access to healthcare and a reliable public data infrastructure, we can begin to develop solutions to some of the most pressing issues in healthcare today.

DATA AS AN ENABLER OF HEALTH

Health-related data is collected at great volume and frequency today. Analysis and use of health-related data have improved and increased exponentially in recent years, resulting in a profound transformation affecting the capabilities of professionals, researchers, and everyday people. The shift affects the entire data spectrum, spanning people's private lives and activities, social studies, the humanities, sport, economics, climate science, and genomics. However, the collection of data in healthcare has probably outpaced most sectors and, accordingly, our ability to translate and interpret that health data into knowledge and actionable information.

Technological evolution has introduced us to new terms and

concepts that now are interwoven with our everyday lives. These include artificial intelligence, machine learning, and big data. However, while our technical capabilities and vocabularies have developed, there remain significant gaps, ideological challenges, and differences of interpretation regarding data-driven approaches to personal and population health. Correlation of biological, behavioural, environmental, and public data can lead to more effective and sustainable delivery of healthcare. But this necessitates a common framework that serves the needs of all stakeholders, facilitating access and meaningful use of data.

SCALABILITY MATTERS IN HEALTHCARE DATA

For effective use of healthcare data, scalability matters. This requires cross-border collaboration on larger datasets. Hence, the emergent interest in cumulative population data from across the Nordics. The health-related data held in the Nordic biobanks, genome centres, registries, statistics agencies, hospitals, and public records have been collected over a lengthy period. It is a significant resource, including almost 100% population coverage, with unique individual identifiers that have been recorded over a 50-year period, and rich data for 70 million people, both living and deceased.

The ability to combine expertise and data across borders will help improve research, the study of disease, the analysis of outcomes, and the early detection of population trends, especially

when compared to the current use of disparate datasets with small sample sizes. At a micro level, analysis and use of this data also has the potential to enable well-informed individuals to take control over their own health, responding to early warnings and designing personalised healthcare plans.

INTEGRATED HEALTH DATA

When information is placed within a meaningful context, it can become knowledge and wisdom. Data such as an individual's name, smoking status, age, ethnicity, blood type, or a test result holds little value on their own. However, when they are used dynamically, placed in new and different contexts, combined and correlated, they offer immense value. The potential patterning of structured and unstructured data held in institutional repositories, together with user-generated data, offers the potential to generate new information, knowledge, and wisdom. With a wealth of health-related data, the Nordics are well-positioned to become a *laboratory of integrated health data*, especially once they have determined the most suitable way to collect new data from individuals in this age of increasing digital connectivity. Over time, we will be able to provide meaningful, contextual, and actionable information related to an individuals' health. This will help improve the quality of interactions between individuals and healthcare professionals as well as inform their own self-care as we shift towards a more preventive health model.

“Over time, we will be able to provide meaningful, contextual, and actionable information related to an individuals' health”

HOW DATA CAN ENABLE THE TRANSITION FROM SICK CARE TO PREVENTIVE HEALTH

Preventive health is driven primarily by those who take proactive ownership and accountability for their own wellbeing. This contrasts with the more traditional, reactive sick care model where interventions are driven primarily by healthcare professionals. Positive outcomes in health are dependent on timely action, whether that relates to clinical interventions or personal lifestyle changes. Integrated health data can inform these actions and the type of guidance that is made available to individuals. The well-informed can self-cultivate preventive health, thereby alleviating the burden on the healthcare system and ensuring that professionals can direct their energies to those most in need of their services. From a professional's perspective, data also can serve as a catalyst to timely intervention, breaking disease cycles, and ensuring the effective delivery of care. Early intervention is not only beneficial to the individual, but is cost-effective, too. In this way, the system and the individual become increasingly dependent on each other.

A COALITION OF STAKEHOLDERS

The effective collection, analysis, sharing, and combination of data by both individuals and healthcare professionals can have meaning and utility not only in the provision of care, but can help us better understand and serve the society in which we live. Seamlessly

integrated data can help us establish a horizontal overview that extends beyond health, making connections with public datasets relating to socio-economic analyses, population trends, and other studies. In addition, viewed vertically, the combination of multiple data sources allows us to extract contextual information about an individual or community. The potential for data cohesion could play a significant role in the shift from sick care to preventive health, but it is entirely dependent on a coalition between policy-makers, healthcare professionals, system providers, and individuals with a concern for data management, integration, and security.

Transdisciplinary research, drawing on interoperable, rich datasets could explore, for example, the link between genomics and diseases, or offer an analysis of inclusivity and the equitable distribution of health benefits. Data could also be used to address the challenge of health illiteracy, with the aim of fostering healthier and more productive communities, as well as enabling the early identification of population health trends. This will require policymakers to consider a number of questions relating to data curation and sharing. How to curate the best digital tools to empower citizens? What can be

done to enable individuals to become more involved and accountable for the management of their own health? How can the effectiveness of healthcare be improved through evidence-based, targeted, and timely treatment? What can be done to make the interaction between the public health system and the broader health industry more efficient and cost-effective?

A VISION FOR PAN-NORDIC DATA COHESION

Underpinning any move towards pan-Nordic data cohesion are shared values relating to trust, fairness, equality, openness, responsibility, and self-cultivation. Within the Nordic nations, there is a social contract between citizen and state, reflected in the welfare system. Individuals work in service of the collective; what they do helps not only themselves, but the broader community. This is fundamental to how Nordic societies operate and could scale in relation to data-enabled Nordic Health practices, bypassing traditional jurisdictions such as country borders. In this sense, the Nordic Health 2030 initiative aligns with the agenda of the Nordic Council of Ministers and its vision of making the Nordics the most integrated and sustainable region in the world.

A new form of cohesion between policymakers, healthcare professionals, system providers, and individuals is one that allows for co-management of health, encouraging greater proactivity in terms of both action and expectations. Such an approach also needs to account for the fact that not all individuals have the same capabilities and resources to make a shift in their lives happen. It has repeatedly been documented that a minority of the population constitutes a majority of the healthcare costs. An interoperable network of data sources will serve to decentralise the healthcare system, enabling individual autonomy, and greater



Liukas ja
kivikkoinen
ranta

Älä mene yksin veteen!
Don't swim alone in water!
Ne eivät ole Esteet!

flexibility for the roles taken on by healthcare professionals and local communities in relation to preventive health. The use of data by individuals and professionals alike will help generate even richer data that can inform the further improvement of both care and individual guidance. This may not go as far as the retrospective imposition of a uniform set of data standards and protocols, but will require people uniting around the promotion of a shared vision:

To improve health across the Nordics, all individuals and professionals should be able to experience meaningful input and output of health-related data in real time.

In order to make this a reality, it will be necessary to coordinate the many different professional and political projects related to health data. It is essential that these have a common purpose and that there is interaction and knowledge sharing between the different teams responsible for them, bringing together stakeholders from private enterprises, the Nordic public sector, and representatives of large-scale EU programmes.

“To improve health across the Nordics, all individuals and professionals should be able to experience meaningful input and output of health-related data in real time”

TOP-DOWN AND BOTTOM-UP SYNERGY

The establishment of a meaningful and improved premise for data cohesion across the Nordics furthermore requires an in-depth mapping of stakeholders needs, including the capture of contextual and supporting metadata that describes and provides information about other data. This will make it possible for data to be discovered, understood, and used in a variety of ways, supporting public services, research projects, and personal use. It is inevitable that we will need agents who are specifically tasked with making contact with stakeholders among policymakers, healthcare professionals, systems providers, and citizen groups in order to promote data availability and potential use cases. They will also need to raise awareness of the variety of ways data can be used, and how the notion that ‘less is more’ means that what can seem to be a minor contribution can have far-reaching positive effects. This ethos has been reflected in Finland recently through the Act on the Secondary Use of Health and Social Data which came into force in May 2019, which entails the launch of FinData in 2020, a one-stop-shop for health data.

Equally pressing is the need for a grassroots societal movement within the Nordics that leverages the opportunities created by the proliferation of technology and improved data capture, harnessing them in support of preventive health initiatives. It is the better alignment of top-down initiatives in conjunction with better activation of civil society that holds the potential to unlock the untapped value of Nordic data cohesion.

FAIR BEYOND RESEARCH

The EU is also leading the way in its exploration of simplified data use for research and innovation, as documented in the 2018 report *Turning FAIR into Reality*. The principles-based approach

and technical requirements advocated by the EU could provide a useful model for a cohesive Nordic health programme beyond their original research purpose.

In order to discover relevant data, perform analysis at scale, or employ techniques such as artificial intelligence to identify patterns and correlations not visible to the human eye alone, we need well-described, accessible data that conforms to community standards and protocols. The FAIR data principles articulate the attributes required to enable and enhance reuse by humans and machines. These provide guidance about making data findable, accessible, interoperable and reusable, and are relevant to all stakeholders in the current digital ecosystem.

TO BE FINDABLE: Data should be easy to find for both humans and computers, with searching enabled and supported by metadata.

TO BE ACCESSIBLE: Data should be stored over the long-term so that it can easily be accessed, downloaded, or streamed.

TO BE INTEROPERABLE: Data should use definitions that can be used by humans and machines to interpret the meaning, enabling automation, comparison, and combination with other datasets.

TO BE RE-USABLE: Clear conditions for reuse should accompany data as well as details about the provenance of the data and how they have been evaluated for reuse in the past.

The EU emphasis on standardisation where possible, open-file formats, metadata, and persistent and unique identifiers, are all pertinent to what we are trying to achieve in the Nordics. They would enable greater interoperability between health professionals, service providers, researchers, government agencies, and individuals. The adoption of common data sharing and governance practices, supported by compatible legislative, security, and accreditation frameworks within each Nordic country, could help overcome current restrictions and barriers of lengthy and complicated access processes.

THE NORDIC WAY

A common ground for Nordic data cohesion can represent a way that is true to Nordic values and the shared ideology for Nordic wellbeing. It can serve as an alternative to the comprehensive approaches of major economies like the US and in China, which feature commercial and state-controlled data ideologies, respectively. Such a ‘Nordic Way’ could be a guiding light for others to follow.

There is an urgent need to promote a shared data agenda that moves beyond party politics and short election cycles. The aim would be to inspire the needed innovation in social contracts and business models by putting health-related data at the centre of a paradigm shift from sick care to preventive health. Ultimately such an agenda could provide the foundation for a Nordic Way and enable both individuals and professionals to experience meaningful use of health-related data in real time. ■

Charles Alessi's breadth and depth of experience working within health provides a relevant and interesting overview of how healthcare is practically being delivered today as well as cutting-edge ideas on how it should be delivered in the future.

THE NORDIC WINDOW TO THE WORLD

AN OUTSIDE-IN PERSPECTIVE ON DATA STRUCTURES,
PRECISION HEALTH AND THE NORDIC POTENTIAL



Aside from working as a general practitioner in South West London for over 30 years, Charles Alessi now serves as the Chief Clinical Officer for Healthcare Information and Management Systems Society (HIMSS) International. HIMSS is a not-for-profit organisation working to improve healthcare in quality, safety, and cost-effectiveness through information technology and management systems. Additionally, he is a senior adviser to Public Health England, a government agency set up to protect and improve the nation's health and to address inequalities. His interests today lie in ageing, dementia and helping patients with two or more chronic conditions (multimorbidity), as well as how digital health and behavioural science can assist people in making better decisions. The Copenhagen Institute for Futures Studies interviewed Charles to get his perspective on what the future of healthcare might look like.

From your perspective, what are the most significant challenges in healthcare today?

It's very clear that the systems we have at the moment are not sustainable. First, we practice medicine by body part rather than looking at an individual holistically. We don't appreciate that non-health determinants are as important as they are. Therefore, we continue to focus on biomedical models which only provides 20% of value to the individual while ignoring the 80%. Secondly, our systems are set up in a way that not only values but also benefits organ-

isations that provide care rather than organisations that prevent the need for people to receive care. Essentially, we reward illness and we don't reward the prevention of illness.

How could the incentive and reward structures of systems be changed to promote the prevention of illness?

Systemically, there are two things that need to change. One that is absolutely fundamental is defining new financial metrics that drive the system. As long as we continue to reward organisations for providing solutions to illness, we cannot expect those organisations to concentrate on prevention. It's not because people working there are malicious or because they are not trying to do the right thing, but because their organisations are set up to treat diseases. The second thing is that we need to assist organisations in making this transition. We need to both reward organisations for delivering good care, but we also need to start the introduction of new metrics which prevent illness in the first place. We cannot expect systems that are already struggling with coping with multi-morbidity, the burden of non-communicable diseases (NCDs) and cardio-metabolic disorders to also be able to cope with prevention. If we don't sort the financial metrics out, this will remain an aspiration.

On that note, in the Nordics, about 9.8% of GDP is spent on reactive treatment of diseases whereas only about 0.3% is spent on prevention. The Nordic Health movement should be built on the principle that

“The Nordics are in such a wonderful place because they started on this journey of looking at general population health and making interventions many years ago”

Nordic governments in the future should spend half of the health budgets on treatment and half on prevention in what is called the 5/5 Aspiration. Based on your experience and knowledge, how can we start to make this shift happen?

First off, let me say that I agree that it is essential that you reallocate funding so it is spent equally on treatment and prevention, but you have to be careful how you do it. If you do it by taking money away from the health system and putting it into a new system, you’re more likely to get pushback from the health system that won’t have enough money to deliver care. Additionally, it is probably not the most efficient way to do it. I think the best way to do it is to leave the money where it is and change the financial metrics that drive the existing health system and give them the challenge. Health systems are pretty effective at following the money, so let’s use that!

During the Nordic Health 2030 workshop series, it was also pointed out that healthcare systems have been trying to make the shift for a long time now...

I agree we have been on the path to try and make a change the last 30 years, and we still haven’t made it. However, I would suggest that we continue on that path with an addition. That addition is something called precision health. It is the flipside of precision medicine and focuses on predicting, preventing, and curing disease precisely. I think that is our only hope. If you manage to do that, there will be two things you will achieve. First, by empowering people, you will get more activated populations, and evidence shows that an activated individual is less likely to express symptoms. The second is that if you manage to increase traction around risk-reducing behaviour preventing disease means that individuals will be healthier longer as well as more productive and contribute more to society. Precision medicine, in the beginning, would decrease costs but because of specialisation we may not see the reductions in cost that we had hoped for. Therefore, the answer is precision health, which combines both preventive as well as predictive health.

What does precision health mean for individuals? How can it activate them to better care for themselves? Could you give some examples of how they could experience health in the future?

If we look towards behaviour, there is no reason why we can’t introduce gamification in the process and establish direct communication with the individual which doesn’t need to be mediated via the medical system. For example, if someone stopped smoking, they would get some points they could cash at the supermarket shopping for groceries. In addition, it could also help alleviate some of the inequalities between people from lower socioeconomic groups through financial incentives to buy healthier foods. And the point here is on incentivising and not forbidding! In the 21st century it is not the clinician’s place to tell individuals how to live their lives. Instead, the clinician is there to ensure you are aware of the fact that if you do something today in a certain way, it could have consequences down the line. The decision is ultimately down to the individual and should always remain their choice.

In order to empower people and make this shift a reality, the Nordic Health 2030 workshop participants concluded that a data sharing infrastructure is crucial. What do you think is required for creating an effective data sharing infrastructure?

As a starting point, we need to understand what we’re collecting and to try and collect it in approximately the same way throughout. To be working with the collected data we need to set up a system which enables that data to be correlated across multiple data types. That same system needs to be able to process payments based on the levels of success in terms of achieving whatever outcome has been determined. The third thing you need is to set up an interoperability layer in which all data is put that is completely transparent both to the individual and to everybody else. This transparency can also help dramatically improve performance of systems through competition. We have to encourage that.

Working for both HIMSS and Public Health England gives you a broad view of international developments in healthcare and with that in mind, what is the potential for the Nordics in general from an outside-in perspective?

The Nordics are in such a wonderful place because they started on this journey of looking at general population health and making interventions many years ago. The main advantage you have

“It’s about time you provided a window to the world to show that it is possible for an individual to move from one jurisdiction to another and have the same sorts of processes in place, which I think is within your capability”

is a different one and it is much more fundamental. The Nordics trust each other in general. Trust in government and in your systems is significantly higher than in a lot of other countries. Trust is at the basis of the relationship. You can have the world’s best IT systems and the world’s best infrastructure, but if you have a breakdown of trust between an individual and an organisation it’s not going to get you very far. Another significant advantage is the strong coherence as a group of countries going back to prehistoric times. The Nordics also have an educated population and the potential to activate that population in getting more involved in their health as well as care.

Do you think there is potential in greater collaboration across borders in the Nordics?

I think the opportunity the Nordics have is enormous. It’s about time you provided a window to the world to show that it is possible for an individual to move from one jurisdiction to another and have the same sorts of processes in place, which I think is within your capability.

Who do you think should be involved in making this happen?

Clearly the population needs to be there, which is a challenge in itself, but it is crucial that a very strong citizen voice is present in the development of these processes. On top of that, our colleagues from the healthcare sector also need to be included, as it is them that need to go through this transition. It’s a very big ask we’re making of them, so they have to be a part of the discussion. Lastly, without governments, the likelihood of anything happening decreases. While the Nordics have a reputation for conducting successful public-private partnerships, I am not entirely sure if it is the best way to go. It really depends on what level of trust the citizens have in their governments. To be honest, in my view, it doesn’t matter who provides the service, as long as they provide consistent, transparent, and high-quality care.

For example, for pharma companies, I think this is a wonderful opportunity to rescue a business model that clearly is under significant pressure. That doesn’t mean they need to take control of an ecosystem, but there are ways they can contribute and remain a vibrant and important player.

What do you think the biggest challenges are in making the transition?

I’m most worried the providers of traditional services, as they are the ones going through the most significant change. People who are caring, be they physicians, nurses or whoever need to be comfortable in the digital age. There’s a lot we should be doing in terms of digital immersion for these individuals to assist them in their digital journey. The training for physicians isn’t quite what it could be, they are asked to fill the gaps, treat disease and now they’re being asked to manage non-communicable disease risk factors all within a very tight consultation.

We also have to manage physician burnout better by ensuring we get the right training for clinicians. Currently, we’re still training physicians for the 20th century and it’s 2019!

There is a heated debate around ethical issues in relation to health data. What is your perspective on this matter?

Ethics are important especially in that people are not discriminated because of the choices they make. The other ethical issue we face is the issue of consent. We need to rethink consent, as we have used consent in a binary fashion to death. So-called blanket consent is what we tended to use up until now, but in the world of precision health, we have got to be thinking far more in a dynamic consent situation. Here, consent is something which is associated with the interchange of information. In addition to how the system treats individuals, it is crucial how this new form of healthcare is deployed.

Everyone worries about ethics and consent when it comes to healthcare data. Nobody cares about ethics when it comes to everything else that we do. Even though it is harvested freely by all other organisations from the place you buy your books and your clothes to the supermarket. I think ethical issues related to health data are in the hands of the citizen. If the citizen is willing to share data with an organisation by giving consent that they trust not to sell their data indiscriminately, I don’t know what the ethical issues are. Ethical issues only arise if somebody is not aware of what is happening. People are fixated around who owns data, it doesn’t matter who owns the data, what matters is how it’s used.

If people are not given a choice, however, and it’s perceived that people will be told what to do, I think you’re going to have revolution in the streets. ■

WHAT DO YOU THINK?

We want your input on how the ideas and concepts presented can become a reality and how they can be improved.



Scan the QR code with your smartphone to access the Nordic Health 2030 survey and let us know.

Part IV

**WHAT DID
30 DECISION
MAKERS
AGREE ON?**

Presenting the outcomes of the Nordic Health 2030 workshop series.

The Copenhagen Institute for Futures Studies facilitated 5 workshops with the participation of 30 leading decision makers within the Nordic health landscape. The overarching aim of the workshops was to inspire an emerging Nordic movement for sustainable health.

WORKSHOP I

STOCKHOLM

January 24, 2019

Identified internal and external pressures on the healthcare system. Outcomes are explored in the article "The New Reality of Health in the Nordics"

WORKSHOP II

COPENHAGEN

February 5, 2019

Identified shared Nordic values responding to future dilemmas within health

WORKSHOP III

OSLO

March 5, 2019

Developed the sustainable health model motivating the Nordic Health 2030 Movement

WORKSHOP IV

HELSINKI

March 27, 2019

Developed the granular philosophy of the Nordic Health 2030 Movement

WORKSHOP V

UN CITY

May 20, 2019

Developed magazine outline and discussing next steps for Nordic Health 2030 Movement

THE NORDIC HEALTH 2030 MOVEMENT

The fundamental shift from sick care to preventive health requires a movement that will inspire and activate people across the Nordics.

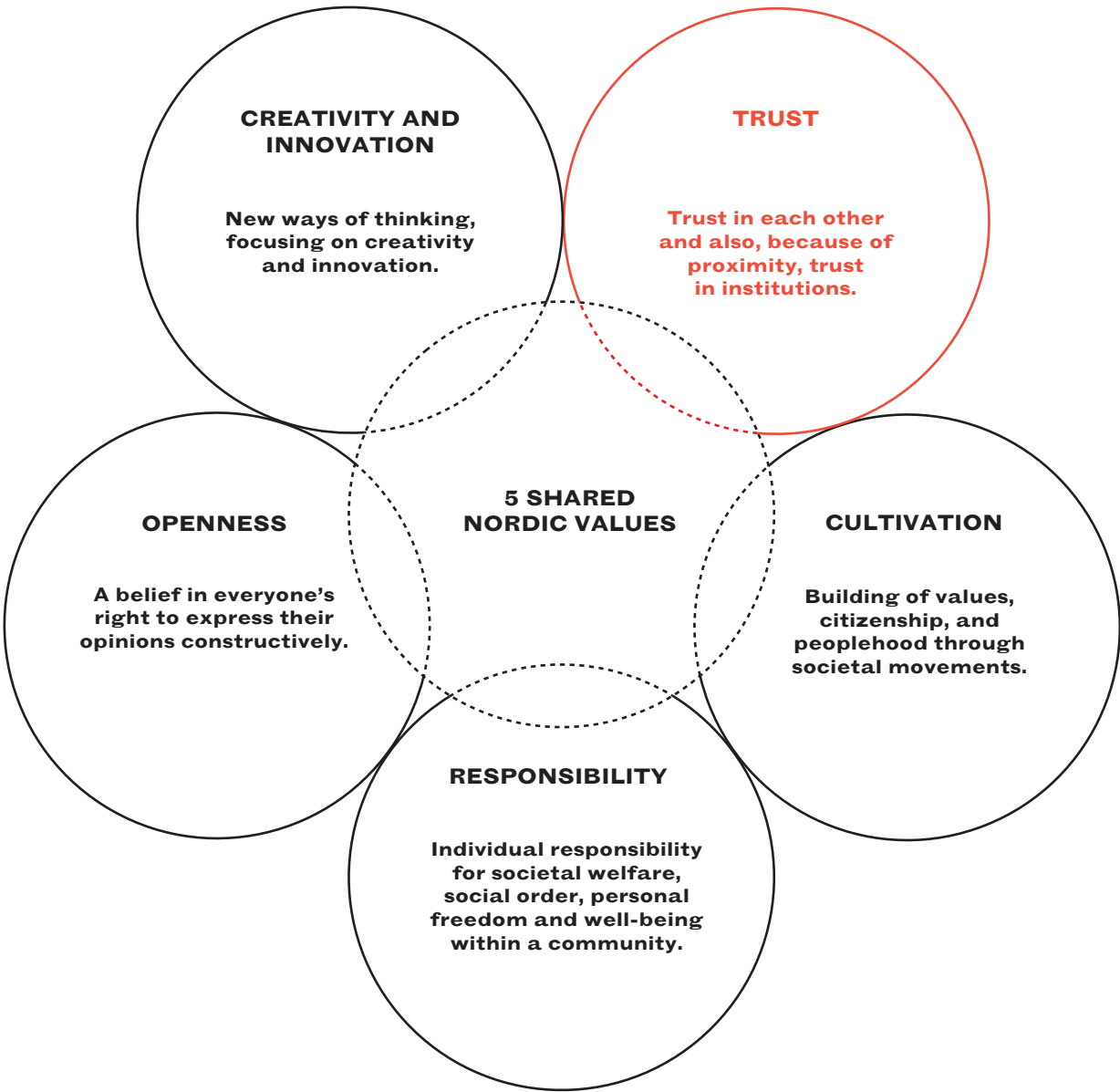
Such a movement is, in many ways, already on its way. A large number of innovative initiatives both on individual, grassroots and institutional levels are emerging. These efforts make use of a variety of bottom-up and top-down instruments to promote preventive behaviours among individuals and redesign our healthcare systems. However, until now, these initiatives have taken place in the relative isolation of one another.

The Nordic Health 2030 movement strives to facilitate a shared agenda and dialogue between the ongoing efforts and stakeholders that are active in the health value chain. Accordingly, the movement serves to inspire stakeholders to take collaborative action. Equally, the movement will grow in strength and impact as surrounding activities inside and outside of the Nordic region continue to gain momentum.

An early version of this shared agenda is now in existence. The following pages lay out the philosophy and the key concepts developed over the course of the Nordic Health 2030 workshop series.

NORDIC VALUES

During the Nordic Health 2030 process, the Copenhagen Institute for Futures Studies facilitated an exercise to identify shared values across the Nordics. The workshop participants identified and refined five values that emphasise fundamental aspects of life, culture, and society shared among the Nordics. Trust, highlighted in red, was highlighted as the most profound value. The shared values should serve as a guiding light for making the shift from sick care to preventive health a reality.

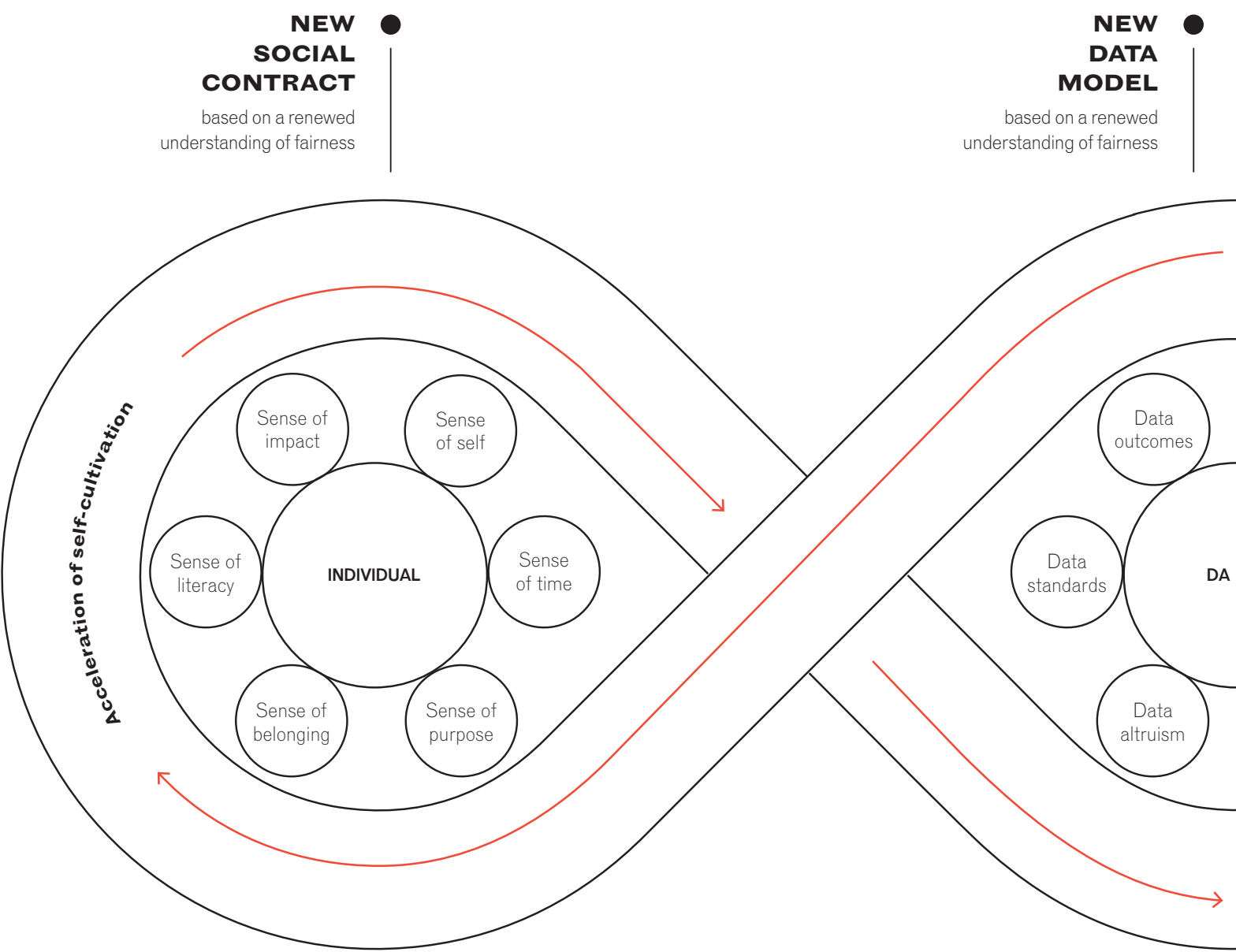






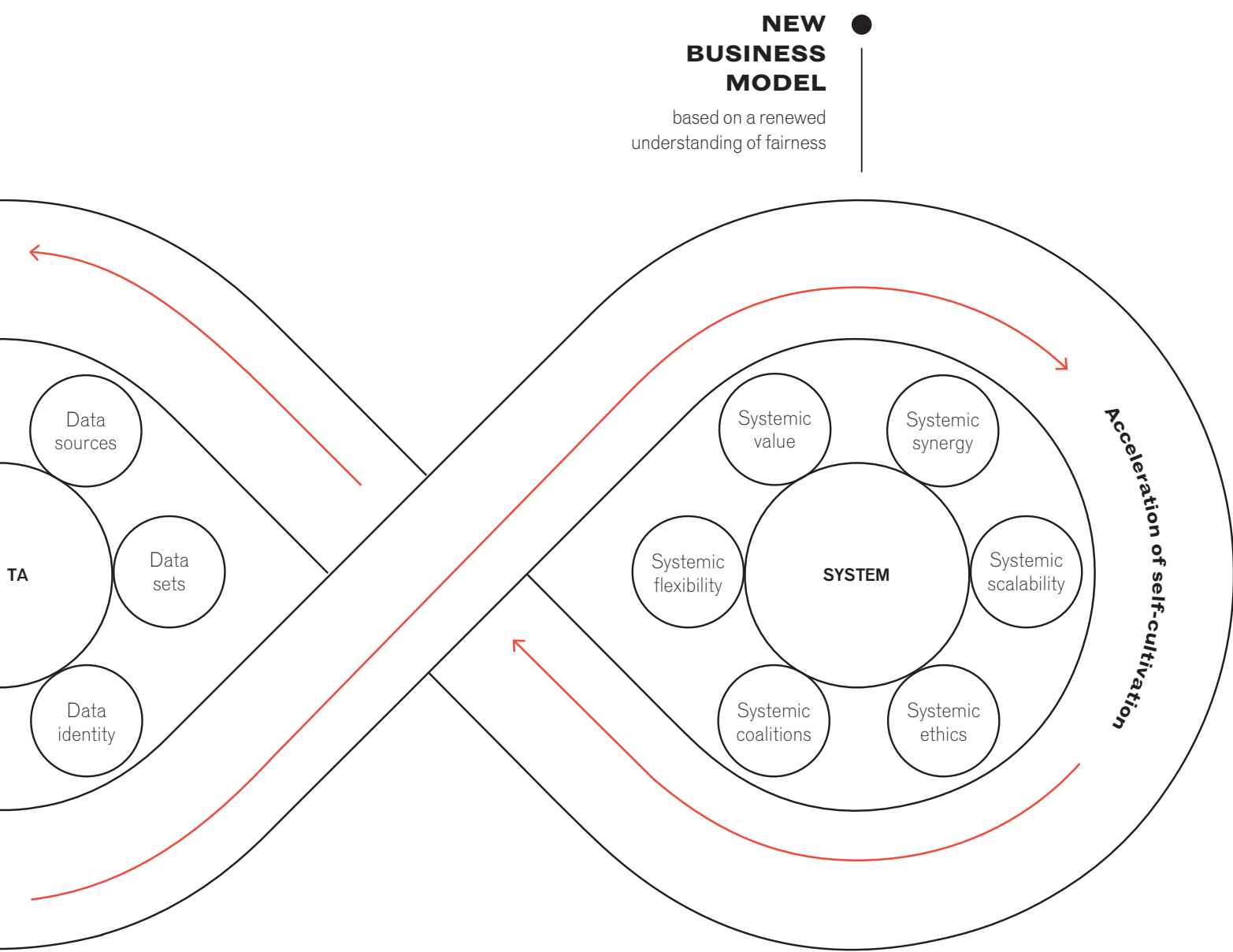
THE SUSTAINABLE HEALTH MODEL

The sustainable health model visualises the philosophy and the key concepts developed over the course of the Nordic Health 2030 workshop series. Sustainability surfaced as the main discussion point throughout the workshop exercises. The loop below illustrates how individuals, data, and the system can enable the urgent transition from sick care to preventive health. The red arrow shows how a societal movement drives the synergy between these three elements that will support preventive health.



THE 5/5 ASPIRATION

A sustainable approach to healthcare requires a fundamental shift from sick care to preventive health. By 2030 the Nordic countries should allocate 5% of the GDP to treatment and 5% of the GDP to prevention.



PHILOSOPHY OF THE NORDIC HEALTH 2030 MOVEMENT

NEW SOCIAL CONTRACT

We must inspire and inform a grassroots movement around the self-cultivation of preventive health to secure the long-term prosperity of the Nordic population. We must encourage the individual to become their own point of care. We must reward the sustainable self-carer proportionately for their efforts, while still providing the necessary support to those who need it.

Sense of self: The individual should be able to gain a holistic understanding of their health.
Sense of time: The individual must be able to predict the most likely development of their health over time.

Sense of purpose: The individual must be able to identify values and preferences that are meaningful to their health.
Sense of belonging: The individual must be able to rely on a network of people and resources that can support their health.

Sense of literacy: The individual must be able to identify realistic changes in behaviour that can improve their health.
Sense of impact: The individual must be able to positively impact their health through their actions.

NEW DATA MODEL

We must establish data infrastructures that accelerate the self-cultivation of preventive health to secure the long-term prosperity of the Nordic population. We must encourage data flows centred on the individual as the point of care. We must reward the sustainable self-carer and stakeholder proportionately for their joint participation in data streams, while still respecting the confidentiality of health data.

Data sources: The individual must be able to capture biological data, behavioural data, and self-reported data about their health.
Data sets: The individual must be able to aggregate, enrich, use, and share their health data.

Data identity: Individuals and stakeholders must be able to apply identified health data without having safety compromised.
Data altruism: Individuals and stakeholders must be able to allow the system to access health data for the greater good of the population.

Data standards: The system must be able to apply interoperable standards to enable the transdisciplinary utilisation of health data.
Data outcomes: The system must be able to demonstrate health outcomes both for individuals and for the population.

NEW BUSINESS MODEL

We must repurpose and redesign the provision of preventive health services to secure the long-term prosperity of the Nordic population. We must encourage systems that enable individuals as points-of-care. We must reward the sustainable stakeholder proportionately for their provision of preventive health services, while still incentivising those who provide high-quality sick care.

Systemic synergy: The cross-functionality of the system must enable the holistic provision of preventive health services across the lifespan of individuals and populations.
Systemic scalability: The built-in intelligence of the system must proactively identify better preventive health opportunities across the lifespan of individuals and populations.

Systemic ethics: Societal discussions must stress how the system can become more sustainable based on a preventive health model and mandate better ways of developing and enforcing the law.
Systemic coalitions: The preventive health model must operate beyond the limitations of short-term political lifecycles and traditional public-private stakeholder relationships.

Systemic flexibility: The transition to preventive health services must be able to scale through the increased flexibility of workforce and technology capabilities.
Systemic value: The incentive structures of the system must reward the acceleration of preventive health services based on demonstrated value.

HOW CAN YOU TAKE PART?

*Join us in the transition towards preventive
health in the Nordics.*



*Scan the QR code with your smartphone to get involved by
signing up for the Nordic Health 2030 Movement.*

Part V

WHO CAN DRIVE THE TRANSITION?

*The Nordic Council of Ministers 2030 Vision and the future
roles of stakeholders in health.*

The Nordic Prime Ministers met in Reykjavik in August 2019, where they adopted a new vision for the Nordic Council of Ministers. Now the work begins to put action behind the words: *The Nordic region will become the most sustainable and integrated region in the world. The co-operation in the Nordic Council of Ministers must serve this purpose.*

2030 VISION FOR NORDIC COOPERATION



Established in 1971, the Nordic Council of Ministers is the official body for co-operation between governments in the Nordic region where all decisions are made by unanimity. The work of the Nordic Council of Ministers is divided into eleven subject-area councils, such as the Council of Ministers for Health and Social Affairs (MR-S), and the Council of Ministers for Nordic cooperation (MR-SAM).

The Secretary General post is currently occupied by Paula Lehtomäki, who took over in March 2019, moving from a position as State Secretary to the Prime Minister of Finland. Paula is the first woman and the youngest person ever to take on the position of Secretary General at Nordens Hus in Copenhagen. The Copenhagen Institute for Futures Studies had the opportunity to meet with Paula and learn more about her plans for strengthening the Nordic region and how cooperation will become even more relevant for the people in the Nordics.

Given the new vision adopted by the Nordic Prime Ministers for the region to be the most integrated and sustainable region in the world by 2030, what are the most important steps to drive this vision forward?

The vision is our ambitious goal for the coming decade, and we are currently developing action plans and programmes to bring it to life. These must be set for 2021 with continuous revision as we progress in order to make sure we achieve the target. We must keep up to date and take advantage of new opportunities to facilitate mobility and ensure our policies so that our societies, our economies and our way of life in general take a more sustainable direction. I want to emphasise the prime ministers' focus and discussions on sustainability and climate change. They have made it clear that they expect clear priorities in these terms. This is going to be at the core of Nordic cooperation and the process we are now embarking on. Further, I believe the vision is so clear that it enables us to harmonise the efforts under one umbrella while making sure that we are working in the same direction. So, what we are doing will be clearer for our stakeholders, while we work to align the many ongoing initiatives that are under the purview of the Nordic Council of Ministers.



“...if I have an accident on my bike on my way to work here, there will be no data available from my personal health history, simply because it is locked up in Finland...”

What kinds of Nordic stakeholder collaboration will be needed to drive this vision?

We need the engagement of a multitude of stakeholders to drive this vision forward, as there are a broad range of issues that need to be solved. If you look at data, and not only health data, we need standardisation, a secure platform, and we need to ensure high quality capture of data, as well as the way we use data. It's a very complicated entity I would say, and it requires shaping regulative frameworks and securing technical solutions in order to make sure that citizens' sensitive data is kept and used in a safe way. We absolutely need private actors involved, they are partly the ones that are going to utilise the data in the future, and we are the ones that help figure out the structures that need to be in place for it to be used. So, I think public-private partnerships should have a central role. They represent a strong and sustainable model for collaboration that ensure that a wide range of voices are heard in the development, implementation, and maintenance of large-scale projects.

What do sustainability and integration mean for the long-term development of Nordic healthcare and welfare models?

First of all, sustainability also concerns social sustainability, and integration means not only integration between the Nordic countries, but it also means integration into society. It's important that you feel that you are a member of society and that you feel that you have equal opportunities. And here we come back to health services and the importance of good and equal possibility to live a healthy life in the Nordics. There is a growing amount of social issues where your health is often linked to your social background, so it is very important that we are able to support equal health for everybody.

How do you see strong Nordic cooperation enabling the region to overcome the challenges ahead?

The background of Nordic cooperation is based on a similarity between the countries. As a result of that similarity, we also have a lot of the same challenges that we tend to look at in a similar manner. So, when we can find solutions together, it's often much more efficient, and that is why we share best practices among each other when each country has realised what is working and what is not. Nordic and European countries share many of the same challenges as well as aspirations to implement concrete solutions

aimed at digitalising and ensuring better, more secure, and flexible use of health data. This is to support substantial value creation for patients and society, including new growth and business opportunities in the life science and health sectors.

Why is there a need for collaboration on health data in the Nordic countries?

For the Nordics to be the most sustainable and integrated region in the world, health data will play a crucial role. Essentially because it can provide us with better health and improve the general welfare, where we still have a lot of work to do. It will allow us to innovate and help countries develop healthcare based on the high-quality data we have recorded over a long time. There is a quite practical example here. Let's say that if I have an accident on my bike on my way to work here, there will be no data available from my personal health history, simply because it is locked up in Finland where I am originally from. If I am unconscious, I cannot give consent for my data to be used or transferred, so in terms of making a digitally integrated region, this is something we are working towards achieving.

In terms of making Nordic cooperation more relevant for the people in the region, how do you see the proactive involvement of citizens making the vision a reality for all?

Yes, sometimes cooperation in the Nordic region can feel a little bit distant from everyday life in the Nordics. So, we need to clarify what we are doing and also remember that our purpose is to serve the people of the Nordics. We are trying to have more active and open channels with civil society now. I'm planning visits to all the Nordic capitals, where we will discuss climate issues. We are also talking to environmental and civil society organisations in order to discuss what should be done on an institutional level in the Nordics. In connection to the work with the new vision during the fall, we will try to arrange a Nordic chat on social media where citizens will have the opportunity to talk directly to us about ideas, initiatives, needs, or suggestions concerning life in the Nordics countries and Nordic cooperation.

In order to achieve the vision for the region, three priorities have been made. The first one is the promotion of a green transition of our societies, working towards carbon neutrality, and a sustainable, circular and bio-based economy. As the health sector makes up a significant part of

“Enabling access to a citizen’s health care data through their Nordic e-ID makes sense. It is a logical next step to work towards in terms of a Nordic digital identity...”

the Nordic economies, how will this transition impact healthcare in the Nordics?

The Nordic Ministers for Business have already agreed to support innovation in the health sector by making it easier for different actors in the industry to access health data across national borders. The ministers will also support the transition to a circular economy in the business community through new Nordic programmes launched by the business ministers in Reykjavik in June this year. Practically, Nordic Innovation’s and NordForsk’s health programmes are vital instruments that contribute to making the Nordics a leading region for research, sustainable growth, as well as supporting entrepreneurship, innovation, and competitiveness in the region. A part of the green transition in health care has to do with the implementation of different e-Health initiatives, where patients for example don’t have to travel to see a doctor, but can have long-distance consultations. This allows for both more efficient care and less transportation.

The second priority concerns the promotion of green growth in the Nordic region based on knowledge, innovation, mobility and digital integration. How do you think this priority relates to the interaction between individuals and healthcare systems?

I think the interaction relates to and relies on a high level of trust, which is a rather unique feature of the Nordic countries. Now that we are entering the digital era with all this information, it is our responsibility to use it for innovation and for the public good in order to maintain the high levels of trust between the people of the Nordics as well as trust in Nordic institutions – especially in health, since data in this area is often considered quite sensitive.

The third priority focuses on social sustainability by promoting an inclusive, equal and interconnected region with shared values and strengthened cultural exchange and welfare. How can we ensure that the principles of inclusivity, equality, and welfare are also present in healthcare?

Demographic challenges have a major impact on health care systems, and in terms of equality we still have quite some work to do. Clearly, there needs to be a focus on how to cover the costs of our increased disease burden and continuously improving treatments, while keeping treatment costs down. We need to make sure that healthcare is economically sustainable for the

region. In terms of inclusivity and equality in healthcare, we have people in multiple regions of the Nordics living in scarcely populated areas like the Arctic. We must also provide them with access to healthcare services. E-health initiatives could especially help citizens living in remote areas that have historically had more limited access to traditional points of care to receive better and more timely advice. Social sustainability has to do with people feeling included and equal in a society, and in healthcare it means that everyone has the possibility for high-quality treatment and health services. It is crucial that all the people in the Nordics feel that they have equal opportunities regardless of their capabilities and mobility.

You are working towards a digital update for the Nordic passport union?

Yes, we sometimes call it the 'Passport Union 2.0', as we have the union from the 1950s, which is a traditional passport union. The aim of the new union is to enable the use of national eID across the Nordic countries. It is the digital counterpart to a physical form of identification in the offline world such as a passport, ID card or driver’s license. It is a verified identity that provides the credentials necessary to trust that a person is who they claim to be online. I think it is important for Nordic citizens to be able to use their national eID and digital services safely in neighbouring countries since the Nordics are already so digitalised.

Could the Nordic e-ID be extended to include not just the personal ID, but their health data as well?

Enabling access to a citizen’s health care data through their Nordic e-ID makes sense. It is a logical next step to work towards in terms of a Nordic digital identity, but there are still many questions to be solved with regard to standardisation of data across the countries, permits, infrastructure and safety.

How can cooperation in the area of health data give the Nordic countries an advantage within the EU?

I believe in a Nordic advantage. Even though we get the framework legislation from the EU, we can form more tailored initiatives that benefit the Nordic region as a whole because we are so similar both socially and structurally. But this still requires political agreement on what we want to achieve, what to prioritise, and how we should all contribute to realising a unique Nordic Way. ■



NORDIC INNOVATION & NORDFORSK

NORDIC INNOVATION

The Nordic Industrial Fund was established in 1973 with the purpose of promoting research, innovation and education within the industrial sector of the Nordic countries. In 2011, it was renamed Nordic Innovation and now has the promotion of cross-border trade and innovation as its main goal. Nordic Innovation is an instrument for the Nordic Ministers of Business and Innovation. The mission of Nordic Innovation is to contribute to making the Nordics a leading region for sustainable growth and to increase entrepreneurship, innovation and competitiveness for Nordic businesses. Nordic Innovation supports projects and programmes where there are complementary skills, knowledge, and expertise in the Nordics in order to stimulate innovation and improve conditions for Nordic markets and exports. Nordic Innovation is a small and agile organisation working together with key stakeholders within the business and start-up communities, cluster organisations, trade promotion agencies, investors, and decisionmakers. By bringing people together and connecting the right stakeholders, Nordic Innovation gives the Nordics an even greater edge.

Svein Berg, Managing Director, Nordic Innovation

“At Nordic Innovation we are very fortunate to be one of the tools for achieving the Nordic Prime Ministers’ vision of becoming the most sustainable and integrated region in the world

by 2030 and, I would like to add, the most integrated health region in the world. We are aiming at finding solutions to how we can bridge Nordic health data and personal data, because that is essential for achieving an integrated health region – but also essential for innovation, cross-border collaboration and, most of all, the benefit of the Nordic people”

Nordic Innovation’s programme on health: Health, Demography and Quality of Life

The overall goal of the programme is that by 2030, the Nordics will make up the most sustainable and integrated health region in the world and provide the best possible health care for all. The programme is built around four action areas, which will continuously be developed as the programme progresses. The aim of the “*Bridging Nordic Data*” initiative is to support and find solutions on how to bridge Nordic health data and personal data for utilisation in the Nordic health ecosystems. Nordic Innovation has been a part of the Nordic Health 2030 process, has co-funded the Nordic Interoperability Project (NIP) with the aim of putting health data to use in cross-border settings, and has financed three hackathons showcasing how health data can provide new health products and solutions. Additionally, an overview of the main legal obstacles and differences in how rules and legislation are implemented in each of the Nordic countries will soon be completed by

Nordic Innovation, as well as an international metadata symposium on the potential of putting Nordic health data at stake. All activities within “*Bridging Nordic Data*” have the aim of pushing the health data agenda for the benefit of Nordic businesses, organisations and Nordic people, making the Nordic region a frontrunner.

The “*Healthy Cities*” initiative has the aim of improving health and quality of life for Nordic citizens by creating a healthy and supportive environment based on innovative solutions for mobility, nutrition and urban spaces. The “*Prevention and Healthy Patient*” initiative will focus on prevention and value-based health care, prepare for the development of solutions using personal health data, and increase the involvement of the patient in treatment to ensure the best possible quality of life. Finally, “*Value Chain Collaboration*” is a contribution to boost exports of Nordic solutions, strengthen Nordic export networks, and create value chain collaborations in markets with a high potential for Nordic involvement. Nordic value-chain collaboration projects are taking place in the US, Germany and Canada, where cluster organisations and Nordic trade promotion organisations are providing platforms and network opportunities for Nordic companies to meet new partners from both inside and outside the Nordics in order to position themselves and create new opportunities.

The vision of the Nordic Council of Ministers is to make the Nordic region the world's most sustainable by 2030. The Nordic Council of Ministers strives to realise the vision put forward by the prime ministers of the Nordic countries and a number of Nordic institutions operating within different sectors. Two institutions under the purview of the Nordic Council of Ministers, NordForsk and Nordic Innovation, are especially active in realising this vision. NordForsk provides funding for and facilitates Nordic cooperation on research and research infrastructure while Nordic Innovation is working to promote cross-border trade and innovation. The complementary nature of the two institutions is promising for joint activities, especially within the areas of health, social sustainability and green growth.

NORDFORSK

NordForsk was established in 2005 by the Nordic Council of Ministers with the task of facilitating Nordic research and research infrastructure collaboration. NordForsk administers Nordic research programmes within a broad range of areas and often with interdisciplinary components. The initiatives are co-funded by the main Nordic financiers of research and innovation, which ensures a high Nordic added value. Through its activities, NordForsk brings together national research groups and promotes research activities of the highest scientific quality. NordForsk seeks to enhance the quality, impact and efficiency of Nordic research cooperation, thereby helping the Nordic region to become a world leader in research and innovation. Facilitating cooperation on digital infrastructures has become increasingly important during the past few years. NordForsk has put an emphasis on the need for better preconditions for research that utilises register data across Nordic borders. Activities include identifying obstacles and challenges that impede Nordic research on health data and to propose ways of overcoming them.

Maria Nilsson, Special Adviser, NordForsk and Leader of the Health and Welfare Programme
"The Nordic registers and biobanks constitute a unique asset of digital information that have great potential for research and

innovation. Research utilising sensitive data is, however, challenging and time-consuming, especially at the Nordic level. This knowledge resource, which is unique to the Nordic countries, is not utilised to its full potential. NordForsk has therefore put a focus on identifying obstacles impeding Nordic research cooperation on sensitive data over the years and has initiated activities with the aim of facilitating health data sharing across borders, keeping the individual's integrity in focus."

NordForsk and health data: The Nordic Programme on Health and Welfare and digital infrastructure collaboration

The overall goal of the Nordic Programme on Health and Welfare is to improve health in the Nordic countries by finding solutions to societal and public health challenges through high-quality research. The Nordic Programme on Health and Welfare was launched in 2014 and has a budget of more than NOK 445 million. To date, the programme has funded more than 30 projects, many of which address opportunities and challenges related to register-based research, i.e., utilising sensitive data in research across borders. The vast majority of projects will utilise health and register data in combination to answer research questions of high societal value.

Initiatives with infrastructure compo-

nents that use Nordic health data include the eScience Globalisation Initiative, the Tryggve project for sensitive data, and the Nordic Biobank Network pilot on colon cancer. The incentives strive to develop best practice in handling sensitive data across borders from different angles and include piloting the development of digital solutions, methods of analysis, and processing of sensitive data.

Together with Nordic experts representing different actors in the health data sector, NordForsk has placed an emphasis on identifying and overcoming the challenges and obstacles impeding sharing of sensitive data in Nordic research. More recently, NordForsk has coordinated activities within the Norwegian priority project, 'Nordic Collaboration for Better Health', with the aim of strengthening Nordic research collaboration on health data. The "Nordic Commons for Health Data" is a vision for a shared virtual space where scientists can work with the digital objects of biomedical research.

The Nordic Commons will allow researchers to find, manage, share, use, and re-use data, software, metadata and workflows. The concluding report on this project, to be published in late autumn 2019 will include recommendations for the next steps towards implementing a Nordic Commons for Health Data. ■

NORDIC INITIATIVES

SPOTLIGHT ON HIGH-IMPACT COLLABORATIVE EFFORTS ACROSS THE REGION

The Nordics have embarked on a number of collaborative efforts for the sharing of data, expertise, and experience in order to drive the development of personalised and preventive healthcare.

EOSC-Nordic is the Nordic branch of the European Open Science Cloud, which is an initiative to accelerate and diversify transdisciplinary research by increasing access to, sharing, and harmonising existing data between countries in order to reduce the need for preliminary data collection in new research projects.

Nordic PerMed is a collaborative research funding initiative supported by a number of stakeholders across the Nordics with the aim of advocating for the benefits of data-driven personalised medicine as well as the potential of the Nordics to implement it efficiently and effectively while setting an example for the rest of Europe and the world.

The Nordic Commons for Health Data is a NordForsk vision of a shared virtual space where scientists can work with the digital objects of biomedical research. This is a system that will allow investigators to find, manage, share, use and reuse data, software, metadata and workflows.

The Nordic Interoperability Project is a bottom-up initiative led by a number of stakeholder organisations that strives to break down barriers to cross-border health data sharing across the Nordic countries. NIP develops technical interoperability showcases that start sustainable, solution-oriented dialogues about the future of data-driven health in the Nordics.

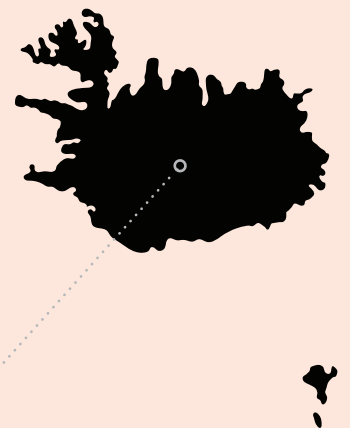
The Nordic Society of Human Genetics and Precision Medicine (NSHG-PM) has been established to foster greater pan-Nordic cooperation in research related to genetics and precision medicine. NSHG-PM also aims to make its findings easily accessible and understandable in order to increase their potential of improving public health and promote the highest possible legal, regulatory, social, and ethical standards.

Tryggve is a collaborative programme that develops scalable data infrastructures for secure, efficient, and ethical storage, analysis, and sharing of sensitive biomedical data within and across the Nordic countries. The programme involves public and private stakeholders and aims to demonstrate the benefits cross-border data and biomedical sample sharing for research.

The Nordic Alliance for Clinical Genomics is an independent NGO that seeks to share valuable health data responsibly among Nordic partners in order to improve medical diagnosis and treatment as well as research.

Headquartered in Reykjavik, Iceland, **deCODE** takes advantage of unique expertise and rich population resources to analyse and better understand the human genome. deCODE has already discovered genetic risk factors for a number of common diseases such as cardiovascular disease and cancer.

Copenhagen Healthtech Cluster established **Data Saves Lives** in 2017. The partnership brings together health actors across public and private sectors to secure better use of Danish health data and has made **The Data Map** that explores 160 Danish health databases.



SciLife Lab - Genomic Medicine Sweden is a national resource hub that provides life scientists with access to state-of-the-art technologies for personalised medicine research. The lab strives to bring together scientists from various fields to produce transdisciplinary research.

The Finnish Innovation Fund Sitra's **International Human Account Network (IHAN®)** project aims to build the foundation for a fair and functioning data economy. The main objectives are to create a method for data exchange and to set up rules and guidelines for ethical use of data on a European level.

FinnGen is a nationwide, public-private genetic research program in Finland that aims to collect and analyse samples from 500,000 Finns (about 10% of the population) in order to improve diagnostic accuracy and develop more effective, personalised treatments.

Finland is trailblazing by passing new enabling legislation on the secondary use of social and health data. The new **FinData** service will start at the beginning of 2020. The process is an excellent example of successful cooperation between public and private stakeholders.

BigMed is a Norwegian partnership of organisations that aims to identify and eliminate obstacles that are hindering the advancement of precision medicine. As a part of this effort, BigMed develops and demonstrates tools for the implementation of precision medicine that create value for both patients, clinicians, and other stakeholders.

The Danish National Genome Center is the national institution for genomic research and bioinformatics that seeks to advance personalised medicine in Denmark. The National Genome Center collects, stores, and analyses samples for research and tailored treatment, as well as provides other research institutions access to research tools.

The Oslo Cancer Cluster is an oncology research and industry partner cluster that strives to accelerate the development of new cancer diagnostics and treatment in order to improve patient experiences. The cluster represents a successful example of broad public-private stakeholder collaboration to advance precision medicine in the Nordics.





WHAT'S HAPPENING BEYOND THE NORDICS?

As the Nordic countries are members of both the European Union and the European Economic Area, any Nordic development is dependent on the broader European context. Innovative health initiatives on a European level have a decisive impact on the future of healthcare in the Nordic region. The Nordic countries have the autonomy to innovate, and with their blend of unique expertise, experience, and drive to collaborate, they are among the best positioned to set best-case examples. Potentially, the Nordic region could, through a joint effort, pave the way for a more equitable, effective, and human-centric healthcare system. By contributing significantly to several large-scale European initiatives and actively participating with local nodes in pan-European initiatives, the Nordic countries have an opportunity to share their expertise, proactively respond to regional developments, and shape the future of data-driven preventive health care in the EU and beyond.



INFRASTRUCTURAL INITIATIVES

Biobanking and BioMolecular resources Research Infrastructure – European Research Infrastructure Consortium (BBMRI-ERIC) is the world largest biorepository of human samples and data. BBMRI-ERIC connects more than 500 biobanks from nineteen countries in the EU. The consortium aims to facilitate research on human samples in order to advance personalised medicine. It brings together a wide range of stakeholders including researchers, biobankers, industry, and patients to support biomedical research.

European Clinical Research Infrastructure Network (ECRIN) is a non-profit research infrastructure that supports multinational clinical trials in Europe. The infrastructure provides increased access to patients, resources and expertise across Europe. ECRIN also aims to enhance the ability of European institutions to conduct multi-country clinical research.

European Research Infrastructure for Translational Medicine (EATRIS) is a research consortium that focuses on preclinical and early clinical development of drugs, vaccines and diagnostics. EATRIS provides support in the fields of advanced therapy medicinal products, biomarkers, imaging and tracing, small molecules, and vaccines.

Horizon 2020 is the financial instrument implementing the Innovation Union, a Europe 2020 flagship initiative aimed at securing Europe's global competitiveness with a programme on Health, demographic change and wellbeing. The outcomes of Horizon 2020 will be continued by Horizon Europe between 2021-2027, which is a 100 billion Euro research and innovation programme in which the EU increases science spending levels by 50%.

INFORMATION AND COLLABORATIVE NETWORKS

WHO Regional Office for Europe's Digitalization of Health Systems, Division of Health Systems and Public Health: The Digitalization of Health Systems Initiative operates under overarching focus areas for facilitating the application of digital health in Member States by enabling the transition to integrated, people-centred models of care and facilitating the move from treatment to prevention. The initiative further supports achieving health-related SDGs by strengthening efforts for universal health coverage and transforming the delivery of care.

European Society of Pharmacogenomics and Personalised Therapy (ESPT) is a non-profit organisation that promotes training and research in pharmacogenomics and personalised therapy in order to improve the quality of information that is used in clinical practice as well as given to patients. ESPT also facilitates contact between stakeholders that share its objectives, particularly those working in Europe.

ELIXIR is an European intergovernmental organisation that aims to unite life science organisations in managing and protecting the data and gathered created by publicly funded research projects. The ultimate goal of ELIXIR is to coordinate bioinformatics resources to form a single data infrastructure that offers convenient access to researchers in academia and industry.

The European Bioinformatics Institute (EMBL-EBI), a part of the collaborative *European Molecular Biology Laboratory* initiative, connects scientists and engineers around the globe and provides the infrastructure needed to share data openly in the life sciences. It develops databases, tools and software that make it possible to align, verify and visualise the diverse data produced in publicly funded research.

THE DRIVERS OF THE TRANSITION

This figure illustrates the outcome of an exercise carried out during the final workshop in the Nordic Health 2030 series at UN City in Copenhagen, where participants voted on which stakeholders should drive certain aspects of the Nordic Health 2030 philosophy.

Stakeholder role:

primary driver

secondary driver

not a driver

			Individual					
Stakeholder category	Stakeholder No.	Stakeholder	Sense of self	Sense of time	Sense of purpose	Sense of belonging	Sense of literacy	Sense of impact
Personal network, primarily analogue	1	The individual						
	2	Family & friends						
	3	Personal health care team						
	4	School or workplace						
	5	Leisure time organisations						
	6	Citizen-to-citizen networks						
	7	Volunteer organisations						
Personal network, primarily digital	8	Social media						
	9	Online patient groups						
	10	Health apps						
	11	Health websites						
	12	Media						
	13	Patient opinion leaders						
Health care system, hands-on	14	Preventive health providers						
	15	Public hospitals						
	16	Private hospitals						
	17	Out-of-hospital services						
	18	GPs						
	19	Specialty doctors						
	20	Local clinics						
	21	Pharmacies						
	22	Life science industry						
Health care system, administration	23	International health organisations						
	24	EU institutions						
	25	pan-Nordic institutions						
	26	National health authorities						
	27	Regional health authorities						
	28	Municipality health authorities						
	29	Payers						
	30	Public health insurance						
	31	Private health insurance						
	32	Patient organisations						
Government	33	School system						
	34	Social system						
	35	Elderly care system						
	36	Community centers						
	37	Outreach programs						
	38	Local organisations						
Tech stakeholders	39	Public data aggregators & brokers						
	40	Private data aggregators & brokers						
	41	Big tech						
	42	Tech start-ups						
Other stakeholders	43	National governments						
	44	Politicians & political parties						
	45	Ethics committees						
	46	Legal authorities						
	47	Academic institutions						
	48	Educational systems						
	49	Interest organisations						
	50	Funds & philanthropists						

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Part VI

WHEN WE MOVE BEYOND 2030

*Scenarios for the future of health envisioned by the
Copenhagen Institute of Futures Studies.*

The following article outlines an aspirational personalised health scenario in 2050. Through this scenario we explore how the changes in the health landscape could create a personalised and preventive health care system.

PERSONALISED HEALTH 2050



The healthcare system is deeply integrated and influenced by social norms, policies, legislation and behaviours. We present a world where systemic, social and personal changes contribute towards a holistic and integrated health scenario. A central aspect of the personalised health scenario is the role of the individual – how does the individual evolve in relation to the system? How does individual behaviour interact with and shape the environment?

The scenario describes the developments in the past decades to shape our present-day reality in the Nordics in 2050.

PRESSURE POINTS FOR THE CURRENT HEALTHCARE SYSTEM

In the 2020s the health system was plagued by an onset of challenges: an ageing population, rising prevalence of chronic conditions, complex patients with multiple comorbidities, resulting in inefficient healthcare spending and a healthcare system grappling to overcome these challenges. Reduced prioritisation and decreasing resource allocation towards healthcare created a system that was wrought with challenges and underperforming. The pressures were felt by healthcare personnel and citizens, culminating in public unrest and a disengaged workforce, and political pressure to address an increasingly compromised and inadequate system. Widespread public support for healthcare personnel captured the zeitgeist and forced politicians and legislators to act.

Significant strides have been taken since then and the emphasis has categorically shifted from late treatment, to prevention, early

detection and intervention. There is increasing acceptance that a combination of primary, secondary and tertiary interventions is needed to achieve a meaningful degree of preventive care. In 2030, EU member states agreed to devote half their health budget to prevention and half to treatment by 2040. This '5/5 concept' accommodated a holistic quality-of-life approach, as opposed to the traditional short-term, incident-based treatment, which concentrated on treating the disease rather than the individual. The 5/5 concept has been applied in conjunction with a wider application of data; by using data and statistics, governments are proactively tracking progress and ensuring that their decisions are evidence-based. During the 2030s and 2040s, the healthcare system was in the process of being remodelled: decision-making was increasingly integrated with real-world evidence, frequently referred to as the data revolution. This allowed for intervention before symptoms were detected, for example, real-time tracking of cholesterol to prevent coronary heart disease before it manifests. Consequently, a measurable reduction in disease burden and an improved quality of life has been achieved that exceeds global trends.

Globally, one of the biggest challenges has been the widening gap between citizens with access to healthcare and those without. This disparity in access primarily affects the global North & South, but even within the EU, 20% of the population struggle with access to healthcare. Efforts to alleviate this disparity have seen some success within the EU. In 2030, a pan-EU health cultivation programme was implemented with educational approaches delivered to all citizens from the age of six and throughout

“Armed with access to data and the understanding of how to deploy this data, individuals are increasingly empowered and knowledgeable”

their lives, with the ambition of empowering individuals and building resilient citizens. On the global level, the global North continue to remain ahead of the global South in relation to access to healthcare. There are, however, developments in technology that hold the promise of closing the gap.

Individuals have experienced frustration with an underperforming health system. There has been a lower tolerance for inefficiencies, and citizens expect integrated solutions from both the public and private sectors. This intolerance and the resulting momentum have been a primary driver of systemic innovation. Individuals are increasingly resilient and resourceful, finding solutions for themselves if they feel that the system has failed them. Armed with access to data and the understanding of how to deploy this data, individuals are increasingly empowered and knowledgeable.

INNOVATION IN HEALTHCARE SYSTEMS

The 2020s saw the emergence of tech players in the healthcare sector. This was initially viewed with scepticism, as the interests of the healthcare system (public good) and the interests of tech players (profit) were at odds with one another. Over time, however, the distinction between public and private became blurred because of changing priorities. Citizens and healthcare personnel demanded efficiency and results, irrespective of the governance structure. The overriding sentiment called for a prioritisation of health, both sick care and preventive care. The healthcare system, which had been largely reactive and continually catching up with developments in the external environment, aspired to be resilient to keep up with the entrance of privately-owned players in the healthcare system in the past decades. Though initially challenged, key players in the healthcare system began to recognise the potential in reorganising the healthcare system, and the 2030s saw an increase in public-private partnerships and innovation targeted towards the healthcare sector.

The 2030s bore witness to an application of real-world evidence data management, digital services and increased connectivity, which facilitated the development of a sustainable healthcare system. With the aim to deliver affordable and cost-effective outcomes, sustainable healthcare systems require cooperation

from numerous stakeholders and coordinated actions across various system components. Key players and decision-makers in the public sector recognised the growing need and benefits of forming a healthcare ecosystem buttressed by public-private partnerships.

Shifting the focus from treatment to prevention and valuing the individual experience, while viewing technology as a tool assisting healthcare professionals and caregivers, paved the way towards a highly efficient and integrated healthcare system. New reimbursement structures and business model innovations combining wellness, quality of life, and health services were implemented. The individual became the primary ‘point-of-care’ allowing for convenient, timely, testing at various locations, such as physician’s office, ambulance, home or hospital, resulting in faster, more cohesive care.

Opening the healthcare sector to tech players created opportunities for more non-traditional parties to enter. This included insurance and pension funds, who entered the preventive healthcare arena as they recognised the benefit of a healthier population and lower disease burden. Though their motive is profit, their entrance in the healthcare sector has had a win-win outcome – healthier individuals and better economic efficiency for the public sector.

In 2050, health providers have access to data due to a global agreement on standards and requirements for interoperability, across both public and private sectors. This development was inspired by the International Telecommunication Union (ITU), which ensures maintenance of the communication infrastructure and continued updates and improvement of standards and protocols. As a part of GDPR 2033 Basel Agreement, EU countries decided to build on the success of the European Reference Networks and made the individual the official carrier of their own data. This was enabled by the 2029 EU agreement to adopt the Estonian x-road approach for interoperability and standards and enriched with the MyData approach, which ensured that citizens maintain the right to access and use data directly involving them. Distributed ledger-enabled technology has supported transparency and traceability, including the right to use data in different settings. This is built on the Responsible Dynamic Consent Princi-

“Individuals are shaping their own journeys towards creating their healthiest selves. Our perception of health and identity is inextricably bound”

ple, which continuously develops models for ensuring individuals’ rights to data and control over its use, and includes the commitment for compiling aggregated data sets to ensure the most accurate understanding of the totality of the human health experience (the Humanome). Data is no longer divided between research, clinical and lifestyle, but assembled as the Humanome, which draws upon the correlation of personal quality of life preferences, biological data, behavioural data, environmental data and public records.

Social expectations around privacy and anonymity have evolved to accommodate high expectations of lifelong health outcomes. Real-world data and real-world evidence are at the centre of service provision.

Individual needs and expectations are more fragmented than ever before, but the influx of tech players and development of innovative solutions means that the one-size-fits-all solution is from days past. Healthcare no longer requires a visit to a doctor, and in many cases a device connected to the global net of data can solve the problem. As a result, individuals can access their very own personalised point-of-care in real-time. Those generations that have grown up with heightened connectivity and are tech savvy prefer this solution, whereas older people and families often crave human interaction and a visit to the doctor. These more direct interactions are also increasingly accessible, as GPs now have more time per visitor. Doctors find their interactions more rewarding, while citizens feel heard.

Individuals are shaping their own journeys towards creating their healthiest selves. Our perception of health and identity is inextricably bound. Health is seen as an identity marker, with younger people defining themselves and others around them based on perceptions of health. Many people start their health journeys from a performance mindset, and there are several companies offering data solutions to create your healthiest self. The performance mindset, however, evolves into a holistic view of health – individuals move away from a mindset where health is used to showcase a perfect life, towards viewing health as a source of renewal and energy. Individuals are reclaiming their health journeys by investing themselves in self-cultivation of preventive health. Children born in the last decade have been the biggest

beneficiaries of this attitude shift, as the conversation around health has been present their entire life, so they are empowered to make healthy choices and live a balanced lifestyle. Everything is enjoyed in moderation.

REDESIGNING HEALTHCARE

Technological development and diffusion have had far reaching consequences for the individual. While the ethical debate in the 2020s centred on privacy and anonymity, it is now focused on accessing the relevant information needed to create the best quality of life. Hacking attempts in the past have been met by successful application of blockchain technology and efforts such as the Internet Freedom League, where countries abide by respecting digital boundaries. As a consequence, digital information is more secure than ever. The development of standards and principles, for example, OPEN data, FAIR Principles, Open Educational Resources (OER), have set data free and democratised access to knowledge, thus empowering the individual to share their data to their own benefit.

Fast technological development has enabled a Humanome approach that reliably provides a much deeper understanding of biology, health, and disease. A new disease taxonomy was established, alongside a better understanding of the environmental impact on the person thanks to extensive sequencing of our natural surroundings. These comprehensive data sources have enabled the ‘connected individual’, which considers the individual within the context of their life, beyond their disease profile. It more appropriately supports individuals taking multiple medications (polypharmacy), and the treatment of complex co-morbidities, with solutions tailored to individual needs, and leads to a greater likelihood of adherence and success. This has allowed for a transition from the quantified self to the qualified self with seamless interfaces to allow citizens to manage a tailored quality of life approach according to their values and personal preferences.

Sophisticated AI has allowed the creation of individual and aggregated data repositories. This empowers people to shape their own data diaries. On the other hand, the healthcare system can develop a stratified understanding of diseases and develop tailored solutions for them. The concept of the Digital Twin has made it





“Individuals are very proactive in developing and understanding genomics, which has become the baseline for modern health”

possible to develop tailored solutions for individuals based on models that are produced using their own data and has been a significant factor in improving quality of life. Beside these developments, in 2035, gene editing reached a level of clinical scalability for most diseases. It partly built on the improved knowledge that single cell sequencing in the 2020s provided, combined with the huge investment in multi-omics. Massive public engagement campaigns have allowed gene editing and data usage to move into mainstream discussion, featuring in popular entertainment and reaching a wide audience. This has encouraged transparent discussion around implementation, leading to strong public support for the technology. The 2020 Earth BioGenome Project, which pioneered the sequencing movement, made sequencing an accepted element of modern life and drove the price of sequencing down significantly. It is commonly referred to in lifestyle tools, including fitness apps, and is a common source of information for food and nutrition choices, supplements, and even pet choices.

Networked approaches to regulation and governance have supported the secure sharing of data across jurisdictions and provided a framework to support regulation of international corporations that deal in health-relevant data. The social contract that requires global organisations to consider the health-related consequences of their services has clarified responsibilities and enabled better practices to be shared.

Citizen-driven health and patient networks have a large role in the New Digital Social Contract, which is both geographical, relating to the local community, and thematic, focused on specific health and disease issues, where the power of large volumes of data is to provide aggregated insights as well as individual specificity. Cooperative movements inspired from the MyData and Swiss health COOP are an important enabler of cross-boundary data schemes where the individual person is the formal data carrier enabling the true personalised health. Crucially, individuals now have real-time oversight of how their data are being used, and the opportunity to exert their preferences. The challenge is to ensure that democratisation genuinely leads to free and fair access to new care opportunities for all, realising universal and equal access to quality, sustainable health care.

High speed global internet provided by key players via high and low orbits has reached all corners of the globe and citizens in 2030. This initiated large-scale development in previously remote areas of the world. VR, AR and distance expertise has grown exponentially to allow care and expertise to travel to the individual on a global scale, drawing on the lessons from the European Reference Networks in the early 2000s, and expanding to all disease areas. Health services can be provided from a distance and are becoming rapidly scalable, with the biggest market to benefit being the global South.

Individuals are very proactive in developing and understanding genomics, which has become the baseline for modern health. Using lifestyle- and real-time data, the best possible quality of life from cradle to grave can now be achieved. Personalisation occurs at the prevention and therapy levels, but also in terms of information and data delivery. Resources, updates, and oversight at different stages in the health lifecycle or lifespan, are carefully tailored to meet the information needs of the individual, at a time and in a format that is most appropriate for them. This supports genuinely informed decision making and allows people from all demographics to be partners in their own health. Despite a large segment of the population enjoying these opportunities, there are also those who for a number of reasons are unable to avail these opportunities. For example, those dealing with addiction, long-standing illness, problems at home, poor mental health or financial troubles may have other priorities. There are many instances of societal structures that support such individuals, this could be in the form of family, neighbours, friends, colleagues, etc. Cultivating a sense of community and intertwining positive interactions in our daily routines go a long way in creating a healthy life.

CONCLUDING REMARKS

This scenario was written as an aspirational scenario towards 2050. Many of the events described could be wishful thinking, but they take their cues from current happenings. While there could also be some who view certain developments as unwelcome, our goal in exploring this Future of Health 2050 has been to create a world that provides preventive and personalised care for all. There are of course many ways to achieve this goal. ■



MOTIVATION We talked to several young people, asking them questions about health. What would help them become more aware of their own health? What would inspire them to take preventive action to strengthen their health? They responded that their personal health is not something that they think about often or identify with strongly. For them, health is a topic to be addressed later in life. Something that they associate with the elderly, especially as they become infirm.

This prompted a new line of enquiry with the young people. What *do* they identify with? Without exception, all of them responded that their primary concern relates to the health of the planet. They strongly identify with any attempts to promote awareness of the climate crisis and feel motivated to take action in support of this cause.

We made something of a breakthrough when we brought these two topics together. Did they know about the correlation between their health and the health of the planet? They all replied, 'No, we don't, but we would really like to know more about this.' Would they try and learn more about their own health — and how to strengthen themselves through preventive action — if they knew this could strengthen the health of the planet too? 'Absolutely,' they said.

Investing in future generations is the only way to eliminate short-termism. Enabling young people to self-cultivate a preventive approach to their health not only could help prevent an imminent healthcare calamity, it also could contribute significantly to long-term efforts to save our planet.

We have written a futuristic take on this opportunity. We call it *The rise of the eco individual*.

The health of the individual is inseparable from the health of the ecosystem. To take proactive responsibility for our health is to contribute towards planetary care. By 2030 a bottom-up movement will pave the way for a more sustainable form of coexistence.

THE RISE OF THE ECO INDIVIDUAL



During the Crimean War of the mid-1850s, Florence Nightingale would earn the epithet ‘The Lady with the Lamp’. It was among the wounded soldiers, whom she visited during solitary rounds at night at Selimiye Barracks in Turkey, that Nightingale came to understand the cause of the high attrition rate for the British forces during the conflict.

Nightingale realised that it was not battle wounds that were causing so many deaths, but a combination of poor nutrition, lack of supplies, stale air, and secondary diseases. Nightingale would later record in her book *Notes on Nursing*: ‘We know nothing of the principle of health, the positive of which pathology is the negative, except from observation and experience.’ She continued, ‘[i]t is often thought that medicine is the curative process. It is no such thing.’ For Nightingale, medicine and surgery could remove obstructions, but ‘nature alone cures.’ The role of nursing, she argued, is ‘to put the patient in the best condition for nature to act upon him.’¹

INDIVIDUAL AND ECOSYSTEM HEALTH IS INSEPARABLE

Florence Nightingale’s methods of observing health patterns and assessing how they were shaped by other environmental factors are an early example of systems thinking applied in healthcare. Systems thinking teaches us that everything connects – that all life on Earth is part of the same biosphere. We humans are interdependent on other living systems with which we interact and from which we learn. A multidimensional perspective enables us to establish a deeper appreciation of what forms complex systems of coexistence.

Such an approach is what filmmaker and educator Nora Bateson refers to as transcontextual research,² the practice of which generates relational information known as ‘warm data’.³ This enables us to see the interdependencies and interactions between wholes and parts, to increase our knowledge about the symbiotic relationships

between living and non-living systems. In this way, transcontextuality highlights how it is impossible for a system to exist in a single context. Nothing is singular, everything is plural.

It is innate in us to attach ourselves to nature. Understanding the incredible and sometimes painful ways in which we connect to such a vitality of coexistence is itself inherently vitalising.⁴ It is our primary source of strength. The health of the individual is inseparable from the health of the ecosystem. To care for the environment and biodiversity, in all their complexity, is to care for ourselves and our loved ones. To take proactive responsibility for our health is to contribute towards planetary care.

**THE ENVIRONMENTAL
IMPACT OF HUMAN
ACTIVITY HAS RESULTED IN
SUPER WICKED PROBLEMS**

The more we learn about the life of the planet, the more we understand humankind's tiny place within its 4.6-billion-year history. Our time on Earth has been short, yet the detrimental consequences of our behaviours and lifestyle choices on the health of the planet have been disproportionate in size. Humankind's inseparability from the ecosystem – and the threat we pose to it – has come into sharper focus.

The environmental impact of human activity has intensified as we have shifted from early nomadism to localised agriculture to technocentric urban dwelling. The resultant climate crisis exacerbates global issues relating to rising sea levels, waste disposal, air quality, acidification, food sustainability, population growth, governance, healthcare, and the likelihood of mass migration, pandemic disease, economic collapse, and global conflict.⁵ The more we learn about their potential interacting effects – as 'super wicked problems' that are impossible to disentangle – the easier it is to imagine our own demise within the timespan of a few generations. This is not a legacy for distant descendants. It concerns our children and their children, deeply affecting how we experience the world.⁶

OUR EGOCENTRIC WAYS MUST NOT ENDURE

We now live at an inflection point in human history. We are confronted with an urgent need to reassess how we interact with all Earthbound life. The way to care for ourselves, our families, and future generations, is to care for life as a whole.⁷ The accelerated convergence of super wicked problems forces us to confront a new reality. This is one that demands radical new ways of seeing – granularly, fractally, holistically, across time, between contexts and dimensions – in order to make any sense of it.

Rather than allowing ourselves to be overwhelmed by the enormity of the situation, we can take the opportunity to generate new knowledge that will provide solutions. Our understanding of the world should be informed by our coexistence and the relationships between systems. This requires a shift in

perspective from either/or to both/and. It is characterised by a kaleidoscopic mixture of pre-industrial and metamodern behaviours, practices, and technologies, blending ancient wisdom with what we have learned in recent decades and reconciling the tensions between different ideological views of the world.⁸ Considered in terms of complex systems, there can be no center, no 'us and them'. More eco, then, than ego. It is not overstating the case to claim that our future depends on it.

WE MUST COME DOWN TO EARTH

If we are to acknowledge our coexistence with and interdependence on other life forms, then change has to start now to ensure the survival of our shared ecosystem. This requires us to move away from seeing ourselves as above and apart from nature. As philosopher, anthropologist, and sociologist Bruno Latour argues, we have to come back down to Earth. We should stop speaking about humans, appreciate that we are in and of nature, and refer to ourselves as terrestrial beings among other terrestrials.⁹

This fundamentally challenges our existential understanding of what it is to be human. What is the edge of a human? What is the edge of an immune system? Our silo-based mentality is rendered obsolete. Science has revealed that the notion of 'we' extends well beyond the human and challenges the extent to which 'I' is sustainable as an ideal. In this new transcontextual reality, as hosts to trillions of microorganisms, every human is, in fact, a humming multitude.

To coexist is to assume a loop with other terrestrials. We experience the integrated, interdependent role we fulfil in relation to other complex systems. We learn from the vitality of our contribution and that of other terrestrials. Our existential vulnerability, paradoxically, can result in re-attachment to the ecosystem, to society, to the local community, to our sense of identity. It is like knowing, but more like letting be known. It is like a knowing that knows itself.¹⁰

For Latour, therefore, it is essential that we carefully consider the other terrestrials with whom we will share resources and create what he calls 'dwelling places' in the future. This will serve to define what we will depend on and what will depend on us: our very template for coexistence. As he phrases it in *Down to Earth*, '[e]xisting as a people and being able to describe one's dwelling place is one and the same thing.' If we can describe our dwelling place, if we can list the properties necessary for our subsistence, we know what we need to defend as if our very coexistence depended upon it.

WE HAVE LOST OUR SENSE OF ORDER

In many respects, industrialisation has ossified our thinking and practices, straining our symbiotic relationship with our environment. This has resulted in alienation from any notion of coexistence, prompting us to question what it now means to live a mean-

“This requires us to move away from seeing ourselves as above and apart from nature. As philosopher, anthropologist, and sociologist Bruno Latour argues, we have to come back down to Earth”

ingful life. Our personal energies are exhausted in service of all-consuming entities – neoliberalism, globalisation, the internet – so massively distributed through time and space that it is impossible for humans to see or touch them directly.¹¹

The human experience of recent decades has reshaped the fundamental structures of our lives. The patterns, codes, and rules with which we can identify are in short supply in an era defined by ambivalence and uncertainty. The accountability for pattern-weaving and sense-making falls primarily on the individual, as we struggle to adapt our thinking, values, and identity.¹² We are left on our own to navigate the temporal and spatial vastness of our own subjectivity. Here our entropic experience of time and space combines the emotions associated with the order of the past and the emotion-based anticipation of future order.¹³ We attempt to use time and space to compute and navigate our lives emotionally.

This has resulted in a ‘shrinking of the present’, a decrease of the period during which expectations based on past experiences reliably match the future.¹⁴ It has also caused an ‘expansion of the self’, in the form of an ever-presence, accompanied by the centrifugal collapse of external spaces into ourselves. We relentlessly seek to accelerate the speed of our lives and to increase our share of the world.¹⁵ What is not self-serving is discarded or disregarded. Ironically, this brings us within grasping distance of the ungraspable reality of things.¹⁶ As we desire to see and touch the things that are impossible for us to see and touch directly, we mistakenly become the order with which we seek to identify ourselves.

WE HAVE SURRENDERED OUR AGENCY

To further strengthen this self-reinforcing loop, we surrender our intrinsic interest and perceived self-efficacy to algorithms. Just as human authority was justified by the liberal story, so the coming technological revolution might establish the authority of data algorithms, while undermining the very idea of individual freedom.¹⁷ We transfer the authority of how we compute and navigate order to algorithms, thereby diminishing our responsiveness to other living systems. We lose our ability to listen to how we listen to the transcontextuality of the world.

Our modern technologies can have a distancing effect. Today, interaction with the world is mediated by vehicles, screens, and artificial intelligence. Even as our interfaces are giving us the impression of enabling bonds with others who are like us, intimacy is counterbalanced here by exhaustion caused by an ever-accelerating, always-on lifestyle. Acceleration in production and consumption – as we have manufactured more, travelled further, expanded our range and methods of communication, and surrendered our agency – has inevitably depleted the Earth’s resources and disturbed its natural balances. The speed of modern life, the rate of exploitation of natural

resources, and the escalating effects of the climate crisis have resulted in the foreboding sense that our experience of alienation is widening.

WE HAVE BECOME DETACHED FROM OUR WORLD

A qualified life, informed by mutual dependence and coexistence within an ecosystem, has been supplanted by a quantified life powered by the egocentric desire for faster and for more, with little regard for the consequences. We have become detached from any understanding of ourselves as vital systems interdependent on other terrestrials. We have lost any connections we might have had with our dwelling place.

This opens up several gaps. Now, what depends on us enables how much we are depended upon. What we know enables how much we know. What we own enables how much we own. The negative spiral contributes further to our exhaustion. Any opportunity for renewal then depends on closing the gaps, in finding solutions in the liminal spaces of the in-between. What depends on us, what we know, and what we

own must purely serve the purpose of qualifying coexistence.

The eras of modernity and postmodernity have served to highlight the supreme irony of our existence. Our consumption ignores the climate crisis, and, on some profound level, we find this unbearable. The ideology of rampant consumerism serves as a blockage to and critique of a more hopeful ideology of coexistence.¹⁸ Today, a vision of the future is more likely to depict a fuel-guzzling spacecraft than an oxygen-generating tree.

WE HAVE ENTERED INTO A STATE OF HYPER-EXHAUSTION

We have entered into a self-perpetuating hyper-exhaustion loop (see *hyper-exhaustion* figure), founded upon our experience of extreme acceleration and widening detachment, that leads us towards collapse. We suffer today from a crisis of identity, losing any sense of purpose in our lives, discovering that the structures that we once identified with have become much more difficult to navigate. We come to view the rest of the world as cold, rigid, ugly, and unresponsive. Our place in the world is further undermined by the surreal realisation that we are witness to the beginning of our own end.

Within the loop, there is a debilitating, self-reinforcing, never-ending cycle of cause and effect that spans multiple interacting contexts. Think, for example, of how slow-moving disasters like drought or the localised collapse of biodiversity can affect an individual’s livelihood. This can result in conditions like increased workloads, household and family tension, uncertainty and concern for the future, anxiety, dietary changes, diabetes, and depression.¹⁹

There is a constant transcontextual interplay in such a scenario between the climate crisis, a multitude of living systems, the economy, mental disorder, non-communicable diseases, and the state

*“We have entered
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detachment”*





of our healthcare system. The more we know about this hyper-exhaustion loop, and the more we try to resist it, the more we become entangled within it. Yet the more entangled we become, the more the cascading effects will exhaust our capacity and capabilities for coexistence. The pressures exerted by the hyper-exhaustion loop are experienced systemically as well as individually.

HYPER-EXHAUSTION WILL CAUSE MENTAL HEALTH PANDEMIC

The acceleration and accumulation of mental health conditions are symptomatic of such a modern sensibility. The obvious conclusion is that the psychological crisis of late modernity, as manifested in the symptoms of stress, depression, anxiety, and burnout-related disorders, as well as in phenomena such as ADHD, can be understood, with good reason, as a crisis of exhaustion.¹⁵

As the climate crisis continues and deepens, we face the very real prospect of a mental disorder pandemic. This will add to a collective experience of hyper-exhaustion. Such a pandemic will be further informed and reinforced both by ecological grief, regarding the damage already done to the ecosystem as a direct consequence of human activity, and by ecoanxiety, in relation to the detrimental future effects and the legacy we will leave behind.²⁰ These have immediate and long-term implications for our state of health – not only mental, but physical and communal too.

The implications are alarming: a mental health pandemic, catalyzed by the climate crisis, could result in the accelerated collapse of our healthcare system. Currently, mental health conditions are already one of the leading causes of disability-adjusted life years (DALYs) recorded by the World Health Organization. They account for 11.4% of healthy years lost among the whole population and 28.6% among the population aged 10-24 years.^{21,22}

It is anticipated that the global cost of mental illness will explode, placing a greater economic burden on our societies than cardiovascular disease, cancer, chronic respiratory disease, and diabetes.²³ In 2010, it was estimated that the global figure stood at USD 2.5 trillion. By 2030, when both direct and indirect costs are taken into consideration, this is projected to surge to a total of USD 6 trillion.

WE MUST ESTABLISH A TRANSCONTEXTUAL UNDERSTANDING OF THE MENTAL HEALTH PANDEMIC WE FACE

Mental disorders, then, poses one of the most significant threats to how we think about, practice, and educate people regarding sustainable health and coexistence. As such a pressing issue, we need to radically review and redesign how we attend to its transcontextual effects. In fact, no other health condition matches mental illness for the prevalence, persistence, and breadth of its impact.²⁴ Where there is detachment, and loss of order and agency, mental

illness and self-neglect can often follow. This is evident in several ways, through eating disorders, self-harm, and self-medication with both drugs and alcohol. Inevitably, this affects our physical health too, with knock-on effects on our loved ones, work colleagues, carers, and the wider socio-economic domain.

This requires the application of a warm data concept where data is put back into its natural contexts, serving to transform our use of it.

With such a concept the ‘super wicked problems’ we are facing – and the responses we need to initiate – can be identified, applied, and even self-cultivated in the liminal spaces of the in-between. We

can move the individual beyond the quantitative to the qualitative, enabling both the individual and the system to explore the unexpected, indirect patterns, and patterning processes that allow something to surface that becomes an entry point into a systemic shift.

We can use warm data to map the causal processes of mental health and how it is directly correlated with the climate crisis. Over time, it helps us understand the mental health pandemic we face in fundamentally different ways.⁴

WE MUST RESPOND WITH MENTAL HEALTH PREVENTION AT SCALE

There is a compelling case to approach mental health as an opportunity for early prevention rather than a risk for secondary disease as historically has been the case. The question is how to respond to a mental health pandemic via the self-cultivation of preventive health rather than reactively through systemic sick care.

While we cannot govern the ecology, we can change the economic system, which is wholly manmade and entirely unfit in its current form for our long-term survival.⁷

We have to work out what constitutes a transcontextual economy, based on set of purposeful incentives that draws on both monetary and non-monetary logics. An economy aimed at rewarding inter- and intra- species solidarity, on the identification and defence of our dwelling places. What, then, constitutes such a return on coexistence (RoC) and how do we scale our healthcare system accordingly?

Individual perspective:

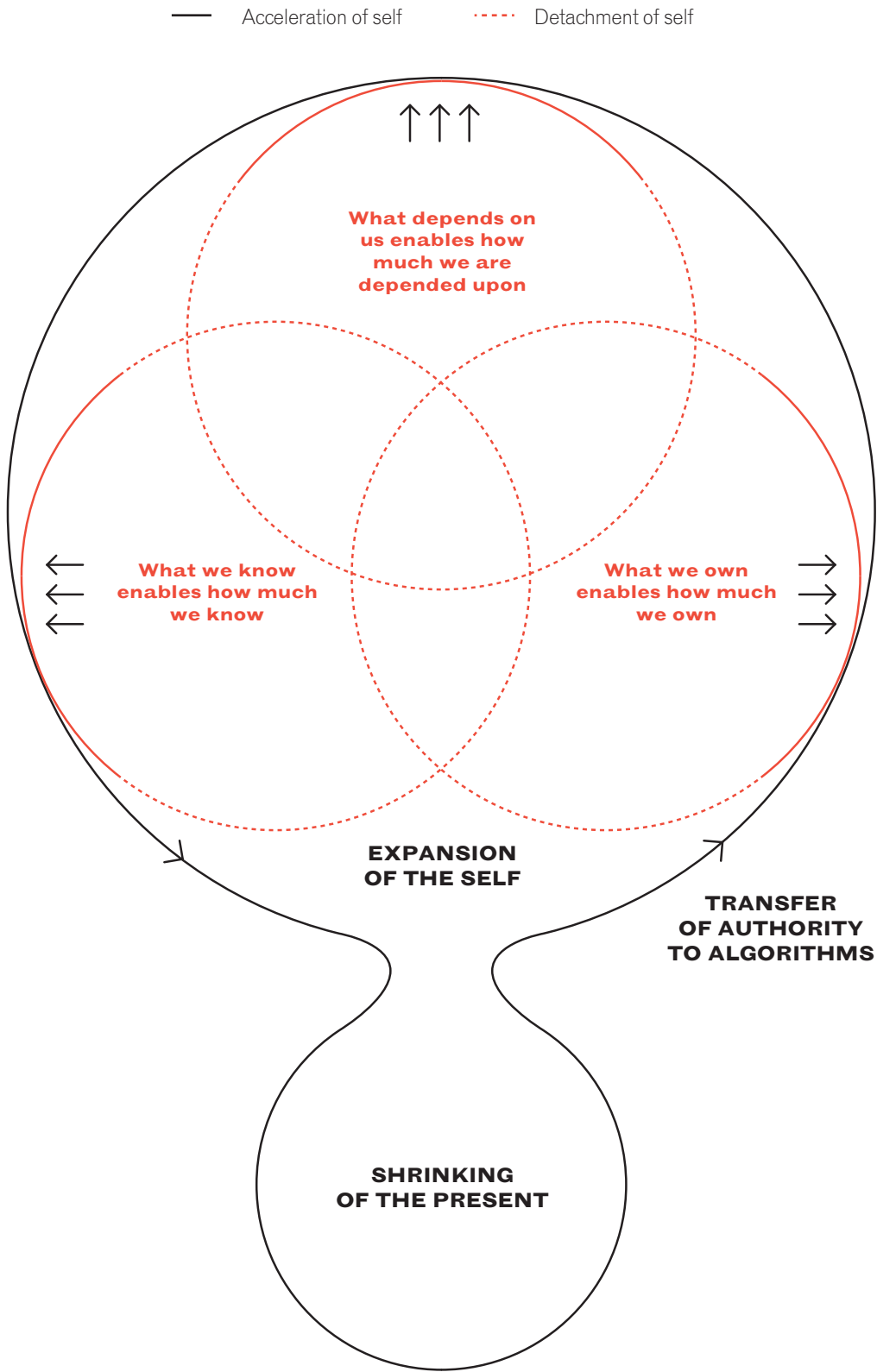
- How can individuals best identify their dwelling place?
- How can a supporting warm-data concept be implemented?
- How can individuals use such a concept to self-cultivate mental health prevention?

System perspective:

- How can we meaningfully reimburse preventive health services?
- How do we best proactively address the interplay between mental disorders and non-communicable diseases?
- How do we nurture a healthcare system that depends equally on super-hospitals, on proliferated technology, on data algorithms, and on empowered communities and individuals?

HYPER-EXHAUSTION

A condition threatening the health of individuals and the ecosystem



We have entered into a hyper-exhaustion loop between the ‘shrinking of the present’ and the ‘expansion of the self’. As we navigate the temporal and spatial vastness of our subjectivity, we mistakenly become the order with which we seek to identify ourselves. Our hyper-exhaustion is further accumulated and accelerated by the surrender of our intrinsic interest and perceived self-efficacy to algorithms.

WE MUST STRENGTHEN OUR RESILIENCE TO BOOST MENTAL HEALTH PREVENTION

One of the most visionary features of Florence Nightingale’s theory about the environment in health is its elimination of the distinction between being sick and being healthy. Since environmental conditions are ever-present but ever-changing, the focus, according to Nightingale, should be to alter the environment to affect a positive change in health. ‘The same laws of health, or of nursing, for they are in reality the same, obtain among the well as among the sick.’¹ This is a future-oriented conviction based on her insistence that humans should not only be well but be able to use every power they have. Nightingale was, by all accounts, an early ambassador of resilience.

Resilience is today primarily regarded as a method by which hyper-exhausted individuals can develop the capacity to withstand more of the same. The resilient personality is oriented towards re-balancing and stabilisation. Ironically, this not only provides a fragile foundation for coping with the uncertainty and instability of contemporary society but also constitutes a core competence in detaching oneself further from the social and ecological disasters produced through our industrial practices.²⁵ In the traditional sense, resilience serves the purpose of accelerating and accumulating even more hyper-exhaustion.

As vulnerability is the underlying, ever-present, and abiding undercurrent of our natural state. The only sustainable choice we have as we mature as resilient beings is how we inhabit our vulnerability. It is how we become more significant, more courageous, and more compassionate through our intimacy with this profound state of hyper-exhaustion.²⁶ Going forward, resilience should not only be about mere endurance but more a manifestation of how we can move beyond the edge of our selfishness. How we can transform to become better versions of ourselves during the most difficulty circumstances. (see *transformative resilience* article)

THE RISE OF THE ECO INDIVIDUAL

The combination of science and technology will enable us to gain a more holistic and granular understanding of the inseparability between our health and the health of our ecosystem. We can become more conscious of the transcontextual nature of human biology – namely, that we are subject to and agents of both nature and nurture in one multidimensional living system. Learning how these two forces interact from within and without such systems provides us with a deeper understanding of how we can identify our dwelling place and renew our relationship with the world.

A renewed focus on coexistence, shifts the emphasis from hyper-exhaustion to hyper-renewal (see *hyper-renewal* figure), from the quantified self to the qualified self. The continuous stream of warm data on biological coexistence can, if qualified, proactively shape and inform the very fabric of our health. Eco individuals

who so desire will gain the capacity to have their warm data, in addition to their cold data, seamlessly aggregated, updated, and processed, for their resilience as well as their physical and mental health. This can provide a baseline literacy that can be self-cultivated in the pursuit of hyper-renewal. (see *the humanome* figure)

THE ECO INDIVIDUAL WILL LIVE IN A STATE OF HYPER-RENEWAL

By contrast, the hyper-renewal loop manifests itself in terms of the slowing down and qualification of attachment, resulting in resilience. To enter the hyper-renewal loop, though, we have to move

from the egocentric perspective of *What’s in it for me?* to the ecocentric perspective of *Who depends on me for subsistence?*

To further strengthen this self-reinforcing loop, we can indeed turn to proliferated technology and algorithms to reclaim our intrinsic interest and perceived self-efficacy. New technologies can offer additional interfaces through which the eco individual can collect and analyse real-time data regarding interactions and interdependencies between systems. As such, we can self-cultivate our ability to listen to how we listen to the

transcontextuality of the world. How we listen to our own health.

Future developments in AI health assistant, sensor, and DNA sequencing technologies, as well as in the fields of epigenetics, neuropsychology, and synthetic biology is likely to be significant factors in the proliferation of such a warm data concept. Take, for example, the application of deep phenotyping that will enable a more profound knowledge about the eco individual than ever previously attainable or even conceived. This is a knowing letting itself be known – a knowing that potentially knows itself. Deep learning and deep empathy can be a significant remedy to the hyper-exhaustion of the eco individual by promoting bespoke prevention and therapies.²⁷ Hyper-renewal, then, is not something eco individuals eventually have to adapt to, but a tangible solution they can proactively seek to implement.

HYPER-RENEWAL IS A TANGIBLE WAY OF QUALIFYING ONE’S ABILITY TO COEXIST

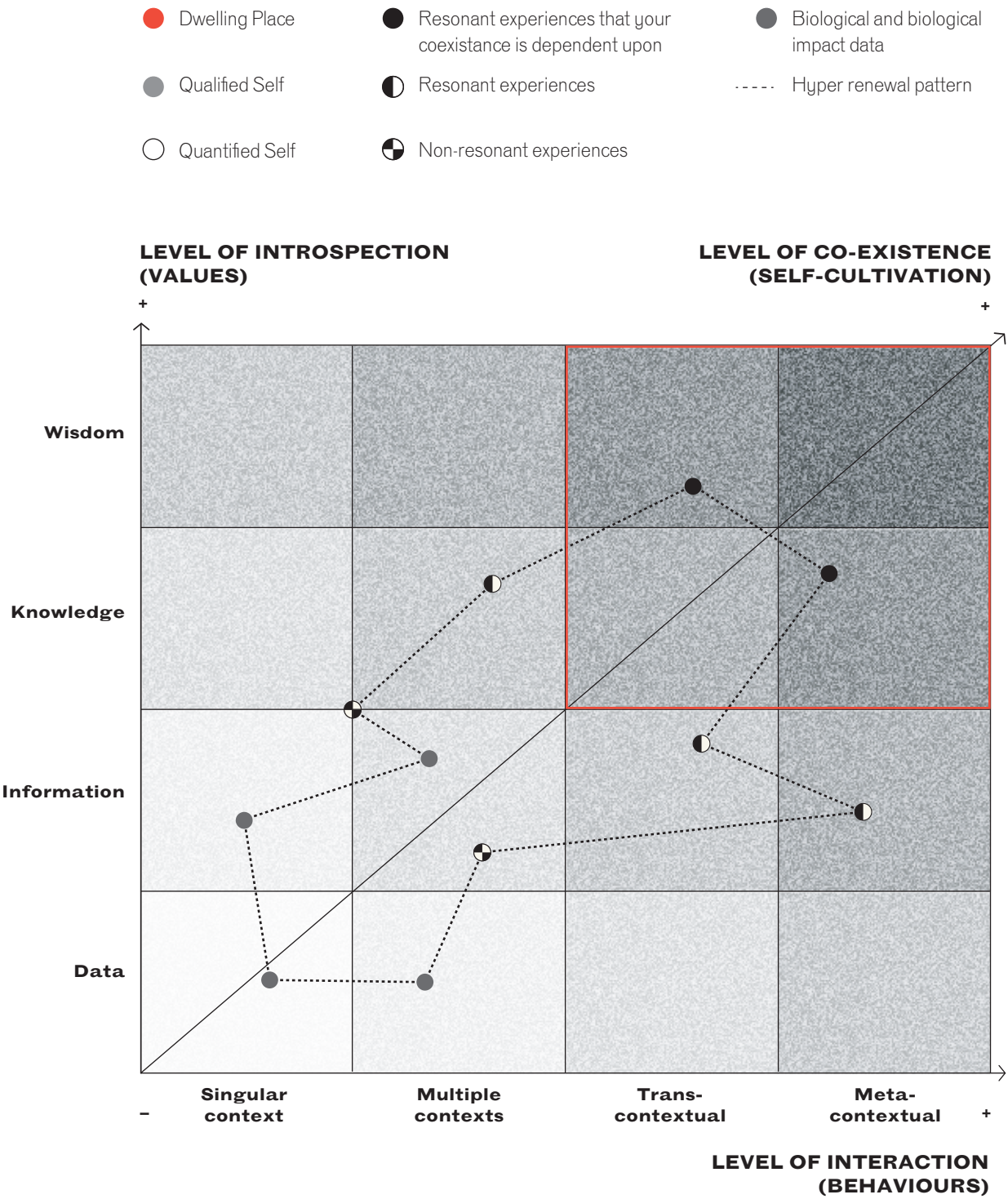
What are the practical applications of a hyper-renewal solution?

The German philosopher and sociologist Hartmut Rosa argues that we should use ‘resonant’ experiences to self-cultivate a meaningful relationship with the world.¹⁵ For Rosa, resonance illustrates how we qualify our coexistence. The sum of our resonant experiences results in attachment and renewal, whereas non-resonant experiences contribute to the hyper-exhaustion loop, detachment, and alienation. There is a correlation, therefore, between resonance and resilience. Resonance serves as a more sustainable coping mechanism when we are confronted with hyper-exhaustion, and it is through the sum of our resonant experiences that we reattach ourselves to the world. Resonance is the key to our hyper-renewal.

“A renewed focus on coexistence, shifts the emphasis from hyper-exhaustion to hyper-renewal, from the quantified self to the qualified self”

HYPER-RENEWAL

A framework for qualifying coexistence





Rosa distinguishes between three varieties of resonant relationships, spread across different axes. The horizontal axis covers social relationships such as friendships, the familial, and even the political. The diagonal axis is concerned with objects and the world of things. This includes material objects, as well as our experience of activities like sport or our interaction with locations and spaces. The vertical axis covers our connection to existence and the world as a whole and can be experienced through our response to nature, art, history, and religion.

Our own renewal is dependent on experiencing resonance across all three axes. These provide insight into the multidimensional nature of our lives. The axes highlight the potential for both attachment and detachment, hyper-renewal and hyper-exhaustion. Rosa refers to each axis as a ‘resonant wire’. When we focus on only one of these, he argues, we will have no other sources of resonance and, as a consequence, little or no resilience when that axis falls mute in a crisis. Where there is accelerated and accumulated resonance, we will find our dwelling place. The practical application of hyper-renewal solutions is, therefore, to enable the eco individual with tangible ways of correlating warm data with resonant experiences.

HYPER-RENEWAL HAS THE POTENTIAL TO GIVE BIRTH TO A SOCIAL MOVEMENT

Social movements have been transformative in the past and will be even more so in the future. With modern worldwide connectivity, social movements can build momentum very quickly. This is especially true when there is an immediate crisis or a cause that prompts people to take to the streets.²⁸ We are already witnessing this with the Extinction Rebellion movement and the young climate crisis activists mobilised by the example of Greta Thunberg.⁶

The rise of the eco individual will not only form and inform such a social movement, it will provide self-cultivation of hyper-renewal at scale. The radical transparency, solidarity, and vulnerability of such a movement will not only inspire eco individuals,

communities, and societies to hyper-renew, but will also prompt the urgent defence of the dwelling places we wish to inhabit. What is effective at a micro level can scale to a macro level, from the eco individual to a multicultural, multinational, and even global society.

Supporting the rise of the eco individual is not only our best hope for long-term survival, it is also our moral obligation to future generations. The citizens of tomorrow are granted no rights, nor in the vast majority of countries are there any bodies to represent their concerns or views regarding decisions taken today that will undoubtedly affect their lives. This is a blind spot so enormous that we barely notice it.²⁹ It is incumbent on us to be good ancestors. Investing in the eco individuality of our children and their children is the best way for us to eliminate the effects of the short-termism that has shaped our own lives and that of previous generations.

THE NEED FOR FUTURE ROLE MODELS

Imagine if Nightingale were a modern-day nurse and role model. She would not only embrace the idea of redesigning our entire healthcare system, but also lead by example. The Lady with the Lamp would be observed alone, during night, making her solitary rounds among the hyper-detached. She would show them how to translate their sense of disconnection into action. She would demonstrate how a practical beginning, however small, can lead to profound change.

Even in the direst and most devastating of circumstances, confronted with the beginning of our own demise, Nightingale would embody how attachment, resilience, and resonance are dependent on the prosperous coexistence between humanity and all other living systems.

That would be a cause she would be ready to defend as though her life depended upon it. ‘Rather, ten times, die in the surf, heralding the way to a new world,’ she once said, ‘than stand idly on the shore.’³⁰ It is time for action, she would argue today. It is time to deliver. ■



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